“In the wilderness?”

Services for people with mild/borderline learning difficulties with/without autistic spectrum disorders or mental health needs at risk of offending or reoffending.

Thesis submitted for PhD(Learning Disabilities)

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Abstract

This thesis explores two ways in which people with mild/borderline learning difficulties (with or without autistic spectrum disorders or mental health needs) who are at risk of offending or reoffending are supported by health and social services – community based services and residential services. Existing literature on offending by people with learning difficulties and mental health needs is summarised and the response of the criminal justice systems to "mentally disordered offenders" is explored. The methodology of service evaluation is also reviewed.

Study One reviews the effectiveness of a pilot multi-disciplinary team set up to meet the needs of people with mild/borderline learning difficulties, mental health needs and high functioning autistic disorders (in particular Asperger's syndrome) with offending/reoffending behaviour from the perspectives of mainstream professionals, team members, service users and carers. Study One concludes that the availability of flexible, person centred support services such as those provided by the team are fundamental to the prevention of offending behaviour and the development or maintenance of independent living skills for this group of people.

Study Two explores the quality of support provided in out of borough residential placements, including a secure unit. Study Two concludes that, with the notable exception of the secure unit, attention to individualised person centred planning including behavioural programmes and the development of independent living skills is patchy. Links with placing authorities are not always robust and there is a lack of suitable community based provision and move-on accommodation. Organisational rules and routines appear to impose unacceptable restrictions on basic choices in everyday life.

The thesis concludes that people with mild/borderline learning difficulties (with or without autistic spectrum disorders or mental health needs) who are at risk of offending/reoffending can be better supported by a particular model of community based teams and key components of this service are described.

These teams should be:

- Based upon principles of user empowerment, particularly in the management of risk
- User centred, flexible and responsive in their approach
- Based upon a whole team approach to providing a service so that an immediate response to someone does not depend on the service user's case worker being available
- Use a care programme approach and have a no closure policy
- Offer individually tailored expertise to meet peoples' needs, in particular access to a psychologist or challenging behaviour specialist
- Offer individually tailored practical support packages which enable both an increase in independent living skills and access to mainstream facilities, including employment
- Offer therapeutic input, particularly groups which enable people to deal with sexual relationships and anger management

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Introduction

There is an expanding body of research which indicates that people with mild or borderline learning difficulties are poorly served by existing services. This group of people are often not linked into existing services despite their vulnerabilities, and may only come to the attention of an official body such as the police, because they are suspected of committing an offence. Unfortunately, this does not necessarily lead to people being able to access the services they need, either because they may not meet eligibility criteria for exiting services, or because services do not provide the particular kind of expertise that that person requires. For people with mild/borderline learning difficulties who have additional needs such as mental health needs and people with Asperger's syndrome these problems are exacerbated.

This thesis is concerned with services for people with mild/borderline learning difficulties (with or without autistic spectrum disorders or mental health needs) who are at risk of offending or reoffending. Part 1 provides a context to a further exploration of these issues. In Chapter 1, the main theories as to why people commit crime are briefly summarised. As many people with learning difficulties, mental health needs and Asperger's syndrome will be treated as "mentally disordered offenders", the term is discussed and an operational definition specified. The literature relating to offending behaviour is summarised and discussed [1]. In Chapter 2, the discrimination experienced by people within the criminal justice system is explored and the effectiveness of diversion schemes and services to support people with learning difficulties, mental health needs and Asperger's syndrome is examined. Differences in agencies' perspectives on risk highlights the increasingly restrictive approach of central government to this group of people and the emphasis on public safety as paramount. This emphasis conflicts with that to be found in social care services and prescriptive definitions of good practice in services for "mentally disordered offenders".

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[1] A literature search was undertaken using keywords to explore electronic databases (Medline, Sociofile and Psyclit) and library databases (Kings Fund, UKC, the National Autistic Society and Revolving Doors). A manual search of key journals such as the British Journal of Forensic Practice, Tizard Learning Disability Review etc. was also carried out.

The methodology and tools in common use for reviewing the effectiveness of services by exploring the nature and focus of service evaluation are reviewed in Chapter 3. Outcome measures are concentrated upon given their increasing popularity and use, and those outcome measures used in both studies are described in more detail. Consideration is given to the possibly oppressive nature of service evaluation.

Study One (Chapters 4, 5, 6 and 7) considers the effectiveness of a pilot multi-disciplinary team set up to meet the needs of people with mild/borderline learning difficulties, mental health needs and high functioning autistic disorders (in particular Asperger's syndrome) with offending/reoffending behaviour from the perspectives of mainstream professionals, team members, service users and carers. Study One concludes that the availability of flexible, person centred support services such as those provided by the team are fundamental to the prevention of offending behaviour and the development or maintenance of independent living skills for this group of people.

Study Two (Chapters 8,9 and 10) explores the quality of support provided in out of borough residential placements, including a secure unit, for people with mild/borderline learning difficulties, mental health needs and autism who have offending/reoffending behaviour. Study Two concludes that, with the notable exception of the secure unit, attention to individualised person centred planning including behavioural programmes and the development of independent living skills is patchy. Links with placing authorities are not always robust and there is a lack of suitable community based provision and move-on accommodation. Organisational rules and routines appear to impose unacceptable restrictions on basic choices in everyday life.

Given that the two groups of people had similar characteristics in terms of diagnosis and offending behaviour, it is possible to conclude that the development of community based teams could support people more effectively in their local communities than the majority of residential provision. These teams should be:

- Based upon principles of user empowerment, particularly in the management of risk
- User centred, flexible and responsive in their approach
- Based upon a whole team approach to providing a service so that an immediate response to someone does not depend on the service user's case worker being available
- Use a care programme approach and have a no closure policy
- Offer individually tailored expertise to meet peoples' needs, in particular access to a psychologist or challenging behaviour specialist
- Offer individually tailored practical support packages which enable both an increase in independent living skills and access to mainstream facilities, including employment
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A note on terminology

The area of disability is a fast changing area with disabled people constantly challenging established perceptions and descriptions of themselves, their impairments and their lives. It is recognised that "labels" cannot encompass or describe the full range of peoples' abilities and characteristics. Where possible people are described in terms that they choose to describe themselves: thus disabled people refers to people who are disabled by society because of a perceived impairment. People with learning difficulties are referred to by this term as it is the term chosen by People First, the national self-advocacy organisation for people with learning difficulties. People with mental health needs and their organisations describe themselves in a variety of different ways from psychiatric system survivors to people experiencing severe psychological distress, to "mad." There does not appear to be one "label" preferred above all others. In the absence of this, the term "people with mental health needs" is used.

It is recognised that there are issues about definitions and how people acquire these and other labels. The role of tools such as IQ tests and diagnostic tools for mental illness are seen to be objective descriptors, when in fact they are anchored deeply in the values of the society which have engendered such measures of "intelligence" and "health", and have been consistently shown not to take account of many factors, in particular, cultural bias. Because most studies have used IQ tests and diagnoses to describe the population studied, these factors are referred to here, because not to do so would give an incomplete picture of research to date.

PART ONE

Chapter 1

People with Learning Difficulties, Mental Health Needs and Asperger's Syndrome in the Criminal Justice System.

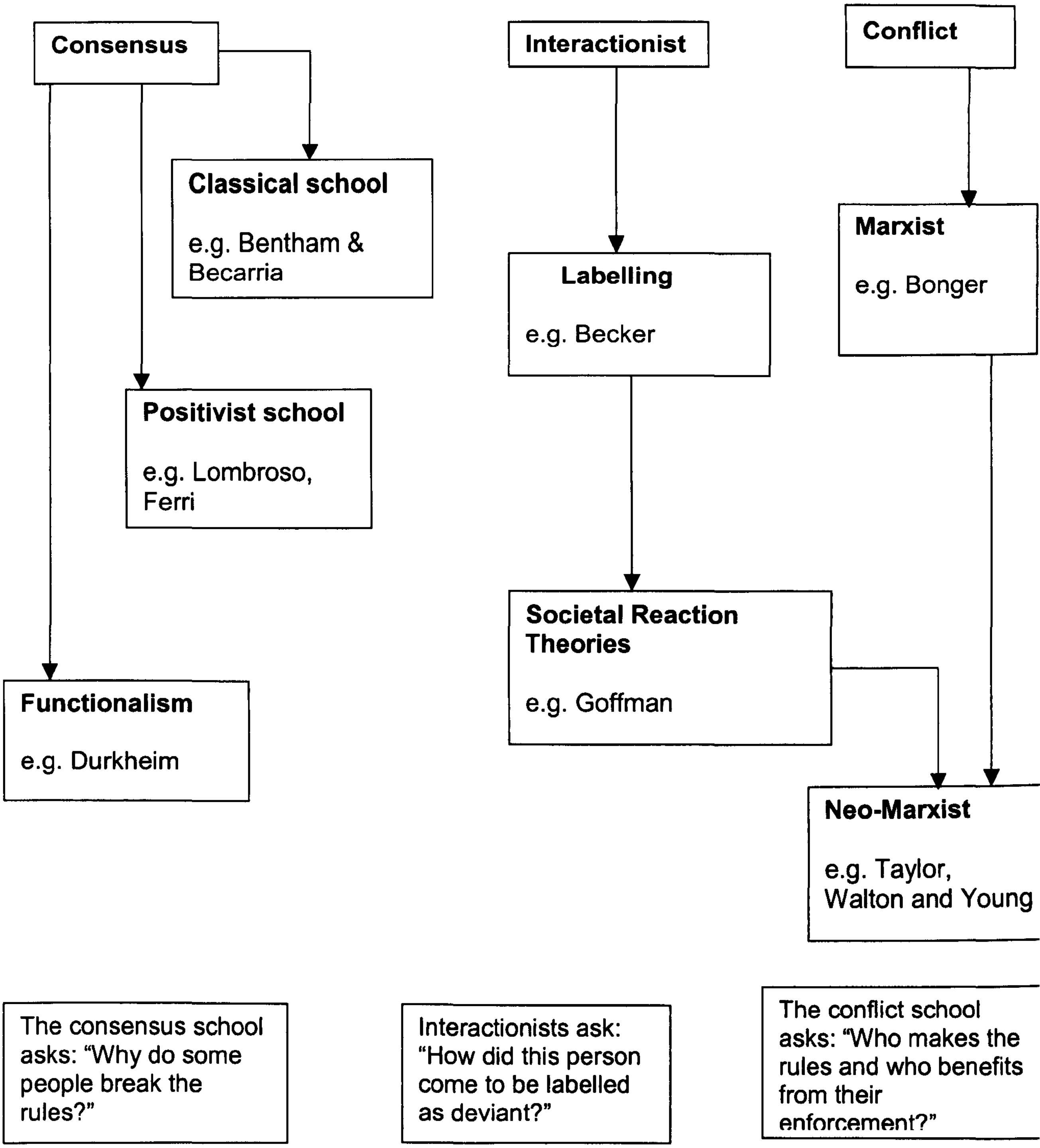
This chapter begins by briefly summarising the main theories of why people commit crime. The prevalence rates and characteristics of people with learning difficulties, mental health needs and Asperger's who offend are then discussed and finally the outcomes are for people who come into contact with the criminal justice system are explored.

1.1 Theories of Crime.

Trying to understand why people commit acts which may be defined as crimes is a relatively new area of thought and can be traced back to the early 18th century, with the development of a secular state and a system of laws, as distinct from a religious state with a system of morals. Hollin (1989) suggests that theories of crime may be divided into three main kinds- the consensus view, the conflict view and interactionist view (see figure 1.1). These theories have been influential in developing the criminal justice system that we have today and our approach to people who may be defined as mentally disordered offenders.

(i)The consensus view

This view holds that society is an integrated structure with a consensus from the majority as to what constitutes crime. The consensus view states that laws exist to maintain order and therefore any transgression of the law must be punished. Two main schools of thought exist within this – the classical school, which dominated criminology between 1600 –1850 through the works of Beccaria (1764) and Bentham (1789); and the positivist school exemplified by such writers as Lombroso (1895), Ferri (1901) and Sheldon (1949). Positivism was extremely influential between 1850 and 1920.



The consensus school asks: “Why do some people break the rules?”

Interactionists ask: “How did this person come to be labelled as deviant?”

The conflict school asks: “Who makes the rules and who benefits from their enforcement?”

Figure 1.1 : Crime and Deviancy Theory Map
(adapted from www.hewett.norfolk.sch.uk/cuttic/soc/crime/devmap.htm)

The classical school of thought was based upon concepts of free will and rationality. Breaking the law was considered an act of choice, and crime could be effectively prevented if the punishment was severe enough to dissuade someone from committing that act. Bentham (1789) developed the theory of utilitarianism – the ultimate good is the achievement of the greatest happiness of the greatest number of people. In the case of crime, the maintenance of law and order benefited the majority, and harsh punishments inflicted on individuals could be easily justified in terms of the benefit to society. Beccaria also argued for "a proper proportion between crimes and punishments" (Beccaria, 1764, p.62). People who were unable to behave rationally such as the "deaf-mute" or someone who was "insane" were treated differently, but in the main, people were held to be responsible for their actions and punished accordingly.

The main criticism of the classical school of criminology is that if criminal acts were committed purely as a result of individual volition only, then there would be no pattern to crime. The development of the collection of statistics, particularly in France, from 1827 onwards, highlighted the fact that there was indeed a pattern to crime, and in particular links to such factors as age and gender, something that the classical school would find hard to explain.

The positivist school of thought tried to explain why some people committed criminal acts through quasi-scientific explanations. This school challenged the idea that people committed crime out of rational choice, but suggested that a better explanation was that there were factors which criminals were unable to influence. Writers concentrated on isolating specific causes which distinguished criminals from non-criminals, using such tools as statistics and anatomy. Lombroso (1895), for example, suggested that some criminals were "born bad" – that there were biological causes of crime and that criminal types could be identified through such features as facial characteristics. Ferri (1901) argued that criminals were determined by a combination of biological, social and environmental factors. Sheldon (1949) suggested that a certain physiology was related to a particular kind of personality that determined criminality.

The logical conclusion of positivism is that if peoples' behaviour is controlled by other factors, then if one eradicates those factors, one can eradicate crime. If social and environmental factors are the cause then, rehabilitation and treatment, rather than punishment, should be the outcome of any criminal act. However, it is unclear what would be an acceptable response for biologically determined causes of criminality – if characteristics are unchangeable or untreatable then eugenics would be a logical conclusion. It is perhaps the positive view which drives the current government's perception of crime. Thus young offenders are rewarded for good behaviour and "treatment" programmes are provided in prison and probation services, whilst people with a diagnosis of personality disorder are locked up for life as if the causes of their potential offending behaviour cannot be removed (as exemplified by the proposed new Mental Health Act).

Positivism has been criticised for the veneer of objectivity which it gives to "crime". Clearly what constitutes a crime varies from society to society and over time. It used to be acceptable in 19th century Britain, for a husband to beat his wife and child providing that the rod was no thicker than his thumb. This would now be considered illegal. Similarly sex between gay men was illegal in the past, but is now legal. Given that crime is a socially defined construct, it may not be appropriate to claim it can be studied objectively in the simplistic way that positivism suggests.

Durkheim (1895) was the first theorist from the consensus view to move away from an individually focused explanation of crime. Instead he argued that social phenomena such as crime and law have an existence of their own regardless of how they are experienced by individuals. He suggested that crime was normal, as there is no such thing as a society without crime, and that it served a useful function to society because it established clear moral boundaries and enabled change. This was particularly important in society in which norms were breaking down and people were no longer clear about how they should behave ("anomie"). Not only does a society which constrains all forms of differences including idealists and criminals stagnate, but some "criminals" such as Socrates and Mandela enable society to move onto a higher plane, by exposing the injustices within the society that criminalises them. Therefore crime should not be seen as evil, but as a necessary part of a healthy society. Durkheim has been criticised for not locating the functionalist view within an historical analysis of society, and for failing to recognise that not all crimes benefit society.

(ii) The interactionist view

The interactionist view argues that society rather than the individual actor creates crime and deviancy. This view holds that there is no such thing as crime – consider the act of killing during a war and in peacetime. It is society's interpretation of an act and its reaction which creates the meaning of that act. Interactionism or societal reaction theories, by examining the process of criminalisation rather than individual characteristics of criminals, changed the nature of the debate about crime and its causes. Goffman (1963), for example, suggested that the acquisition of a stigmatised identity, such as that of a criminal, was a two-stage process. The first stage was learning the values and beliefs of mainstream society and the general idea of what it would be like to be viewed abnormally. The second stage began when people were viewed in this way, and discovered the consequences of this perception. Once an act was committed that was perceived as criminal, and the label "criminal" was given, then society would react to that person in a particular way, e.g. by excluding him/her. Any subsequent behaviour would be interpreted as criminal and the person would be unable to challenge or change the behaviour towards him/her resulting in the person becoming "locked" into that role. It was argued that people become criminals as a result of these processes and that labels provide a way of maintaining social control, and differentiating between us and them – the normal and the abnormal.

Labelling and societal reaction theories have been criticised for not explaining why someone becomes labelled as a deviant. In addition because of their concentration on meaning and relativism, they run the risk of denying the existence of such things as "crime" and "madness." Finally, labelling theories cannot account for the positive embracing of identities and labels which may be seen as stigmatising. Stigmatised groups such as gay men and lesbian women, Black people and disabled people have reclaimed the labels and use them to challenge dominant perceptions.

(iii) The conflict view

Conflict views are usually described as oppositional to consensus views as they argue that crime is the product of conflict between different groups in society and the law is not the representation of the majority but instead maintains social control (Hollin 1989). Marxist theories of crime assert that crime is created by the unequal distribution of wealth and the maintenance of economic and political power of one group of people over others by criminalising certain acts by certain groups and legitimising others (Bonger, 1996).

Marxist or radical criminology has been developed by such writers as Taylor, Walton and Young (1996) and Hall (1996). Muncie et al (1996) describe radical criminology as an attempt to synthesise existing theories in order to create a new criminology which does not focus on crime, but on criminalisation and control. Thus elements of individual meaning, social power and control were taken from the interactionist view and grounded in a historical critique of society, in particular an analysis of the economic modes of production. Marxist theories criticised the view that the criminal justice system operates objectively and exposed discrimination in the over-representation of young Black men and the working classes. It is argued that unlawful acts are committed at all levels in society, but only those committed by the working class are criminalised. Statistics therefore do not reflect the true picture and crimes by the state, such as pollution, and the agents of the state, such as violence by the police, should be included in any description of crime. Marxist theory has been criticised for being somewhat limited in its analysis and so has been developed to take account of gender and race issues (e.g. Scranton and Chadwick, 1996). Clearly a disability dimension is also required.

Conflict theories argue then, that not only is crime an inevitable product of a society based upon inequality, but that the criminalisation serves a useful purpose in ostracising those who dare to challenge the state through the process of criminalisation and the creation of the "them and us". Taylor, Walton and Young (1996) argue that a theory of crime which does not challenge the inequalities in society will inevitably slip into correctionism, rather than address the reasons why some people become "criminals". It is perhaps because of the difficulties of challenging the foundation on which capitalist society is based, that Marxist theory has had limited impact on social policy.

(iv) Post-criminology?

New theories of criminology, particularly feminist theories and those which are beginning to deconstruct theories of crime based upon Foucault's analysis of power, suggest that there is no one theory which will properly address all the dimensions necessary to understand crime. Muncie et al (1996) described post-modernism, with its rejection of established concepts such as crime, as challenging accepted epistemologies and leading to a new understanding of the relations between poverty, criminalisation, inequality, racism, sexual violence and repressive state practices. This view has itself has been criticised for its slide into relativism leading to the lack of a clear framework with which to identify injustices and argue against them.

(v) Conclusion

Theories of crime may be seen to have evolved from looking at individual characteristics of criminals to looking at social characteristics of individuals to looking at what society gains from the perception of some people as deviant or criminal. However, this would perhaps be a mis-representation of the development of analyses of criminology as early classical theories continue to inform the new Right's law and order policy and positivism the new Left's policies on crime and disorder. Research still aims to look at why people commit crime in order to change those factors and reduce the occurrence of crime and recidivism as shown by Farrington and West's analysis of working class boys in London (1993). This longitudinal study found that there was a link between childhood "risk factors" of troubleness, daring, a delinquent sibling, a convicted parent and chronic offending in later life. They also suggested that based upon this study that the majority of chronic offenders could have been identified by the age of 10 and that there was an argument for treatment at this age to prevent later persistent offending.

The view that is held here, however, is a Marxist view of crime, criminalisation and control. Mentally disordered offenders, perhaps more than any other group of people, expose the contradictions in the capitalist state, straddling as they do the position between social junk and social dynamite. Marginalised by a society which discriminates against people who are deemed unable to contribute economically, they are often ignored until they come to the attention of the criminal justice system where the failure of the welfare state is exposed. The difficulty then is how to deal with a group of people who are seen to be vulnerable and at risk, yet also a threat to law and order. The constant tension between care and control within the welfare state and treatment and punishment within the criminal justice system is becoming even more strained as a result of having to deal with a group of people whose only common factor is the experience of exclusion and discrimination.

1.2 Who are Mentally Disordered Offenders?

Mental disorder is defined in section 1(2) of the Mental Health Act 1983 as

> *"mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of the mind."*

There have been many criticisms of this definition, not least because of the lack of specificity of some of the concepts used. People with learning difficulties fall under two main headings within this legislative framework – that of mental impairment or severe mental impairment- and in order for disposal to hospitals to be triggered they are required by the Mental Health Act to also have "abnormally aggressive or seriously irresponsible behaviour." (See Appendix 1 for a fuller description of sections under the Mental Health Act 1983).

Newham (1994) suggests that:

> *"mentally disordered offenders should include the much larger number of people who are mentally disturbed or hard to place, and who might be unnecessarily criminalised by their involvement with the criminal justice process"* (Newham,1994, p.16).

She further suggests that the concept of mentally disordered offenders should include the following groups:

1. Serious offenders who fall within the legal framework of the Mental Health Act 1983.
2. Petty offenders suffering from a mental disorder whose offending does not warrant much longer-term official involvement by probation or other services

3. Sex offenders who may benefit from a form of community based psychological counselling
4. Substance misusers for whom treatment is a viable option
5. Violent offenders who might benefit from psychological intervention
6. Detainees under s136 whether or not they are suspected of any offence
7. People whose mental state gives serious cause for concern, but who fall outside the legal classifications and the current service network.

This clearly represents a substantial widening of the term mentally disordered offenders, and whilst this reconceptualisation is based upon an awareness that vulnerable people who come into contact with the criminal justice system require services that they are not receiving, it in no way guarantees access to support. The current construction of services, based as they are upon diagnostic criteria, leads to problems for people who have significant needs but may not meet service eligibility criteria despite the range of services that they may come into contact with (see Appendix 2). This aspect of service delivery is discussed in more detail later.

Wider definitions seem to be used more frequently than the tighter legal definition of mentally disordered offenders. The definition of mentally disordered offenders which is generally used (e.g. James, 1996) is that which NACRO formulated in 1993.

> *"Mentally disordered offenders are defined as those offenders who may be acutely or chronically mentally ill; those with neuroses, behavioural and/or personality disorders; those with learning difficulties; some alcohol and substance misusers; and any who are suspected of falling into one or other of those groups. It also includes those offenders where a degree of mental disturbance is recognised even though that may not be severe enough to bring them within the criteria laid down by the Mental Health Act 1983"* (quoted in Newham, 1994).

Although wide ranging this definition does not include people with high functioning autism or Asperger's syndrome as these people will fall outside of the mental illness and learning difficulty categories. Clearly people with high functioning autism or Asperger's need to be included in any definition of mentally disordered offenders because of the particular vulnerabilities of this group of people which mean that they frequently require access to support in order to prevent offending or reoffending. However, as this definition fairly succinctly defines the population who are usually studied under the broad definition of mentally disordered offenders, it is used within this document, with the addition of people who have Asperger's syndrome.

Care should be taken when using any definition of mentally disordered offender because although they have the appearance of objectivity, these definitions are based upon models of individual pathology. Such an approach presupposes the existence of two discrete and mutually exclusive groups of people – us and them, the normal and the abnormal, the healthy and the sick (Peay, 2002).

> *"Mentally disordered offenders occupy that social space between the two poles of these binary oppositions: first, as the mad forced insane by crushing external pressures and unable to resist due to presumed inner psychic weakness; second, as the bad, the criminal, the offender and the monster"* (Mason and Mercer, 2000, p.169).

Thus disabled people who come into contact with the criminal justice system are often perceived as doubly deviant, due to their disability and criminal behaviour.

Peay also warns of the danger of being singled out as a special group requiring special attention as it all too often results in special discrimination.

> *"Stigmatising involves projecting onto an individual or group, judgements about what is inferior, repugnant, or disgraceful. It translates disgust into the disgusting, apprehensions of danger into dangerousness. It is thus the creation of spoiled identity; first it singles out difference, next calls it inferiority and finally blames those who are different for their outcomes."* (Porter 2001, quoted in Peay 2002).

1.3 Characteristics and Prevalence Rates of People with Learning Difficulties and Mental Health Needs in the Criminal Justice System.

There is a wealth of information on the characteristics of people with learning difficulties and mental health needs who engage in behaviours which are potentially chargeable offences. However this information does not constitute a coherent body of knowledge which may be used to inform practice and service development, given that much of the research is contradictory in its conclusions.

Interest in the links between learning difficulty, mental health needs and crime is not a new subject, but probably the most influential studies have taken place over the last 50 years, a period years which has seen significant changes in the way that services have been provided to people with learning difficulties and mental health needs. The move in focus of service provision from incarceration in institutions to care in the community, together with the development of philosophies such as normalisation (Wolfensberger 1983, Brown and Smith 1992, Dalley 1992), user empowerment (Servian 1996, Davey 1999, Barnes and Bowl 2001)and the social model of disability (Oliver 1996, Aspis 1997,Chappell 1997, Goodley 2000) have created a changing context in which people with learning difficulties and mental health needs live their lives, as well as shaping a range of reactions from involved services. Lund's (1990) retrospective analysis of people with learning disabilities in Denmark who received a community care order (something like the hospital order operational in England) shows quite a different response to people committing crimes in Denmark in 1973 and in 1984. He found that the process of deinstitutionalisation together with philosophies of normalisation led to a decreased use of the community care order for people with borderline learning difficulties, and concluded that "ordinary penal sanctions are used in their stead." (Lund, 1990, p.730).

Clearly whilst studies in different countries give us indications of what prevalence rates and characteristics may be for us in England and Wales, the varying service philosophies and different legal frameworks mean that a range of conclusions may be reached about the kinds of offences committed by people and the likelihood of defined groups of people to commit offences. A survey of the level of learning difficulties in the prison population in Ireland, for example, identified prevalence rates of 28.8% due to the non-existence of mechanisms for identifying and diverting people with learning difficulties who came into contact with the criminal justice system (Murphy et al, 2000). For this reason the following summary of research will concentrate on studies conducted in England and Wales.

Studies generally take one of two different approaches – in the first approach, a population of people with learning difficulties or mental health needs are studied and prevalence rates and characteristics based upon this. These studies tend to be larger. The most important example of studies of this kind are the Hodgins studies (1992, 1996). These suggest, based upon two birth cohorts, one in Sweden and one in Denmark, that people with learning difficulties are more likely to commit crimes.

In the second approach, populations of people at different points in the criminal justice system are analysed to ascertain what proportion of people have learning difficulties or mental health needs and what kinds of crime they have committed. These prevalence rates are often compared to general prevalence rates in the community and under or over representation is ascertained. These studies tend to be smaller in size.

Whilst making fascinating reading, both approaches bring with them difficulties of interpretation. Widely varying rates of offending and descriptions of likely offending behaviour have arisen from these studies. Differences in methodology such as definitions of learning difficulty or mental health, sample sizes and the question of who administers measures or questionnaires have all led to different conclusions. MacEachron (1979) summarised some of the issues she discovered when looking at research carried out in America into prevalence rates and predictors. With particular reference to prevalence rates of offenders with learning difficulties, she found that these varied from 2.6% to 39.6%, and that this wide variation could be explained by

> *"..the population base used to estimate prevalence rates [i.e. a total population tended to produce lower prevalence rates than a sample] and the way mental retardation is defined and operationalized [there was a wide variation in accuracy of tests used and by the use of unadjusted test scores when looking at IQ measurements]."* (MacEachron,1979, p.166).

McBrien (JARID 2003) summarised 14 different studies which examine populations at different points within the criminal justice system with a view to identifying alleged offenders or offenders with learning difficulties and concludes that six different methods are used to identify learning difficulty, only one of which includes attention to socially adaptive behaviour (the remainder focusing on IQ alone). She concludes that

> *"..the majority of the UK research has used less than adequate classification of intellectual disability, which renders resulting prevalence rates unreliable"* (McBrien, 2003, p.99).

This explains why marked disparities have been found in studies which have taken place at the same points within the criminal justice system - in police stations, courts, Special Hospitals and prisons.

However, given that the criminal justice system acts as a filtering system, it represents a useful framework for summarising research which has been carried out in England and Wales. It should be noted that research tends to focus on people with either mental health needs or learning difficulties. Issues of dual diagnosis have not been explored by these studies, possibly because of the small numbers in these studies, the problems of diagnosis, and the possibility that offending behaviour in people with learning difficulties may be viewed as challenging behaviour and interpreted as being a result of the learning difficulty rather than looking for other reasons such as mental health needs (Zigler and Burach, 1989). Prevalence rates of mental illness found in people with learning difficulties generally appear to vary between 10% and 80% across studies (Caine and Hatton,1998). However given that people with both learning difficulties and mental health needs may be more likely to have offending behaviours (Day, 1990; Linnaker,1994;Clare and Murphy, 1998), this area requires greater attention in the examination of challenging and offending behaviours.

The prevalence rates, characteristics and experiences of people with Asperger's syndrome will be summarised separately as this is still a relatively new area of research which is still developing.

1.3.1 Entering the Criminal Justice System : Offending vs. Challenging Behaviour

Clearly not everyone who commits a criminal offence comes into contact with the criminal justice system. This may be because the crime is never reported or the person who committed the crime is never found. For people with learning difficulties and mental health needs who are in contact with other services such as those provided by social or health services, their actions may be more visible. However this does not necessarily mean that alleged offences are reported more frequently to the police.

Studies have been carried out in populations of people with learning difficulties in a particular area in order to establish levels of reporting to the police. Lyall et al (1995) carried out a survey of all people with learning difficulties living in residential homes or attending day centres in Cambridgeshire (n = 358) and established that 2% (n=7) of this population had been reported to the police for allegedly committing offences. Despite this, there had been a number of serious incidents which had not been reported. The reasons given for this by care staff were that they believed that the police would not take people with learning difficulties seriously either as witnesses or suspects, there was a feeling that the situation should be dealt with "in-house" and that there was a lack of policies and procedures to guide staff regarding reporting to the police. The first reason for low level of reporting to the police was perhaps borne out by the fact that in the main no action was taken by the police and only one person of the seven reported to the police was cautioned. In addition, no referrals were made to specialist health services in order to offer the suspect support, following the alleged offence.

McNulty et al (1995) found higher levels of reporting to the police (about 5%) in a study carried out in London and higher levels of response from the police. The study focused on 180 people with learning disabilities living in supported houses. In 9 cases the police were called by staff who mainly wanted help with restraining service users (5 out of 9 cases). Most people suspected of offences were cautioned and nearly one-third were charged. Less than half the staff found that the police were sensitive in their approach – the greatest difficulties were encountered when staff were reporting alleged offences on behalf of a resident who were victims of crimes. Statements were taken in only one of these cases (n =8). This study would suggest that crimes committed by people with learning difficulties are only taken seriously if reported by a member of staff.

Crichton (1999), in a study which used a vignette to explore the views of 120 staff working in group homes for adults with a learning difficulty, found that the majority of staff rated the reporting of an incident of sexual abuse to the police as one of the least helpful responses. The most helpful was considered to be making a careful record of what had happened, talking to the perpetrator and the line manager. Crichton concludes that

> *"[p]ossibly subjects had become so habituated to similar behaviour as to not consider it sufficiently serious to involve the police. Alternatively, the belief that the fictional perpetrator should also be treated as a victim, or the belief that the police would have little to contribute, may have affected this response. "* (Crichton, 1999, p.222).

McBrien et al (2003) carried out a study of people with learning difficulties known to statutory services in one local authority (n = 1,326) who had either offending behaviour or were at risk of offending, and concluded that 26% of these were potential or actual offenders based upon case analyses of a screening questionnaire completed by staff. 9.7% of people had had previous contact with the criminal justice system, and 2.9% of these had received a conviction. McBrien et al found that people who had had contact with the criminal justice system were significantly more likely to commit offences, including sexual offences, against children. This study also suggests that there is significant under-reporting of offences to the police.

The numbers in most of these studies were small, but is clear from the McNulty and Lyall studies and studies of the response of the criminal justice system to people with learning difficulties who are victims of crime (e.g. Williams, 1995; Mencap,2001) that the response of the police is often dismissive.

For people with learning difficulties who are in contact with social or health services, there may be another factor in terms of non-reporting of possible offences, and that is that their behaviour may be seen as challenging rather than offending, and therefore more appropriately dealt with by members of staff. There may also be fears that people with learning difficulties may end up in prison with disastrous results (Murphy and Mason, 1999).

Challenging behaviour has been described by Emerson as:

> *"culturally abnormal behaviour of such intensity, frequency and duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to serious limit use of or result in the person being denied access to ordinary community facilities."* (Emerson, 1995).

Challenging behaviour may be found in 10-15% of people who use health, social or educational facilities and severe challenging behaviour may be found in 5 –10% (Emerson,1998). People with severe learning difficulties are more likely to have challenging behaviours. Challenging behaviours are more common in men and people often have more than one challenging behaviour. The concept of challenging behaviour encompasses a wide range of behaviours, some of which are also offending behaviours, e.g. assault with and without a weapon and theft (Emerson et al, 1990). Confusion does exist in services as to what constitutes challenging or offending behaviour. Lyall et al's study (1995) showed that even in cases of rape, not all alleged perpetrators would be reported to the police by members of health and social care staff. In 1994, a conference held by the Mental Health Foundation (Newham, 1994) to look into the needs of mentally disordered offenders, asserted that there was a clear distinction between offending and challenging behaviour. It may be that this "distinction" does not exist in reality but does drive professionals' perception of the behaviours – they are deemed to be challenging rather than offending and thus considered to be the responsibility of the service. Alleged perpetrators of criminal acts, such as physical or sexual assault are often punished through service specific sanctions such as the removal of privileges, or more commonly, permanent or temporary exclusion. It may also be that the behaviours which involve other service users and formal and informal carers are viewed as challenging rather than offending. Thus it may be only behaviours which are committed in the public domain or against members of the public that may be defined as offending rather than challenging.

For people who are not in contact with services, and this constitutes the majority of people with mild or borderline learning difficulties, allegedly committing an offence may result in contact with the police, if they are caught, in common with non-disabled people. People with mild/borderline learning difficulties may be more likely to be apprehended by the police and charged with the offence because there is a tendency for people with learning difficulties to be lacking in skills relating to concealment and to have an increased desire to please their interrogator (Prins, 1995; Winter et al, 1997). If people are not identified as having a learning difficulty when arrested, then they will not be diverted and will end up in the mainstream criminal justice system, where they are less likely to do well.

For people with mental health needs, where they are in contact with services, incidences of offending behaviour may be dealt with as either further evidence of a continuing illness and therefore requiring a service response, such as increased or changed medication, or the alleged offender may be reported to the police. It has been suggested by Mason and Mercer (2000) that when this happens they are dealt with extremely seriously in terms of disposal, and there is certainly anecdotal evidence to support this, e.g. Gunn and Taylor (1993), Curtis et al (2000).

Research also suggests that people with mental health needs are more likely to be caught if they engage in offending than non-disabled people. Robertson (1988) looked at remanded prisoners with a diagnosis of mental illness and compared their circumstances of arrest to those of the general population. He found that people with schizophrenia were more likely to be arrested because they remained at the scene of the crime (in 75% of cases compared with 37% of non-disabled offenders) or they gave themselves up (28% of people with schizophrenia compared to 1.2% without schizophrenia).

The studies carried out so far indicate that people with both learning difficulties and mental health needs who are in contact with services may be similar in so far as they may be dealt with within the confines of that service. Clearly this raises issues in terms of justice, with service users often being found "guilty" by members of staff without the opportunity to present their own stories. Where people are reported to the police, and for people with known learning difficulties, this only represents a small minority, the police rarely prosecute as the following studies show. The likelihood of prosecution appears to be related to the severity of the crime and the number of offences. People with mental health needs are more likely to come into contact with the police directly as a result of their behaviour related to the offence, rather than being reported via any services. The numbers of people at the police station who have learning difficulties or mental health needs therefore do not reflect the entire population of people with learning difficulties or mental illness who have committed offences, nor are the numbers comparable with the remainder of the offending population who are not subject to the same filtering processes. However, the studies which are based in police stations represent the closest we have to a full picture of people with learning difficulties and mental health needs who offend given that they have undergone fewer filtering processes than studies at other points in the criminal justice system.

1.3.2 People with Learning difficulties and Mental Health Needs at the Police Station

There have been a number of pieces of research into the prevalence rates, characteristics and experiences of people with learning difficulties, people with mental health needs and people with both mental health needs and learning difficulties at police stations. These studies vary between trying to establish the impact of the implementation of particular processes, such as the "Notice to Detained Persons", to looking at what kinds of offences may be committed by people with mental health needs or learning difficulties and the consequences of those actual or alleged offences. Most researchers concentrate on either people with mental health needs or people with learning difficulties when looking at people who have been suspected of committing an offence or require a place of safety and are taken to a police station. (The main exception to this focus on either people with learning difficulties or people with mental health needs in police stations is the work of Gudjonnsson et al, (1993,1995) who look at the experience of "vulnerable adults" in the police station.) For this reason, the findings of studies are summarised separately under the headings of either learning difficulties or mental health needs.

(i) People with learning difficulties at the police station

There are three studies which have looked at the prevalence of people with learning difficulties in the police station. Two of these were carried out in

Cambridge (Lyall et al, 1995 and Winter et al, 1997) and one in two police stations in south London (Gudjonsson et al, 1993). These studies found quite different prevalence rates with the Gudjonsson study identifying a prevalence rate of 8.6% for people with an IQ of 69 and below and 42% for people with IQs between 70 and 79 and the Lyall study identifying prevalence rates of 15.2%. The numbers were too small in the Winter study to identify prevalence rates (n=21). However of those identified as having a learning difficulty through screening, only 2 people had an IQ less than 70 which means they would be classified as having a mild learning difficulty. This indicates a lower prevalence rate than that determined by Gudjonsson. Interestingly, although all interviewers were forensic psychologists in the Gudjonsson study, they were only able to identify 3% of the population as having a learning difficulty without testing.

Differences in prevalence rates may be explained by both the methodology and the location. The Gudjonsson study and the Winter study used screening questions (see table 1.1) followed by a number of tests including the short form of the WAIS-R. Performance on IQ tests is known to be affected by anxiety as people may score lower in times of stress, for example at a police station, and so studies which use IQ scores may over-identify people. It is known that there are higher prevalence rates of people with learning difficulties in lower socio-economic areas such as Peckham which may have also contributed to the figures identified in the Gudjonsson study. Winter also suggests that the screening questionnaire may have led to an under-identification of people with a learning difficulty in his study.

Four Item Screening Questionnaire

1. Do you have difficulty in reading and writing?
2. While at school did you receive some extra help because you had difficulty learning?
3. Did you attend a special needs school?
4. Please name the last school you attended.

Table 1.1: Four Item Screening Questionnaire (Lyall et al, 1995)

The Lyall study also identified people with a learning difficulty by the use of this four item screening questionnaire which was administered by the custody sergeant. No other tests were administered to identify learning difficulty. The Lyall study may have over-identified numbers of people with learning difficulties as people may attend special schools for other reasons than intellectual impairment. Equally it may have under-identified numbers of people with learning difficulties if they did not wish to be identified as such. Not all people taken into custody were screened using this questionnaire – some officers only used it intermittently and others did not use it at all.

All studies found that the most common offence was theft. The Lyall study found that the exception to this was the group of people who had attended a school for children with emotionally disturbed behaviours. The majority of suspects with learning difficulty were male and in their twenties. When comparing offenders to a group of non-offenders with learning difficulties, Winter et al (1997) found that people with learning difficulties were more likely to offend if:

- Their parents were separated or divorced
- There was previous contact between forensic services and the family
- They were unemployed
- They had significant behavioural problems at school
- They had high levels of drug use.

There was also a possible relationship between significant life events and offending. This relationship has also been established in connection with people with mental health needs and offending. A study into 436 male prisoners in America (MacEachron, 1979) identified similar social characteristics in both people with learning difficulties (IQ below 70) and non-learning disabled people. Prisoners with a learning difficulty were more likely to be in their 30s, have been in special education classes, be single, unemployed or with a low income, have a history of drug and alcohol problems and come from a large family. 73% of prisoners with a learning difficulty had been in prison before.

Two of the studies identified high rates of recidivism. In the Winter study all the study group had committed previous offences. In the Gudjonsson study, over 70% (of the people with learning difficulties and people with mental health needs identified at the police station) had committed previous offences and 36% had served a previous sentence. The Lyall study did not look at this.

By far the most common outcome for the suspects in the Lyall and Winter studies was being remanded in custody. In the Lyall study, half of the people who had received special education attended court, as compared to 37% of the alleged offenders who had not received special education. One person from the Lyall study received a custodial sentence.

(ii) People with mental health needs at the police station

People who may be described as being mentally vulnerable and who are found at the police station may be there either because they have been arrested or because they have been taken there initially as a place of safety. Prevalence rates vary from 1.2% to 7% for people with a diagnosis of mental illness who have been arrested, depending on the definition of mental illness (Robertson, 1996; Guite and Field, 1997). Gudjonsson identified 7% of those arrested as having a mental illness – either severe depression or schizophrenia (Gudjonsson et al, 1993). The difference between Gudjonsson's figures and those of other studies may have arisen from methodology and definition - Gudjonsson's figures were based upon an assessment of mental state at the time rather than a formal diagnosis. For London, actual numbers have been estimated at about 10,000 people with mental health needs who come into contact with the police during one year (Revolving Doors Agency, 1996).

It is difficult to establish prevalence for particular diagnoses of mental illness for people have who are arrested. Based on custody records in a police station in London, Robertson (1996) identified 2/3rds. of those arrested who had mental health needs, as having schizophrenia. Revolving Doors identified a wider range of conditions, with 38% of the study group having an affective disorder (clinical depression), and 15% a psychotic illness (Finn et al, 2000). Different results were obtained because of the differing methodologies. The latter study relied upon the police from 3 police stations (2 in London and 1 in High Wycombe) identifying people with mental illness who were eligible for assessment and treatment under the Mental Health Act 1983. Whilst the police were accurate in 97% of these cases (Finn et al, 2000), it is likely that the police missed some people who were unwell because of their tendency to concentrate on behavioural abnormalities as evidence of mental illness (Gudjonsson et al, 1993; Walker, 1996).

Most people with mental health needs are arrested for petty offences such as breach of the peace, a public order offence or an acquisitive offence (Robertson,1996; Finn et al 2000). People with mental health needs are between 2 and 3 times more likely to be arrested for alcohol related offences than the general offending population (Finn et al 2000). The majority of mentally disordered offenders found at police stations, i.e. 77 – 80%, have previous convictions (Guite and Field, 1997).

People with mental health needs who commit offences tend to be older than the general offending population (Robertson, 1996 and Finn et al, 2000). Finn suggests that this is because the incidence of diagnosis of mental illness increases with age, and the incidence of offending decreases with age resulting in a concentration between ages 35 and 45. Like the general offending population, most offenders are men (Guite and Field, 1997), although in the Revolving Doors study, 1/3rd of those identified by the police were women. There is also an over-representation of young Black men amongst mentally disordered offenders. This may arise from the over-representation of Black men in the category of schizophrenia (and now personality disorder); racial bias in the reporting of crime and institutional discrimination in the police force and social and health care systems (Burney, 1995).

The outcomes for people with mental health needs varies considerably from police station to police station because of variation in practices. People who had committed similar offences were between 3 and 8 times less likely to receive bail from a London police station than from the High Wycombe police station (Finn et al, 2000). In general, people with mental health needs are more likely to be charged for less serious offences, such as begging, usually because they are persistent offenders. People with a diagnosis of serious mental illness, such as schizophrenia tend to be remanded into custody rather than bailed if they are homeless or displaying florid psychotic symptoms probably because of the perceived risk of reoffending rather than as a result of the nature of the offence (Robertson, 1996).

(iii) Discussion

The studies of people with mental health needs and learning difficulties at police stations have identified a number of themes:

- The profile of people with learning difficulties at police stations is similar to that of the general offending population in terms of gender and the most common offence type of offence, i.e. acquisitive
- People with learning difficulties and mental health needs who are taken into custody seem to have a high rate of previous convictions
- The profile of people with mental health needs who are arrested and taken to police stations is different from that of the general offending population. This population tend to be older, there is a higher proportion of people from Black and minority ethnic communities and the most common offence tends to be a public order or breach of the peace offence, often connected to drinking.
- Both people with learning difficulties and people with mental health needs were often more persistent offenders than offenders from the general population. This may not mean that these groups of people are more likely to reoffend, but rather that they maybe more likely to be rearrested.
- Both people with learning difficulties and mental health needs were likely to have had a significant life event in the last 6 months
- People with mental health needs were more likely to be homeless than the general offending population
- There were low levels of charging for both people with learning difficulties and people with mental health needs, compared to other suspects.
- Outcomes varied according to police station.

The studies therefore suggest that a significant minority of people, who are vulnerable for a number of reasons, repeatedly come into contact with the police, but do not receive the assistance that they require to overcome the difficulties that they experience. Instead they are often returned to the community where they continue to struggle, often reoffending and coming yet again into contact with the police. This circle may only be broken when people become identified as persistent offenders or commit an offence of such seriousness that the police are forced to take appropriate action.

The role of the police in this situation may be seen as both the gatekeeper to support services as well as maintaining law and order. However, the police are not trained to identify vulnerable people (Mencap, 1991) nor are there robust referral mechanisms to appropriate services for the police to use. Indeed where the police have tried to refer on to other services, they have found that this is difficult if not impossible, because the eligibility criteria are too tight (Robertson, 1996). Some studies have found that the police, despairing of any response from social or health care services have funnelled people into the criminal justice system (Teplin, 1983). The boundaries appear to be becoming increasingly blurred between the criminal justice system and the welfare state, leading to a resurgence of interest in transcarceration and Penrose's law (where the proportion of people incarcerated in psychiatric institutions or prisons remains the same, but the ratio of people in each one varies in accordance with social policy) (Hudson, 2003).

1.3.3 People with Learning Difficulties and Mental Health Needs in Court

(i) <u>People with learning difficulties in court</u>

There has been only one unpublished study looking at the prevalence rates and characteristics of people with learning difficulties who appear before magistrates courts (French et al, 1995, reported in McBrien, 2003). This study identified a prevalence rate of 1.4% of people with learning difficulties attending magistrates courts over a period of 6 weeks. French et al used the same screening questions as Lyall et al (1995) to identify people with learning difficulties.

There are also studies of court diversion schemes which identify extremely low numbers of people with learning difficulties due to appear in court (e.g. Cooke, 1991; Joseph and Potter, 1993; James, 1996). This suggests that either there is an under-identification of people with learning difficulties or that people with learning difficulties who are alleged offenders are not often prosecuted. These findings conflict with those of the Lyall study where over half of the people who had received special education attended court. It is likely that the difference in numbers is due to methodological issues and the fact that many people end up in special education for a variety of reasons, not just learning difficulties.

Research in court also tends to focus on the experience of people with learning difficulties as victims rather than alleged perpetrators of offences (e.g. Williams, 1995; Monaghan and Patak, 2000). Studies of the experience of people in court evidence the difficulties people experience in understanding and contributing to the hearing or trial (Kebbell et al, 2001).

(ii) People with mental health needs in court

Studies which look at the prevalence rate and characteristics of people with mental health needs who appear before court often do not distinguish between people with mental health needs and people who have been diverted at court as a result of identified mental health needs (e.g. Guite and Field, 1997). Whilst people who are diverted from court should always have mental health needs (or learning difficulties), not all people with mental health needs are diverted from court. Revolving Doors found that only 40 % of people with mental health needs were diverted from court in London (Revolving Doors, 1996).

One example of this kind of study is that carried out by Robertson et al (1996). Psychiatrists involved in court diversion schemes were asked to identify people with major mental illnesses over a 6 month period. 90% of those identified had previously received psychiatric treatment, 2/3rds were Black and most were male. When compared to those detained by the police, those appearing before court showed a higher incidence of older men and people from Black and minority ethnic communities. People who appeared before court were five times more likely to have committed a violent offence, than people who did not go to court.

(iii)Discussion

It is hard to draw any hard and fast conclusions about prevalence rates and characteristics relating to people with learning difficulties and mental illnesses who attend court. Clearly people with learning difficulties and mental illnesses do attend court, but there is a need for further research into how many, what offences may have been committed and what the outcomes are.

1.3.4 People with Learning Difficulties and Mental Health Needs in Prisons

There has been rather more research into the prevalence rates and characteristics of people with learning difficulties and mental health needs who are both remand prisoners and sentenced prisoners. Studies which focus on prisons may be criticised for assuming that the criminal justice system operates on principles of fairness and consistency. There is clear evidence that there is inconsistency between police stations (Finn et al, 2000), which together with concerns reflected in the amount of guidance and legislation from central government regarding consistency in sentencing practice in courts, indicate that people with similar characteristics who commit the same crime may be disposed of differently in different areas of the country. There is also evidence that people may be imprisoned because of beliefs held by the court about the nature of that person's learning difficulty or diagnosis of mental illness rather than the offence itself (see Gunn and Taylor, 1993, p.75-77, for a description of some cases). Institutional discrimination, that is, discrimination inherent in the policies, procedures and practices of the system, may further confuse the picture by leading to false convictions (Chappell, 1994).

(i) <u>People with learning difficulties in prison</u>

There has been only one study of people with learning difficulties in prisons in England and Wales (Murphy et al, 1996). This study looked at the prevalence of people with learning difficulties on remand and concluded that not one of the men who identified himself as possibly having a learning difficulty through a screening interview (see table 1.1) had an IQ of 70 or less and it appeared that no men in a comparison group had learning difficulties either.

Those studies which have looked at people with mental health needs have often also identified people with learning difficulties in prison. Four studies have been carried out in remand prisons, using very different methodologies. These have all shown extremely low prevalence rates of learning disabilities from 0.0034% - 1% (Coid, 1988; Birmingham et al, 1996; Brooke et al, 1996) with the exception of Singleton et al (1998) which identified a prevalence rate of 11% (as calculated by McBrien, 2003) using an adapted version of the Quick Test. Singleton et al (1998) did not calculate prevalence rates themselves due to a recognition that the scores obtained were systematically lower due to both the administrative process used in carrying out the Quick Test (this involved adaptations to facilitate the computerisation of the results) and the social and cultural bias of the participants. The Singleton study therefore appears to over-represent the number of people with learning difficulties on remand.

One study has been carried out on male sentenced prisoners in 16 prisons, and this study identified a prevalence rate of 0.4% for people with learning difficulties in prisons (Gunn et al, 1991). The Singleton (ONS) study also looked at sentenced prisoners.

(ii) People with mental health needs in prison

Recent studies suggest that 39% of sentenced prisoners and 66% of remand prisoners are likely to have had a diagnosis of mental illness at some time in their lives (Revolving Doors, 1996 p.6). The higher rates of prisoners on remand with a diagnosis of mental illness probably result from the fact that mentally disordered offenders are often remanded into prison for psychiatric reports despite Home Office circulars and guidance to the contrary. Factors such as homelessness, which are particularly prevalent amongst people with mental health needs, may also lead to people being put on remand. The chances of a remand prisoner suffering from a depressive episode are twice those of a sentenced prisoner (Singleton, et al 1998). Some studies have identified lower levels of prisoners on remand with a diagnosis of mental illness – i.e. 21 – 26% (Hyslop,2000; Birmingham et al, 1996). These differences have arisen because of differing definitions and methodologies. Studies which include substance abuse as a psychiatric disorder, for example, show significantly higher prevalence levels (e.g. Brooke et al 1996).

A series of studies was carried out on behalf of the Institute of Psychiatry in the early 1990s (Gunn et al, 1991). These studies looked at the psychiatric assessments of people entering Brixton, Holloway and Pentonville Prison. The findings are based upon the concept of psychiatric "caseness", that is, only people who have a diagnosis of mental illness which warrants psychiatric intervention, are counted. This means that reported prevalence rates are lower than other studies. The Office of National Statistics have also conducted a survey of prisoners in England and Wales (Singleton et al, 1998). Both the

Institute of Psychiatry (IOP) and the Office of National Statistics (ONS) identified the kind of mental illness suffered by prisoners. The findings are summarised in the table below:

Study	Remand prisoners with psychotic illness	Remand prisoners with neurosis	Sentenced prisoners with psychotic illness	Sentenced prisoners with neurosis
ONS survey	10%	40%	7%	59%
IOP survey	2.4%	5.2%	4.8%	26%
Birmingham et al	5%	10%		
Brooke et al	5%	26%		

Table 1.2: Analysis of mental health states of prisoners

People with mental health needs are not always recognised as such and therefore do not receive appropriate treatment. Birmingham et al (1996) found recognition rates of only about one quarter of the study group (n =148) as having a mental health need by the prison doctor or hospital officer and only two fifths of prisoners who required urgent psychiatric treatment had actually been placed in the prison hospital.

(iii) <u>Transfer of remand prisoners to hospitals</u>

Prisoners on remand may be transferred to hospital. Studies show wide variations in the numbers of prisoners transferred dependent upon the availability of psychiatric expertise and beds (Anderson and Parrott, 1995, Banerjee et al, 1995, Weaver et al, 1997). People who are transferred are likely to have psychotic symptoms, violent behaviour and a previous history of mental illness. Banerjee et al (1995) found that only a third of those urgently transferred had been in contact with health or social care services at the point of arrest. Hagell and Dowling (1999) found that people who had been transferred were more likely to end up with therapeutic and non-custodial sentences.

(iv) <u>Discussion</u>

Studies of people with learning difficulties in prisons show extremely low prevalence rates. Conversely the prevalence rates of people with mental health needs in prison increase. People with mental health needs and learning difficulties were also more likely to be found in remand populations than sentenced populations, presumably due to diversion and non-custodial sentences. Studies in general focus on the prevalence rates of people in prison mainly because of the justifiable concerns that people with mental health needs are over-represented in prison and that they do not have access to the support that they require.

1.3.5 People with Learning Difficulties and Mental Health Needs Detained in Hospitals

People with learning difficulties or mental health needs who fall under section 2 of the Mental Health Act 1983 may be formally detained in hospital for either assessment and/or treatment or where people present a risk to themselves or others (see Appendix 1). People also may be referred to hospital if they are found unfit to plead (Criminal Procedure (Insanity and Unfitness to Plead) Act 1991). In this case people remain in hospital until they become well enough to stand trial. People with learning difficulties often spend a disproportionate length of time in hospital before they return to court to stand trial (Grubin, 1996).

Most studies refer to populations of hospitals as a whole rather than focusing upon one group of people. For this reason, this section looks at the findings study by study.

(i) Walker and McCabe

Walker and McCabe (1973) carried out one of the largest studies of people with learning difficulties or a diagnosis of mental illness detained in hospitals in England and Wales as a result of allegedly committing an offence. They examined 1,200 dossiers (969 men and 231 women) for a 12 month period from April 1963. For people with a diagnosis of mental illness as with other studies described earlier, Walker and McCabe found that people with schizophrenia tended to be older than the general offending population. They also found that people with learning difficulties (described as "subnormals" under the terms of the Mental Health Act 1959) tended to be younger than the general offending population. They explained this as being because many people had been institutionalised during their earlier life and had ended up offending or being admitted because they were unable to cope with life outside of an institution. Most of the patients were men, but there was a higher proportion of women in this study (just over 1/6th of the sample). This higher proportion is in keeping with the higher proportion of women in psychiatric institutions generally. The patients were characterised by low numbers of people who were married, high numbers of unemployed people, and an over-representation of African-Caribbean men with a diagnosis of schizophrenia. Of the patients in this sample, people with learning difficulties and people with a diagnosis of psychopathic illnesses were more likely to have been living at home prior to the offence, and people with a diagnosis of mental illness were more likely to have been homeless. The most common diagnosis of men within the sample was schizophrenia (42%), followed by people with mental impairment (learning difficulties). 34% men and 38% of women had a learning difficulty. More than 71% of people had committed previous offences, and there was a high rate of previous admissions to psychiatric hospitals with nearly one–quarter of people having been admitted to hospital on 3 or more occasions.

Walker and McCabe identified acquisitive offences as being by far the most common. In the main these were petty offences committed by people who were cold, hungry and often had no money. They found an over-representation of men with learning difficulties amongst the sexual offenders, with men with severe learning difficulties more over-represented than men with mild/moderate learning difficulties. 59% of sexual offences were committed by men with learning difficulties who represented just over 1/3rd. of the sample. Walker and McCabe's category of sexual offences included indecent exposure and offences from minor indecencies to rape. Walker and McCabe concluded from this that people with learning difficulties were more likely to commit sexual offences. However, this is clearly a misinterpretation of the data. What their findings show is that people with learning difficulties who commit sexual offences are more likely to be found on a hospital order than the general offending population who commit sexual offences (probably because people with learning difficulties are less likely to go to prison).

Similarly, Walker and McCabe assert that their findings confirm the well known association between arson and learning disability. Over half of arson offences were committed by the 1/3rd. of the sample of people with learning difficulties on a hospital order. Again, this mis-represents the likelihood of people with learning difficulties committing arson per se because their findings are only valid for the hospital population that they studied not the general population of people with learning difficulties. As with sexual offences, the apparent over-representation in hospital of arsonists may well result from the low likelihood that people with learning difficulties will be sent to prison.

Walker and McCabe also looked at the length of stay in hospitals, and found that a substantial minority of people remained in hospitals for more than 7 years. They felt that those patients who were detained in Special Hospitals may have deserved to remain there as they were by far the most dangerous. However, 10% of the sample comprised of unrestricted patients who were still in ordinary hospitals seven years later. These were mainly people with learning difficulties who are described by Walker and McCabe as having settled down contentedly in hospital, given that their levels of absconding were low!

(ii) <u>Dell and Robertson – Broadmoor Hospital</u>

The value of hospital disposals has also long been the subject of discussion. Is the purpose of hospital sentences to treat people or to prevent them from reoffending? Often the purpose of hospitals is seen as being both. In a study of patients in Broadmoor, Dell and Robertson (1988) found that where patients' mental health improved, discharge was based upon whether or not it was felt that the patient would re-offend. Most men in this study had committed homicide or an offence which involved serious violence. Of those with a diagnosis of mental illness, the most common diagnosis was schizophrenia.

Dell and Robertson interviewed patients to ascertain how helpful they found Broadmoor. 55% of men with a diagnosis of mental illness said that they had found it helpful whilst 25% said that they had not. The most common reason for finding Broadmoor helpful (45%) was that it had helped them with their illness. Joseph and Potter (1993), in their examination of a court diversion scheme, found that 32% of patients with a diagnosis of mental illness showed an improvement in their mental state as a result of their time in hospital.

At the time of the study, very few men with a diagnosis of psychopathy were receiving treatment. The majority (14%) were receiving individual psychotherapy. Two-thirds of the men were not receiving any therapeutic support. However three-quarters of men said that that they thought that Broadmoor had helped them. The most common reason (45%) was that they had learned more about themselves.

Significantly, Dell and Robertson found that 45% of men with a diagnosis of mental illness said that they would have preferred to have been sent to prison because of the clarity about the length of sentence in prison. However, only 37% of men with a psychopathic disorder shared this view. Dell and Robertson also discovered that although the length of time people stayed in hospital was justified by the hospital staff due to the presence of on-going symptoms which required on-going treatment, there was also an understanding that people who committed serious crimes should remain in hospital for longer.

(iii) Mason and prevalence rates in hospitals

An analysis of the Home Office annual figures of numbers of people detained under the Mental Health Act 1983 in National Health Service facilities and Special Hospitals from 1984 to 1996 found that whilst the total number of people detained under section 3 of the Mental Health Act 1983 was rising, the numbers of people with mental impairment detained was falling (Mason, 1998). The ratio of offenders detained in these establishments with a diagnosis of mental illness compared to those with mental impairment was 6:1 in 1996. The majority of people with learning difficulties came under the category of mental impairment rather than severe mental impairment and were in NHS facilities and Special Hospitals as opposed to private facilities.

Mason also analysed the kind of offences committed by people in NHS facilities from 1987 – 1996. Like other studies of hospital populations, sexual crimes (30.3%) and arson (20.8%) figure strongly. Violent crimes (23.3%) and murder (15.1%) were the other kinds of offences committed. Interestingly the annual analysis of crimes committed shows a marked decrease in the number of offenders detained in Special Hospitals who have committed sexual offences and arson between 1992 and 1993/4 onwards. It would be interesting to explore the reasons for this further.

(iv)Discussion

The hospital studies give us more information on the types of offences and the kinds of people who are sent to hospital through the criminal justice system. As might be expected, most of the crimes are particularly serious.

Although most of the population detained in hospital are people with mental health needs, there is still a significant minority of people with learning difficulties, admittedly some of whom could have a dual diagnosis. Given the different nature of their disability, the question as to whether people with learning difficulties should be considered as part of the group "mentally disordered offenders" needs to be revisited. Every revision of the Mental Health Act has seen unsuccessful lobbying from organisations who argue that people with learning difficulties have very different needs to people with mental health needs. The response of the government has been that as their behaviour is the same, they should remain within the definition (Robertson, 1981). Clearly although people with learning difficulties commit crimes, they do not require treatment in the same way that people who are experiencing florid psychotic symptoms do for example. People with learning difficulties do not get better in the sense of being "cured" of their learning difficulty, but they do develop skills and learn new ways of dealing with issues. Hospital is not the best place for this as it is very rare for hospitals to have intensive skill building programmes.

For people with mental illnesses who have committed crimes, the question still remains – are hospitals there to treat or punish? This question is often not answered clearly and people often remain in hospital for much longer than they would have remained in prison. Whilst this will always be justified by the authorities in terms of health or risk, the Baxstrom case [2] (Steadman and Halfon, 1971) gives us a valuable lesson in why people should not be kept institutionalised longer than is necessary.

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[2] 967 people were released from two hospitals in the USA for the "criminally insane" in 1966 following a ruling from the US Supreme Court. All had been detained in hospital for longer than the maximum sentence for their crime. Very few of these people re-offended with only 21 out of the 967 people being returned to the secure hospitals in the 4 years following their release.

1.3.6 People with Learning Difficulties and Mental Health Needs in the Probation Service

Little research has been carried out in the Probation Service on how the service responds to mentally disordered offenders. Vaughan and Badger (1995) suggest that existing legislation is limited in terms of both meeting the needs of mentally disordered offenders who are diverted from the criminal justice system into the community and in terms of offering community disposal options which are actually used. Probation orders with a condition of psychiatric treatment have been little used, guardianship orders are almost non-existent and community disposals under the Criminal Procedure (Insanity to Plead) Act 1991 are only applicable to the very small number of people who may be found unfit to plead. Consequently the number of convicted mentally disordered offenders supported in the community at any one time are fairly low. Vaughan and Badger estimate that between 600-700 people at any one time are conditionally discharged from Special Hospitals under active supervision in the community (Vaughan and Badger, 1994, p.150). These people may be the responsibility of the Probation Service or social services. A survey carried out by Revolving Doors (1996) into mentally disordered offenders reported that at that time 180 probation orders with psychiatric conditions were received by the Probation Services which covered Greater London, although they suspected that this figure was an underestimate.

Evidence suggests that the number of community sentences is increasing in general, as community sentences are tightened up and no longer seen as a soft option. The number of probation orders increased by 3% from 1996 to 1997 and one-third of those had restrictions attached (Sherrif, 1998). The use of community disposal options for mentally disordered offenders is fraught with difficulties, given the current prevailing public perception of crime and safety and the consequent emphasis on risk assessment and protection of the public. It is interesting to note that the public perception does not reflect the real extent of crime and there is an over-estimation of the levels of crime in general (Kershaw et al, 2000).

Mason (Mason, 1998; Mason and Murphy, 2002 (a) and (b)) has carried out a series of studies into the Probation Service in South East England. In the

Canterbury study (Mason, 1998), a prevalence rate of 5.7% of people with a confirmed learning disability was identified. Most of the 70 people in the sample group were aged between 21 and 30 and the most common offence was assault. There was a high proportion of previous offences, leading Mason to suggest that the older age group of people with learning difficulties on probation was because they have previously received other options from the court and continued to offend. Further, about 10% of people on probation were found to have IQs of 75 and under.

The Kent study (Mason and Murphy, 2002 (a)) looked at the outcomes for people with learning difficulties who were on probation. 90 people, who were due to finish their probation orders within a specified 6 month period, were screened using the Learning Disabilities in the Probation Service screening tool. This tool comprised the Quick Test (QT) and the Clock Drawing Test (CDT) which are two measures of cognitive ability (see Mason and Murphy 2002 (c)). The mean Quick Test IQ for the whole sample was 10 points below the mean for the test indicating low levels of intellectual functioning for many of the group. 7% (n = 6) of the sample achieved QT and CDT scores in the bottom 5% of normal distribution and a total of 19% (n = 17) gave some evidence of having mild/borderline learning disabilities in their answers to targeted questions. Mason suggested that this might actually be an underestimate of the extent of learning difficulties on probation because of the biases of the QT. Not one person with learning difficulties was in contact with Social Services. The majority of the total sample were male (86%), white (97%) and unemployed (68%). The mean age was 32.3 years. The most common crime was violence related. 40% of people had been in prison at least once, and 65% had been on probation at least once before.

When comparisons were made between the group of people with a probable/borderline learning difficulty (n=17) and a randomly selected comparison group, people with learning difficulties were found to have committed an offence at an earlier age, received a conviction at an earlier age and were more likely to have offended with their peers. Mason found no difference in the presence or cause of any breach action undertaken, but probation officers reported that the group of people with learning difficulties were less able to keep appointments or follow rules – both tasks that are essential to successfully completing a probation order.

Mason and Murphy concluded that the Probation Service needed to review the way it functioned in order to take account of the needs of people with learning difficulties so as to provide a service which takes account of their cognitive skills and does not unfairly discriminate against them. Additional support needs to be given to people to develop the skills such as time-keeping. The effectiveness of probation as a disposal option should be re-evaluated within the context of people with learning difficulties offending with peers – maintaining people within the same community without addressing this issue may not be the most appropriate solution.

1.3.7 Reoffending

Reoffending rates in untreated groups of offenders with learning disabilities range from 41.3%(Klimecki et al, 1994) to 68% (Scorzelli and Reinke-Scorzelli, 1979 quoted in Lindsay and Macleod, 2001). Klimecki et al (1994) and Day (1993) also found that the risk of reoffending is highest in the first year – Klimecki et al identified reoffending rates of 84% in the first year as compared with 80% for non-disabled offenders. Other data on recidivism rates for non-disabled offenders suggests that recidivism increases with the period of follow up. (e.g. Bailey and McCulloch, 1992). Follow-up studies of a sex offender treatment service support the theory that recidivism increases with time. Lindsay et al (2002) established a reoffending rate of 4% in year 1 and 21% in year 4. Mason and Mercer (2001) also suggest that the reoffending profile of mentally disordered offenders is similar to that of the non-disabled population.

Rates of reoffending may be used to try and predict who may reoffend as well as how successful a service is. The latter has received short shrift amongst professionals who argue that since reoffending can only be detected through reconviction, it is an inexact measure of success and a better measure of success is whether or not someone's mental health has improved (Guite and Field, 1997) or whether a service is of good quality (Lawrie, 1997). The studies which have been carried out into reoffending mainly relate to the tracking of cohorts from Special Hospitals, presumably because this group of people have committed more serious offences, and key studies are summarised below.

(i) Follow up studies of Special Hospitals

Walker and McCabe (1973) studied the recidivism rates for the Special Hospital population referred to before.

Study	Gender	Reconvicted and admitted to hospital or prison	Reconvicted	Total Reconvicted	Readmitted to hospital
Walker & McCabe : 2 year follow up	Men	30.8%	11.6%	42.4%	21.1%
	Women	21.9%	8.6%	30.5%	21%
Robertson: 15 year follow up	Men			68%	
	Women			67%	

Table 1.3 : Analysis of reoffending rates

At the two year follow-up period, 36.5% of men and 48.5% of women who had been released had neither been readmitted to hospital nor sent to prison. People who had been in hospital for shorter periods of time were more likely to be recommitted to hospital or prison. Walker and McCabe concluded that it was possible that people whom the hospital felt would not benefit from staying longer were being discharged earlier. People who received after-care were more likely to stay out of court and hold down a job.

Robertson (1981) carried out a follow-up study 15 years later on the same population that Walker and McCabe had studied. He suggested that men with learning difficulties had a similar career pattern to non-disabled men. There were high rates of reoffending with 68% making at least one court appearance following discharge. 28% men were given a prison sentence. The types of offences were mainly acquisitive (89%). Men with learning difficulties were convicted of slightly more sexual offences than the study population, however this is not surprising given that the original Walker and McCabe study identified a significant over-representation of sex offenders in the learning disability population (see p. 46). 14% of men returned to hospital within a few days of discharge and 19% within 6 months. Reconviction rates were similar for men with learning difficulties and mental health needs, but men with a diagnosis of mental illness tended to be older than the general offending population.

The reoffending pattern was similar for both men and women in the Robertson study, with only 33% of women with learning difficulties not reoffending during the 15 year follow-up period. 69% of the women's offences were acquisitive. There was a tendency for a small section of the study group to be responsible for a disproportionate amount of offending in both the group of women with learning difficulties and women with mental health needs, e.g. 5 women with learning difficulties were responsible for 77% of offences.

Robertson did not look at the impact of after-care on reoffending or readmission rates on the study population.

Buchanan (1998) tracked a cohort of 425 patients discharged from all three special hospitals in 1982 and 1983, looking in particular at criminal convictions received within 10.5 years of discharge. The majority of these patients were men (82%). Most patients were discharged from the special hospitals to less secure hospitals (66%). 29% of patients were discharged to the community and 5% went back to prison.

	Mental illness	Psychopathic disorder	Mental Impairment	Severe mental impairment
Diagnosis of cohort on discharge	45%	33%	17%	11%
Diagnosis of convicted offenders at 10.5 years after discharge	26%	44%	32%	11%

Table 1.4 : Analysis of discharge cohort and convicted offenders by diagnosis (Buchanan)

Percentage of convicted offenders	Violent offence	Sex offence	Serious offence	Percentage of cohort who were convicted
At 5.5 years following discharge	9%	5%	10%	26%
At 10.5 years following discharge	15%	7.5%	15%	34%

Table 1.5 : Analysis of convicted offenders (Buchanan)

Buchanan found that people were more likely to be convicted if they were male, younger and were discharged to the community. Buchanan found that the difference between the conviction rates for mental illness and psychopathic disorders was significant. Clearly this would also be the case for mental impairment if the categories were combined. Significant correlations were found with age at discharge, prior conviction and a legal classification of psychopathic disorder.

Buchanan compared his findings to those of Tennent and Way study (1984). They carried out a follow up study of patients leaving all three special hospitals for an average of 8.8 years. At this point, 55% had been convicted of an offence. 21% of patients had committed a violent offence, a category with very similar definitions to Buchanan's serious offence. Buchanan suggested that this cohort had higher rates of offending than the cohort that he followed because they were more likely to be discharged to the community as secure step-down provision did not exist then. This may also be the reason for the much higher rates of offending identified in the Robertson study as compared to the Walker and McCabe study. It may also be that the longer the follow up period the higher the reoffending rate becomes – however, Robertson identified a reoffending rate which was double that of the Buchanan study with a time difference of only 4.5 years.

Jamieson and Taylor (2002) dispute the association between reoffending and community living. In their study of a discharge cohort from all special hospitals in 1984, they found that 36% of people for whom records could be traced (n = 192) had reoffended. 22% (4) of people living in institutions had reoffended and 37% (65) of people living in the community had reoffended. Of the surviving members of the cohort (n= 166; 49 people had died), only 12 people were still in institutions and 154 were living in the community. The small numbers of people living in institutions may make affect the generalisability of this finding. Jamieson and Taylor did not investigate the kind of support that people were receiving in the community and the impact of this on reoffending.

Buchanan also does not go into detail about the kind of services the cohort he studied received, but it is interesting to note that the two groups of people who had higher levels of offending (people with a diagnosis of personality disorder and people with learning difficulties) are groups that are now the focus of reconfigured services due to the inadequate levels of provision for these groups within forensic services.

(ii) Follow up Studies of Learning Disability Secure Units

Day (1988) looked at the outcomes for 20 men with learning difficulties who had received treatment in a secure unit in a follow-up study on average 3 years after discharge. He found that over half had reoffended. People who had committed offences against other persons were less likely to reoffend than property offenders. Property offenders tended to reoffend by committing other property offences, whereas those who committed offences against other people committed a wider range of offences. Good outcomes were associated with type of offence (against the person) and good or fair response to in-patient treatment and regular supervision following discharge.

Clare and Murphy (1993) carried out a follow up study on the first 6 patients to leave an assessment and treatment service an average of four and a half years after they had left. Four people had been referred for violent behaviour, one for bizarre sexual behaviour and one for arson. The study looked at levels of challenging behaviour (using the ABSII, Nihira et al, 1974) skills and social functioning (using the Vineland Adaptive Behaviour Scale, Sparrow et al, 1984), quality of care and quality of life. Total challenging behaviour scores had improved for four out of six patients whilst receiving an in-patient service, and for five out of six people, there were reductions in the challenging behaviours for which they were referred: these scores decreased for 5 out of 6 people at follow up in the community. Clare and Murphy suggest that the comparison of results of scales whilst in the unit with those after discharge should be treated with caution because of the impact of different informants on the inter-rater reliability.

All of the patients increased the level of their skills and social functioning whilst using the in-patient service. At follow up in the community, four people had increased their skills further and two people had small decreases. All of the people had lived in a locked psychiatric ward before they went to the assessment and treatment unit. At follow-up, everyone was living in unlocked homes in the community, with two people living in ordinary houses. However, 3 people did not prefer their current placement when compared to the assessment and treatment unit or the hospital. People were accessing more day opportunities although they were in segregated settings. They also used more community facilities and had more contact with their family.

Clare and Murphy concluded that there were no re-occurrences of the behaviours for which people were referred in the follow up study. They warn that for activities such as arson however, there is often a long time gap before any reoffending occurs. They also note that restrictions within peoples' living environments may lessen their opportunities to commit further acts or offences – this was certainly the case for one of the people in the follow up.

Xenitidis et al (1999) carried out a file analysis on the first 64 patients who had used the same assessment and treatment service as the one in the Clare and Murphy study. This study focused on the incidence of aggressive behaviour as an indicator of success of treatment. 64% of patients had a forensic history and the majority were male (72%) and white (80%). Nearly five times as many patients were discharged to the community as were admitted from the community. Unfortunately no data was available on the success of the placements. Xenitidis concluded that the assessment and treatment unit was effective in reducing both the severity and the frequency of challenging behaviour.

Halstead et al (2001) reported on a follow up study of discharges from an NHS learning disability secure unit. 35 patients who had received at least one year's treatment were followed up for a maximum of 5 years. The majority of patients were male (83%), white (80%) and 71% had been convicted of at least one offence. 46% had been admitted from prison. 89% of patients had a mild/borderline learning difficulty. Only one person was not placed under a section of the Mental Health Act. 57% of patients had a primary diagnosis of schizophrenia and 11% had a diagnosis of depression. 32% had a behavioural disorder.

Hostel	Another hospital	Special Hospital	Own home
49%	37%	6%	9%

Table 1.6 : Discharge destinations

During the follow up period, 29% of patients remained in hospital, including special hospital. At the final follow up, 6% (n=2) were dead, 34% (n = 12) were hospitalised and 60% were living in the community. People who were admitted from prison, special hospital or regional secure unit, were more likely to end up in ordinary housing or hostels.

Admitted to special hospital	Offending behaviour	Convictions
9%	34%	3%

Table 1.7: Outcomes at Follow-up

Three people were admitted to special hospital following offences (2) and the identified likelihood of offending (1). 34% of people had committed acts which may have been deemed offences, but only one person had received three convictions for threatening behaviour, alcohol and property related offences. No statistically significant correlation was found between personal characteristics, outcome or duration of treatment or levels of support. However, people who managed to stay out of trouble were on average 7 years older at discharge. Halstead also reported that people with lower IQs or a diagnosis of mental illness may do better at follow-up. This may be because they are more likely to fall into the existing eligibility criteria for services.

(iii) Studies of Secure Units

Studies of secure units are usually fairly small scale (with the notable exception of Friendship et al, 1999) and focus on those at the medium secure level. Most studies do not explore the outcome of receiving treatment in a secure unit following discharge, but rather examine who uses those facilities (see Hagell and Dowling (1999) for a summary of research).

Friendship et al (1999) followed up all patients discharged from an NHS medium secure unit between 1980 and 1994 (n=234) for an average of 6.6 years (the follow up period was between 6 months and 14 years). 71% of the sample had a diagnosis of schizophrenia and 13% a diagnosis of personality disorder.

Study	Follow up period	Percentage of reconvictions	Acquisitive offences	Serious offences	Readmission
Friendship et al	Average of 6.6 years	24% Adjusted rate* 30%	56%	12%	
Falla et al	Average 3 years and 4 months	16%		7%	11%
Castro et al	Minimum of 6 months	19%			

*Adjusted rate does not include people discharged to secure settings

Table 1.8: Reconviction/readmission rate and type of offence during follow up period

Non-custodial outcomes	Custodial sentence	Hospital order
69%	18%	13%

Table 1.9: Outcomes for convicted offenders (Friendship et al study)

A statistically significant relationship was found between the number of previous offences, age at first admission to psychiatric hospital and length of admission and reoffending.

Falla et al (2000) carried out a follow up study on 85 patients who had left an NHS medium secure unit in Kent. There was no information on the diagnosis of patients, but, given that this was a "generic" medium secure unit, most patients would have a diagnosis of mental health. The average follow up time was 3 years and 5 months. The "failure" rate which included readmissions was 27%, with 11% of patients being readmitted and 16% reconvicted. 7% (n=6) patients had seriously reoffended during this time.

Castro et al (2002) carried out a follow up study of 49 patients (identified through self-selection) from an independent sector medium secure unit. This group of patients reflected the socio-demographic variables of all patients who were discharged. Approximately 50% were white and 30% were African-Caribbean. Over 80% were male and over 70% were aged between 18 and 34 when admitted. There were slightly less people with a diagnosis of schizophrenia in the follow up group.

A minimum of six months after discharge, 19% of patients had further convictions. Reoffending was significantly correlated with sexually aggressive behaviour. No significant correlation was found between previous convictions and reoffending. No clear data was available on total readmission rates to hospital for this group.

These follow up studies of patients from medium secure units, like many other studies of this population, are, at best, confusing and at worst, contradictory, in many of their conclusions – for example relationships between age and reoffending. Like other studies too, the populations are predominantly male, and where ethnicity is referred to, predominantly white. Reoffending rates vary, but frequently reach 20–30% after several years. The majority of reoffending is acquisitive or non-serious offences. These studies highlight the fact that many people who leave secure provision reoffend, but not all are convicted as a result.

(iv) Discussion

The studies quoted above show that the level of reoffending on discharge from special hospitals varies between one quarter and two-thirds of people released. Studies of reoffending by people discharged from medium secure units vary from 4% to 24% within the first few months. Studies carried out in police stations also showed higher rates of reoffending with a retrospective data collection identifying a prevalence rate of nearly 80%. Reoffending rates do seem to be linked to the type of provision both in terms of security, which lessens opportunity for reoffending and in terms of appropriateness of support, which increase peoples' skills etc and lessen the need for reoffending. Thus lower rates of offending on discharge from secure provision may be because people who are discharged from these facilities are rarely discharged to the community to live independently, but are usually discharged to other restrictive environments.

Reduced rates of reoffending may be linked with good in-patient care and support following discharge. A study in Glasgow (Cooke, 1992) found that 15% of those who had received treatment from a forensic clinic had reoffended compared to 41% of those who had not received such treatment. Studies of people with learning difficulties shows the impact of treatment on reoffending following treatment, particularly with sex offenders (e.g.Lindsay et al, 1998). Beail (2001) reports that of 13 men with learning difficulties who underwent treatment (psychodynamic psychotherapy), 11 men had not reoffended 4 years after completing treatment. Two men did go on to reoffend. Of 5 men who had refused treatment, all reoffended with 3 men receiving custodial sentences. Clare and Murphy (1998) also warn of the necessity of continued support for people even when they appear to be doing very well. Although the research summarised so far is based on very small studies with no control groups in order to test the impact of treatment and support on reoffending, it does suggest that good support following discharge is essential to enabling people to develop a crime-free lifestyle.

1.4 People with Asperger's Syndrome and the Criminal Justice System

Existing research on people with Asperger's syndrome who offend is very sparse and indeed the links between Asperger's syndrome and violent or offending behaviour is the subject of controversy. One of the difficulties in terms of research, is the difficulty of diagnosis. Prevalence rates identified by Ehlers and Gillberg (1993) suggest that there is a minimum prevalence rate of 3.6 per 1,000, with a male to female ratio of 4:1, and a possible prevalence rate of 7.1 per 1,000 with a male to female ratio of 23:1. However, the experience of people with Asperger's syndrome is usually that of a late diagnosis, often in their late teens. Frequently people go completely undiagnosed or attract a variety of different psychiatric diagnoses – schizophrenia being the most common.

People with Asperger's syndrome are usually described as committing offences as a result of their disorder. Hewitt (1992), in the one of the annexes of the Reed Report, suggests that it is the 20% of people with autism who do not also have severe learning difficulties who are likely to offend. Although there are no established prevalence rates due to the lack of research into this area, she suggests that the kinds of offences committed by people with autism fall into the following categories:

- Cases where the person with autism, because of social naivety, is deliberately led into criminal acts by other
- Acts of aggressive behaviour as a result of disruption of the person's routine
- Asocial behaviour as a result of a lack of understanding or a misunderstanding of social rules
- Anti-social behaviour caused by obsessional tendencies.

Research carried out by Tantum in 1988, into a group of 60 people identified through contact with psychiatric colleagues, has been influential in shaping the views relating to people with Asperger's and offending. These 60 people were identified by psychiatrists as having "lifelong social isolation and eccentricity" which was not caused by a psychosis. 46 (77%) were subsequently diagnosed as having Asperger's syndrome. 23% of the whole group had committed criminal offences usually against property and the person. In addition, isolated incidents had been committed by 24 out of 54 of the subjects for whom forensic information was available. Of these only 12% had been charged. Tantum did not find any evidence of any offence committed as a result of special interest or obsession.

Tantum has been severely criticised by Ghaziuddin et al (1991) for misrepresenting the nature of people with Asperger's as being prone to violence and for a lack of clarity around diagnostic criteria. The criteria that Tantum used were clearly open to subjective interpretation, and in asking colleagues to identify cases he was probably obtaining a biased sample of people. They suggest that his assertions add to the burden of being diagnosed with Asperger's or caring for someone with Asperger's. Ghaziuddin et al carried out a survey of all publications which examined the behaviours of people with Asperger's since 1944. Of people identified in the publications, only 2.27% - 5.58% (depending upon diagnostic criteria) had a clear history of violent behaviour.

Scragg and Shah (1994) examined the prevalence of Asperger's syndrome in Broadmoor hospital. Using Gillberg and Gillberg's diagnostic criteria they identified a prevalence rate of 1.5% - 2.3%. The majority of people had committed violent crimes and one person had committed arson. Scragg and Shah suggested that the difference between their findings and those of Ghaziuddin were caused by problems with the under diagnosis of people with Asperger's in the Ghaziuddin studies.

Hare et al (unpublished) carried out a survey into people with autistic spectrum disorders who were placed in Ashworth, Broadmoor and Rampton Hospitals. A prevalence rate of 2.4% - 5.3% was identified. Hare et al found that people in Special Hospitals with autistic like features were mainly male, reflecting the nature of both the offending population and the population of people with autistic spectrum disorders. The average length of time that people remained in Special Hospitals was 2 to 3 years longer than the average length of 8.5 years reported for patients who did not have an autistic spectrum disorder. Only 10% of the group had already been diagnosed as having an autistic spectrum disorder. A significant proportion had a primary diagnosis of schizophrenia. There was a high level of homicide and violence and a low level of sexual offending in the autistic group. There was some evidence that the offences were linked to special interests.

Research into people with Asperger's syndrome who offend is still a developing area and hampered by difficulties of diagnosis, hence the range identified in prevalence rates. All we are able to conclude at this stage is that people with Asperger's do sometimes commit crimes, and that when they do commit crimes of a violent nature, they may be sent to a Special Hospital. However, it must be remembered that many people identified by the Special Hospital studies were misdiagnosed as having a mental illness, in particular schizophrenia, and it is unclear how much this has contributed to the apparent outcome for people with Asperger's syndrome given that people with this diagnosis do not fall under the Mental Health Act unless they have an additional diagnosis of mental impairment, mental illness or psychopathic disorder.

1.5 Conclusion

Based upon the studies summarised here, it is possible to conclude that people with learning difficulties and mental health needs have different experiences and outcomes when they encounter the criminal justice system.

People with learning difficulties appear to be over-represented at the police station and under-represented in prisons compared to the prevalence rate in the general population - a prevalence rate of 2 or 3% for learning disabilities would be expected compared to Gudjonsson's prevalence rate of 9% for police stations and a maximum of 1% for prisons. Based upon Mason's study we know that people with learning difficulties may be over-represented in the Probation Service compared to the general offending population. However, because of gaps in our knowledge of the pathways, particularly around who goes to court and what happens there, and because police stations vary considerably in practice, we do not know what happens to most of the people with learning difficulties who come into contact with the criminal justice system. There are no studies which look at the secure sector as a whole and those that exist do not look at referral patterns across this kind of provision. The one study that examined referral patterns over the last 10 years found that most referrals came from prison or courts and the police. However, no people with a learning disability were found (Hardwick et al, 2003). We therefore do not know whether the numbers of offenders with learning difficulties is increasing or decreasing in secure facilities. We do know that the independent sector is expanding to meet the apparent demand for provision for people with learning difficulties (Moss 2000, Vaughan and Done 2000). Alexander et al (2002) report referral rates to a specialist forensic secure unit for people with learning disabilities as being 2 per month, compared to the referral rate to the independent sector which is nearly 4 per month. Given that the majority of referrals come from hospitals or prison, it may be that people are referred to secure provision as part of the pathway out of the criminal justice system or when they are seen to not be doing well. A small proportion of people may be referred there instead of the traditional provision – this may particularly apply to people with learning difficulties who may be referred to secure provision rather than special hospital.

Questions as to why people with learning difficulties are over-represented at police stations given that only a small proportion of people with learning difficulties who commit possible offences are reported to the police are answered variously by different commentators. It is not proposed to go into these in any great depth, but reasons may be summarised as being either that people with learning difficulties are more likely to be caught or that people with learning difficulties are more likely to offend as in the Hodgins studies.

Hodgins (1992, 1996) suggests, based upon two birth cohorts, one in Sweden and one in Denmark, that people with learning difficulties are indeed more likely to commit crimes. The Sweden study reported that that men with learning difficulties were 3 times more likely to offend and 5 times more likely to commit a violent offence than non-disabled men. Women with learning difficulties were 4 times more likely to offend and 25 times more likely to commit a violent offence than non-disabled women. The Danish study reported similar findings. However it is difficult to generalise these findings to a wider population given that in the first study people were defined as having a learning difficulty who had been placed in special classes, without an analysis of why they were placed there or what the criteria were for admission to special classes and comprised only 2.6% (n=191) of the total sample (15,117). The second study presents similar problems in terms of interpretation as it is based upon a comparison of different groups of people who have been hospitalised with a group of people who have not been hospitalised. It would be reasonable to assume that people who have been hospitalised may not be representative of the general population of people with learning difficulties.

So we do not know with any certainty why people with learning difficulties are over-represented at police stations. It may be merely that they look or act differently, and that the police interpret this behaviour as suspicious and so they are picked up in connection with an offence that they have not committed. It may also be that the means of identifying people with a learning difficulty are inaccurate, resulting in an over-identification of people with learning difficulties.

We do know that where people with learning difficulties are convicted and sent to hospital or prison, they may languish for long periods of time in the former, as they will not be getting “better” (Grubin, 1996) and in the latter, they may be subject to abuse from other in-mates and fall foul of rules which they do not fully understand (Brown and Courtless, 1971). Reports (e.g. the Reed report (1992) and the Mansell report (1993)) have recommended that people with learning difficulties should not usually be given custodial sentences, and prison officers have called for special facilities in the USA (where the proportion of people with learning difficulties in prison is higher that that in the UK) to enable people with learning difficulties to be better managed in prison (e.g. Brown and Courtless, 1971). In the Probation Service too, people may be set up to fail as a result of having expectations placed upon them which they are unable to understand fully (Mason, 1998).

People with mental health needs have a different experience when they encounter the criminal justice system, but appear not to fare any better. People with mental health needs may come more often to the attention of the police as a result of their behaviour and may be taken to the police station or other place of safety. They may also commit crimes which are more visible, or they may commit crimes and then give themselves up for a number of reasons. People with a diagnosis of mental illness are more likely to be remanded on bail because they are homeless, and because of the minor nature of their offences, may receive shorter custodial sentences. This results in high prevalence of people with mental health needs in prison and frequent periods of imprisonment for people who require support but who do not receive it often because their health needs go unnoticed or because they are not in prison long enough to trigger a post-prison care plan (Hyslop 2000). A substantial number of people with mental health needs who receive a longer sentence also do not receive proper health care because their mental health needs go unnoticed. Where people with mental health needs are recognised as such they may be diverted to hospital detained in hospitals for periods of time which are substantially longer than a prison sentence would be. They may also end up “stuck” in Special Hospitals because of the label of mentally disordered offender and not be able to move onto more appropriate facilities (Dell and Robertson, 1988).

There appears to be an over-representation of people with mental health needs who appear at the police station and who are arrested when compared to the prevalence rates of mental illness in the general population. The disproportionate number of people with mental health needs in the criminal justice system increases after the police station stage with around 55% of these people ending up in prison and roughly 3.4% ending up in a Special Hospital, suggesting that few charges are dropped and diversion prior to custody is relatively infrequent.

For people with learning difficulties and mental health needs who come into contact with the criminal justice system then the outcomes are not very positive, where we know something about them. Normalisation would suggest that people with learning difficulties and mental health needs should come to the attention of the police when they offend, but given the lack of appropriate facilities within the criminal justice system, in particular, in the prisons, alternative outcomes need to be developed which take account of both the person's vulnerabilities and their offending behaviour. The constant contact between groups which are discriminated against and the criminal justice system brings into question the role of the criminal justice system and the ability of key agents to balance welfarism and legalism. In order to legitimise the system and to continue its portrayal as an objective enforcer of laws for everyone's benefit, people who are seen to be vulnerable, because of individual characteristics, must be treated differently. Clearly this is not a new issue, and thus there are reports, legislation and government directives which have recognised this issue and developed different ways of meeting the needs of offenders who have been called "mentally disordered offenders."

Chapter 2

How does the Criminal Justice System Recognise and Respond to Differences?

Historically the criminal justice system has treated people who fall under the umbrella of mentally disordered offenders differently to mainstream offenders. This may be seen as characteristic of a benevolent society attempting to ensure that the needs of vulnerable people are met, or as a way of ameliorating the injustices within society that are perpetrated by the criminal justice system and its legitimisation as an objective tool of justice. The main tools for responding to vulnerability are the use of Appropriate Adults at the police station and diversion from the criminal justice system either through the Mental Health Act 1983 or through the development of diversion schemes. The latter may account for the substantial number of people who are returned to the community. This chapter examines the role and effectiveness of both these tools.

2.1 Institutional Discrimination and the Criminal Justice System

Institutional discrimination exists when organisations function in such a way that their policies, procedures and practices effectively discriminate against particular groups in society. An example of this would be that an organisation that produces all its information in English in a written format is discriminating against people with visual impairments, those who cannot read and those who cannot understand English. Institutional discrimination is recognised to some degree by the Disability Discrimination Act 1995. This act required all organisations providing public services to make reasonable adjustments to their policies, practices and procedures to ensure that disabled people were not unfairly discriminated against. Criminal court proceedings are not exempt from these requirements.

There has been recognition, particularly recently, that the criminal justice system is not objective and does discriminate against, e.g. Black people and people from minority ethnic communities as evidenced by the MacPherson Report 1999. However, in the case of people with learning difficulties, much of the attention has focused on the experience of people who are victims or witnesses of crimes, rather than suspects. Study after study has reported the unacceptable levels of harassment and crimes committed against people with learning difficulties and the equally unacceptable response from police in refusing to take these matters seriously (Sharp 2001, Mencap 1999, Williams 1995). This has culminated in a number of campaigns and reports recommending changes in policy to rectify this injustice e.g. Community Care's " A Fair Hearing" campaign, and the Home Office's report, Speaking up for Justice (1998) These have led to changes in legislation relating to vulnerable witnesses (the Youth Justice and Criminal Evidence Act 1999) which has created a much more acceptable approach to enabling people with learning difficulties to participate fully in the legal process as witnesses (Monaghan and Pathak, 2000). People with mental health needs who are suspects may still be subject to discrimination, however, as they may be perceived as dangerous rather than vulnerable because of their diagnosis, and therefore subject to more restrictive measures.

For people with learning difficulties and mental health needs who are alleged offenders, there are still on-going barriers which prevent their full and equal participation in the criminal justice process. Daw (2000) suggests that Article 6(3) of the Human Rights Act 1998 (the right to a fair trial) is particularly relevant to people with learning difficulties and people whose disability may be exacerbated by the stress of proceedings. Article 6(3) is applicable from the moment a person enters the police station and states the following:

> *"Everyone charged with a criminal offence has the following minimum rights:*
>
> *(a) to be informed properly, in a language which he understands and in detail, of the nature and cause of accusation against him;*
> *(b) to have adequate time and facilities for the preparation of his defence;*
> *(c) to defend himself in person or through legal assistance of his own choosing or, if he has not sufficient means to pay for legal assistance, to be given it free when the interests of justice so require*
> *(d) to examine or have examined witnesses against him and to obtain the attendance and examination of witnesses on his behalf under the same conditions as witnesses against him;*

> *(e) to have the free assistance of an interpreter if he cannot understand or speak the language used in court."*

The current operation of the criminal justice system is clearly in violation of article 6(3) of the Human Rights Act 1998 due to the rights contained in (a), (b) and (e) often not being upheld.

Institutional discrimination in the criminal justice system presents in two main forms:

1. the use of complex language, including legal jargon, within a complex process, which people who are cognitively impaired are unlikely to be able to understand
2. the structuring of the interview process in the police station and in the courts in such a way that people with learning difficulties are disadvantaged

In addition, Chappell (1994) suggests that individual discrimination against people with learning difficulties, also exists, with extremely severe consequences. She cites a substantial number of wrongful convictions where there has been police or forensic malpractice, e.g. Stefan Kisko and Engin Raghip, and suggests that people with learning difficulties are

> *"..seen as easy targets in cases where there are demands to secure convictions at any cost"* (Chappell, 1994, p.28).

The following analysis is based upon research which relates specifically to people with learning difficulties rather than mental health needs, but these forms of discrimination apply equally to people with mental health needs too.

2.1.1 Inaccessible Language and Incomprehensible Processes

There have been a number of studies into the caution and the notice to detained persons in order to ascertain how easy or difficult they are to understand (Clare and Gudjonsson, 1991; Gudjonsson, 1991;Clare et al, 1998).

"You do not have to say anything. But it may harm your defence if you do not mention when questioned something which you later rely on in court. Anything you do say may be given in evidence" (Home Office, 1995)

Table 2.1 : The Caution

The caution is used in the process of the police investigation of a crime and is a statement given by the police to the suspect where the police have sufficient admissible evidence for reasonable suspicion that the person has committed a crime. It is intended to bring home the severity of the situation, in particular the imminence of formal charge and prosecution (Walsh and Poole, 1983). The current caution came into force in 1994 as a result of the Criminal Justice and Public Order Act 1994, which modified the right to silence. The police must explain the caution if the suspect does not appear to fully understand it.

Unfortunately, Clare et al (1998) discovered that not only do the general population have significant problems in understanding the caution, the police themselves experience difficulties in both understanding and explaining the caution. Only half (48%) of the police officers interviewed explained all three sentences correctly, and when they were able to focus on one sentence at a time, only 86% were able to explain it fully. When all three sentences were presented to members of the general public only 7% of people fully understood the caution. The sentence which people found most difficult to understand was the one relating to the loss of the right to silence. This clearly leaves people who are cognitively impaired as a result of a disability or mental health need, stress or anxiety caused by the arrest and subsequent interrogation, or drug or alcohol abuse, in an extremely disadvantaged position. They are highly unlikely to be able to understand the caution and the police are not necessarily able to explain it in simple language.

The "Notice to Detained Persons" presents similar problems. The custody officer must inform the suspect who is under arrest of his/her rights. The "Notice to Detained Persons" is a written leaflet which outlines these rights and which must be given to suspects on entering custody at the police station. The four main rights are :

- the right to have somebody informed of his/her arrest
- the right to consult with a solicitor
- the right to consult the Codes of Practice
- the right to a copy of the Custody Record

Gudjonsson (1991) analysed the content of the "Notice" using the Flesch formula. He found that the notice would be understood by only one quarter of the general population, and that people with an IQ below 80 would understand fewer than half of the sentences in the notice. As a result of this, Clare and Gudjonsson (1992) piloted a revised version of the notice, but this was not acceptable to the Home Office.

In addition to the formal procedures that must be undertaken, the language which is used is often complex and difficult to understand. Some of the terms are extremely important and central to the process, e.g. the term "guilty." Smith (1993), in a study of 45 alleged offenders with learning difficulties concluded that 16% (7) of people had a complete lack of knowledge or a nearly complete lack of knowledge of the term "guilty"; 22% (9 people, including the 7 above) had a complete lack of knowledge or a nearly complete lack of knowledge of the term "not guilty", and 4 people continued to reverse the terms despite extensive explanation.

There is also some evidence to show that people with learning difficulties may not understand the legal process and the consequence of their actions or statements. Clare and Gudjonsson (1995) showed a fictional video of a man making a "true" confession to the crime of burglary, followed by a false confession to a murder in a police interview, to two groups of people – one group had learning difficulties and one group average intelligence as defined by full scale IQ scores. The video tape was stopped at various points and questions were asked about how well people understood the video, the consequences of the false confession and the perceived need for legal advice.

Clare and Gudjonsson found that contrary to expectations, people with learning difficulties did recognise that where someone was convicted for murder, they would be likely to go to prison and that someone who had committed a crime may benefit from legal advice. The main difference between people with learning difficulties and without learning difficulties was in their perception of what would happen to someone who was innocent, regardless of the nature of the confession. In the first instance, people with learning difficulties did not think that someone who was innocent would need legal advice. Secondly, there appeared to be some perception that the person's guilt or innocence would be evident to others. Clare and Gudjonsson suggest two reasons for this. The first is that of "learned helplessness:"

> *"..[T]he participants with intellectual disabilities may have drawn on their own experiences as individuals with limited credibility, unaccustomed to having their statements – whether truthful or not – believed unless ratified by a more powerful person"* (Clare and Gudjonsson, 1995, p.123).

The other reason relates to peoples' difficulty with understanding others' mental states. The former explanation, perhaps reformulated as disempowerment, could lend a valid explanation not only as to why people with learning difficulties may not understand the legal process in the same way as other people do, but also why they are more likely to acquiesce, make false confessions in the interview process and feel helpless to challenge the authority of interviewing police by requesting assistance. A third reason may be that people with learning difficulties may be more trusting of people in positions of authority, compared to non-disabled people.

2.1.2 The Interview Process and the use of the Appropriate Adult

It is well known that particular methods of questioning are likely to elicit certain kinds of responses from people with learning difficulties (Heal and Sigelman, 1985; McVilley, 1995). In order to ascertain reliable information questions should be open rather than yes/no questions because of the tendency of people with learning difficulties to agree with the interviewer on leading questions (suggestibility) or to give positive answers regardless of their own views (acquiescence). This tendency to acquiesce should not be seen as a direct result of the person's disability but rather as a result of the fact that so much of people with learning difficulties' lives is controlled by others and of the difficulties in understanding complex language (Simons, 1993). Unfortunately the police station interview is unlikely to take these factors into account.

The possibility of false confessions which lead to subsequent convictions is also higher for people with learning difficulties, particularly where there is extended interrogation over a period of days. Pearse et al (1998) carried out a study into the connection between psychologically vulnerable people and the likelihood of a confession. This study found that there was no connection between models of interview and confessions, as confessions tended to be made early on in the interview. Other studies found that this may be particularly relevant to people with learning difficulties who may yield to misleading questions in the initial part of the interview and then refuse to change their story (Gudjonsson, 1990; Clare and Gudjonsson,1993) resulting in false confessions. Chappell (1994) suggests that people with learning difficulties may be more likely to confess because they are afraid and want to end the interview. Gudjonsson (1992) suggests four reasons for false confession, two of which are particularly relevant to people with learning difficulties. These are that people who are compliant and may respond to forceful and persistent questioning may confess and people who may become confused and convince themselves during the course of the interview that they are guilty, may confess. The latter is particularly relevant to people who may have a lifetime of having their own experiences and views invalidated and reconstructed by others.

In order to facilitate the identification of those who may give false confessions because of their propensity to suggestibility, Gudjonsson (1984, 1987) developed the Gudjonsson Suggestibility Scale. This scale is based upon responses to a verbal story. It is not clear how widely this is used, but Beail (2002) suggests that the scale may be used to undermine the statements of people with learning difficulties by claiming that they are unreliable. He argues that the scale is inaccurate in determining peoples' ability to recall autobiographical information. Milne et al (2002) however, confirm the scales' accuracy in identifying peoples' ability to recall visual events.

The fact that people with a mental disorder may be vulnerable during the interview process is addressed by the provision of an Appropriate Adult during the police interview. Code C of the Codes of Practice relevant to Police and Criminal Evidence Act 1984 states that people may unwittingly give information which is unreliable, misleading or self-incriminating. Gudjonsson (1993) suggests that mentally disordered people are vulnerable because they may not fully understand the significance of the questions and the implications of their answers or they may be unduly influenced by short-term gains (for example the offer to end the interview or send someone home if the person confessed) or the interviewer's suggestions. Thus the Appropriate Adult (AA) has a particularly important role to play in protecting the interests of people and in ensuring that justice is carried out.

Rhead (1997) suggests that the role of the AA is to :

- assist and protect the suspect and ensure interviews are conducted fairly, e.g. to ensure that the suspect understands questions properly
- advise the suspect about a number of crucial decisions that need to be made whilst at the police station, such as when to remain silent and to refuse to answer questions
- be aware of the rules governing identification and providing samples
- countersign decisions
- make representation regarding bail
- put a case forward to the custody officer about whether a suspect should be charged.

These responsibilities are clearly onerous, and therefore it is particularly worrying that where AAs are provided many of them may be untrained and therefore unable to fulfil this role or they may be operating in a role which may possibly conflict with that of the AA. Nemitz and Bean (1998) found that a volunteer AA scheme operated by MIND viewed the role of the AA primarily as a way of diverting people from custody and often breached confidentiality and the Codes of Practice by passing information about the suspect on to other agencies. A study of the use of AAs in the Metropolitan Police District based upon data extracted from 27,000 custody records, found that few stations had access to a pool of volunteers (9.1%) who were usually trained by Social Services departments. AAs in the main consisted of social workers (43.6%) who were often expert in terms of knowledge of the client group, but not the role of an AA. Nearly half of the AAs were relatives, friends, care workers, and on two occasions the AA was a passer-by and a hotel doorman (Medford et al, 2000). Pearse and Gudjonsson (1992) and Memitz and Bean (1994) found that AAs rarely intervened in the process of the interviews and in fact the expectation of the police was that they would not interrupt the interview. Brown (1997) also suggests that AAs are not fulfilling their role in terms of safeguarding suspects because they do not have time to assess the suspects, and have a limited impact in interviews.

Every study carried out into the use of PACE and AAs has identified a significant under-representation in the number of vulnerable adults identified by the police. Bean and Nemitz (1994) in a study of over 20,000 custody records in Yorkshire found that an AA was called in only 0.2% of cases. The custody sergeants in these studies were so confident of their judgement that they did not always confirm their diagnosis with the police surgeon as required in the PACE code. Gudjonsson et al (1993) found that AAs were only called in 4% of the cases when looking at suspects in two south London polices stations. They identified 15% of cases as requiring an AA. Medford et al (2000) found that AAs were only called in 1.7% of cases. In this study the researchers identified an additional 2.6% of people who were thought to be vulnerable within the terms of PACE.

All of these studies acknowledged the problems that the police have in terms of identifying people who are vulnerable. Gudjonsson et al (1993) found that the police could identify people who had florid symptoms or severe learning difficulties. People who were depressed or had mild learning difficulties were likely to be missed. This is confirmed by the later studies. Worryingly, the role of the AA does not appear to be clearly defined. Gudjonsson et al (2000) found that doctors, lawyers and police in a study looking at factors relevant to perceptions of fitness to be interviewed saw the role of the solicitor and the AA as being interchangeable. Medford et al (2000) further found that police officers were often deferring the decision to call an AA to the forensic medical examiner which was both inappropriate and in contravention of the PACE codes because an AA should be called as soon as there is a suspicion that one is needed. This has led to a call for guidelines on fitness to be interviewed and the role of the AA (Gudjonsson et al, 2000).

2.1.3 Challenging Discrimination

Gudjonsson et al (1993) have proposed a number of ways to ensure that people who are vulnerable have access to support such as an AA. They suggest that:

- there should be an operational definition of mental disorder and vulnerabilities

- there should be clearer guidelines for police officers relating to criteria for access to an AA
- all police officers should be provided with basic training in identifying people who are vulnerable
- some of the onus of identification of vulnerable individuals should be placed upon the detainee themselves through the use of a simple enquiry by the custody officer
- regular custody officers should be employed
- a review of the role, function, qualification, training and availability of the AAs should be carried out.

These recommendations, whilst commendable in their intent, clearly identify the vulnerable person as being the "problem" and look to put mechanisms in place to enable people to cope with a discriminatory system. The recommendation which looks at putting the onus on vulnerable people to identify themselves is of limited value. People with mild/borderline learning difficulties may not wish to identify themselves as vulnerable. Many studies show that people with learning difficulties prefer not to or do not identify themselves with other people with learning difficulties (Gowans and Hubert (1983); Oliver (1986): Booth and Simons (1989)). People who are depressed also may not be able to identify themselves as being vulnerable (Barnes and Bowl, 2001).

Consideration should be given to rendering the system more accessible (in terms of language, transparent processes etc.), together with providing additional support for everybody on request, if a non-discriminatory criminal justice system is to be in existence. It is recognised that if the Home Office cannot even accept a revised Notice to Detained Persons that actually ensuring that the entire process is less complex and easier to understand is something which is unlikely to happen in the near future, and that this probably will not happen unless there is substantial legal challenge. This reluctance to render the system easier to understand does raise questions about the nature of justice which the system aims to deliver. In addition, as with most adjustments which enable disabled people to achieve their civil rights, there are always additional benefits for non-disabled people. Gudjonsson et al (1993) report that the additional stress and anxiety caused by being arrested negatively impacts on peoples' cognitive skills. Thus a system which is easier to understand would benefit everyone, not least the police.

2.2 Diversion Schemes

Dingwall and Harding (1998) suggest that diversion away from formal criminal proceedings has a long history. It is an awareness and critical perception of the impact of diversion which has come to the fore recently. Whilst diversion schemes are seen by some as growing out of benevolent motives, others see such schemes as a response to the crisis in the criminal justice system and in particular the overcrowding of the prisons (e.g. Laing, 1999). Yet others view diversion schemes as the expansion of psychiatry (e.g. Mason and Mercer, 2000) and social control (e.g. Cohen, 1996), from the prisons and asylums into the community.

The latter view, based upon a conflict theory of crime argues that far from being an alternative to prisons and asylums, diversion is actually an expansion of both institutions into the community. With respect to mentally disordered offenders there are two ideological changes which have resulted in this development of diversion. Firstly, as a result of challenges to the profession of psychiatry through societal reaction theories and others which questioned the reality of madness and legitimised deviance, the power base of psychiatry has been increasingly threatened. Foucault (1984) describes a number of cases which came to the attention of the public in France – these were a number of violent crimes which were inexplicable and irrational. Psychiatry began to link up with the legal system offering not only an explanation but an answer as to what to do with this group of people, who would now be termed mentally disordered offenders – treat them.

Secondly, prison and other institutions have generally become less well-regarded by people for a number of reasons – they are seen as out-dated expensive institutions which do not rehabilitate people, but may teach them how to be better criminals or expose them to abuse (e.g. Brown and Courtless, 1971). For this reason, diversion has become a cornerstone of state policy, and where prisons or institutions remain they may have become more punitive. However, rather than reduce the number of people that the criminal justice system or other agencies come into contact with as a result of offending, diversion has actually increased the number and led to the development of monitoring and surveillance techniques such as risk assessment and management. The result of diversion is not that people are diverted from the criminal justice system but that the criminal justice system has expanded and engaged social and health care agencies in maintaining control. In addition, not only have the boundaries between prison and community become blurred with a proposed new Mental Health Act which will give powers to make care and treatment orders for patients living in the community, but the population that the criminal justice system targets may become blurred too – the new Act proposes that people should receive services because of the possibility of offending, the power to restrict the liberty of people with severe personality disorders indefinitely because they are deemed to be a risk to the public rather than because they have committed a crime. The debate around people with severe personality disorders or psychopathic disorders is particularly of concern as there is some debate as to whether or not the condition exists. Indeed some argue that it is

> *"little more than a clinical judgement masquerading as a clinical diagnosis."* (Prins, 1991, p.119).

The role and effectiveness of diversion schemes will be explored further taking these views into account.

2.2.1 What are diversion schemes?

Diversion schemes are methods of identifying mentally disordered offenders within the criminal justice system and diverting them away from possible penal sanctions through assessment and referral to more suitable services. There are a number of different kinds of diversion schemes in place across the country, and some places have no formal diversion schemes at all. Not only are there difficulties in terms of identifying vulnerable people within the criminal justice system, but there are also significant problems in identifying appropriate services to refer people to.

2.2.2 The growth of diversion schemes.

Laing (1999) identifies the origin of diversion schemes in the early 1990's as resulting from the failure of the criminal justice system to use the therapeutic powers within Mental Health Act 1983 to effectively divert mentally disordered offenders away from prison to places where they could access treatment. In 1988, for example, magistrates courts remanded only 2% of the total court turnover for report (Laing, 1999). The number of hospital orders declined, the number of restriction orders remained low, and the number of interim hospital orders made by the Crown Court remained limited. As stated earlier there was also significant under use of probation orders with psychiatric conditions attached to them and guardianship orders were practically non-existent. This period was characterised by long delays for mentally disordered offenders in accessing appropriate facilities. There were two main factors contributing to this situation. One was the lack of communication between relevant agencies such as the criminal justice system and the mental health system which resulted in people not accessing facilities where they existed. Another and perhaps more important problem was the lack of resources and facilities within the health and social services to enable diversion to take place. This on-going situation, together with the crisis in the prisons, resulted in the Conservative Government introducing an explicit policy of diverting mentally disordered offenders away from the damaging effects of custody and imprisonment and into the health and social services through specific guidance, the Home Office Circular 66/90.

The Home Office circular 66/90 emphasised the provisions already existing in the Mental Health Act and provided guidance to ensure that they would now be used to their fullest extent. In particular the police were urged to make more use of section 135 and 136 of the Mental Health Act (which relate to their powers to remove someone to a place of safety) and of their power to caution or take no further action; the Crown Prosecution Service was urged to use its power to discontinue prosecution where it did not serve the interests of the public to pursue it and the courts were reminded of their duty to consider therapeutic proposals; and the Probation Service was described as having a special role to play in terms of informing the court and supervising the mentally disordered offender in the community and liasing with health and social care services.

Money was made available to develop diversion projects which identified and deflected people from the criminal justice system. By 1997, there were over 200 schemes in operation across the country (Laing, 1999).

2.2.3 Types of diversion from the criminal justice system.

The National Schizophrenia Foundation (1999) have summarised the main ways in which agencies may informally divert people away from the criminal justice system through discontinuing the prosecution or by formally assessing and referring people to health or social services:

Agency	Course of Action
Police	• Take no further action • Administer a caution • Informal admission to hospital • Formal admission to hospital
Crown Prosecution Service	• Discontinue proceedings
Magistrates court	• Absolute/conditional discharge • Acquittal • Remand to hospital for psychiatric report • Probation order • Hospital order • Interim hospital order • Guardianship order
Crown court	• Absolute/conditional discharge • Remand to hospital for psychiatric report • Probation order • Hospital order (with/without restrictions) • Hospital direction • Interim hospital order • Guardianship order

Table 2.2 : Informal and Formal Diversion from the Criminal Justice System
(National Schizophrenia Foundation, 1999, pp23-4)

In addition, people may be found unfit to plead, following a trial of the facts under the Criminal Procedure (Insanity and Unfitness to Plead) Act 1991 and receive one of four disposals routes: a hospital order (with or without restrictions), a supervision or treatment order, a guardianship order or an absolute discharge (Grubin, 1996).

Different models of diversion have developed. These are summarised in the following table:

Area of criminal justice system	Model
The police station	The Police Station Assessment model e.g. a forensic community psychiatric nurse (CPN) (later expanded to two) accepts referrals from the police in 3 stations in Westminster, makes assessments and refers people to psychiatric teams and hospitals.
The court	The Nurse Assessment Court Model. e.g. a CPN attends Sheffield Magistrates Court every day, screens cases, carries out an assessment and then refers that person on, liasing with the appropriate services. The Psychiatric Assessment Model e.g. a psychiatrist attends the four magistrates court within the Bracton Clinic catchment area (South London) once a week and carries out an assessment and referral function. The Multi-Agency Assessment Panel Model e.g. a CPN convenes a multi-disciplinary panel to which mentally disordered offenders are referred in the MenDos Scheme in Dorset. The panel is normally convened at the request of the court but the police, CPS, probation or social services may also refer.
The prison	The Prison Psychiatric Assessment Model e.g. two psychiatrists and a psychologist assess people thought to be at risk by prison officers at Brixton prison. This team also assess people remanded into custody for assessment and those who require psychiatric assessment as a result of the nature of the charges against them. This may result in transfers under the Mental Health Act 1983.

Table 2.3: Models of Diversion Schemes
(based on information from Laing, 1999).

As can be seen, the term diversion covers a wide range of schemes and activities that have been in operation for varying lengths of time. The HOC66/90 included an appendix which gave examples of models of diversion schemes, but because of the lack of research information about diversion schemes it is hard to say that one model is more effective than another. The reason for various models being developed appears to be resource led (Hedge, 2000).

2.2.4 Effectiveness of Diversion Schemes

Are diversion schemes working? If effectiveness is considered in the context of identifying mentally disordered offenders and ensuring that they have access to treatment and appropriate services then it is clear that they have limited success.

Reference has already been made to the difficulties of identification encountered at the police station and in the courts. However, where people are identified as mentally disordered, they are more likely to have their cases dropped against them than non-mentally disordered offenders (Guite and Field, 1997). In 40% of cases of people identified as being possibly mentally disordered at the police station, no further action was taken, whilst 29% of cases were not proceeded with in court, compared to a general population proportion of 4% (Hudson, 1995).

If effectiveness is even more narrowly defined as access to hospital then diversion may have worked on a national basis as the following table shows:

MHA	1988	1989	1990	1991	1993	1995
s.35	234	297	299	364	320	350
s.37	762	952	957	970	943	937
s.38	54	62	86	85	93	116
s.47	94	120	145	182	284	250
s.48	82	98	180	264	483	473

Table 2.4: Therapeutic disposals 1998 –1995
(Source: Laing 1999, p.184)

This table shows that the number of people sent to hospital has increased dramatically, particularly amongst those who were living in prison, but this does not necessarily mean that diversion is working. The figures need to be contextualised within the whole system and compared with, e.g. numbers of people sent to prison. It may also be that some of the people identified through court diversion schemes may not have received a custodial sentence had they been tried.

A study of a court diversion scheme in Clerkenwell found that just under half of all referrals to the psychiatrists operating the scheme were diverted to hospital (James and Hamilton, 1991). The scheme itself led to a four fold increase in the number of hospital orders. A similar diversion scheme based at Bow Street and Marlborough Street magistrate's court referred 25% immediately to hospital and an additional 8% were admitted from custody to hospital. 60% of the referrals were assessed as having either schizophrenia (39%) or another psychotic illness. Most of the offenders had committed petty offences such as theft (Joseph and Potter 1993).

However, not all people diverted from court receive treatment in hospitals. 50% of the people identified in the Bow Street study were released into the community (Joseph and Potter, 1993). Exworthy (1994) and Joseph and Potter (1993) estimate that about 24% of people referred for a psychiatric assessment in court are admitted for in-patient care. Robertson (1996) questions whether diversion schemes which are concentrated at the court are actually targeting the right people. In his study of how mentally disordered people enter the criminal justice system, he found that people with a diagnosis of mental illness were often arrested for minor crimes such as theft and did not reach the court. Police were often unable to access local services as the suspects did not meet the eligibility criteria for admission and in general, Robertson concluded that the benefit of treatment which was a by-product of the earlier system of remanding had now been lost and people with mental health needs arrested for persistent begging, who did not reach court and therefore the diversion scheme, now stood less chance of receiving help than before.

The Islington Mentally Disordered Offenders Project targeted people who did not have a diagnosis of a serious mental illness who appeared at court. These were referred to community services, in particular the probation service, with CPN support. Many of these offenders, although extremely vulnerable and living in desperate conditions had not previously received help from established services such as social services and it was concluded that community care arrangements for this group of people were potentially fragile in an evaluation of the project (Burney and Pearson, 1995).

The impact of local diversion schemes has indeed been varied. There has been no national evaluation due to the lack of comparable data and as far as is known, one model does not appear to be more effective than any other. James (1996) concludes that proactive liaison is invaluable. Studies into court diversion (James et al, 1997) and police diversion schemes (James, 2000) have found that police diversion schemes are picking up people with a diagnosis of severe mental illness who do not reach court. A comparison of the referrals to a police diversion scheme in Westminster and referrals to the court diversion scheme found that the diagnostic profiles of the two groups was very similar, but that the court group were more likely to have used drugs and have committed more serious offences. CPNs received referrals from the police, made assessments and then referred on to other agencies – 34% of people (with a 31% admission rate) were referred to hospitals and 32% to community mental health or social services. It was not known how many, if any, were accepted by community based services.

Whilst many diversion schemes seem to be effective in identifying people with mental health needs and referring them to appropriate services, the needs of people with learning difficulties are not addressed in the same way by such schemes (James 1996). The Joseph and Potter (1993) study found that only 2% (n=4) of people were identified as having a learning disability through the scheme. James (2000) in his study of a police diversion scheme reports that over the period of study, 3.5% (n=8) of the people referred to the police diversion scheme were people with learning difficulties and 2.4% (n=6) of the people referred to the court diversion scheme. Of those referred to the police diversion scheme, none were admitted to hospital, whilst half of the people referred to the court diversion scheme were admitted. No reason was given as to why. Revolving Doors (Finn et al 2000) show similarly low figures for people identified at the police station as being vulnerable. The only exception to low referral rates are multi-agency panels, where identification rates of 13% were found (Hedderman, 1993). It is possible that this is because referrals were not based upon assessment of the person, but rather a paper referral.

The effectiveness of diversion schemes in terms of whether they reduce offending or re-offending is less clear. There has been no significant reduction in the number of people in prison, and the number of offences is falling (Home Office, 1999). There are clear reservations about the effectiveness of such schemes based at courts, as the expansion of diversion projects to police stations show. The high rates of people with mental health needs in prison suggest that it is not working well (Revolving Doors, 1996). However, it is possible that schemes merely delay or recycle offending populations and that people identified at the police station may not have entered the criminal justice system anyway. Their offending behaviour may continue if it has occurred because of a breakdown in support systems or an increasing mental health need (James 1996). It does appear that diversion in fact creates a new "criminal population," and an increasing number of mentally disordered offenders. Whilst it is recognised that people are stigmatised as a result of coming into contact with social and health care services, people who are vulnerable and who are failed by these services appear to be also "criminalised" as a result of not meeting eligibility criteria and offending without appropriate support, resulting in an identification as "doubly deviant."

2.2.5 Diversion to What?

The Reed Report (1992) reinforced the Home Office Circular 66/90 by emphasising that mentally disordered offenders should receive care from health and social services, prosecution should be avoided unless it was in the public interest and every opportunity to divert mentally disordered offenders should be pursued. It envisaged assessment and diversion schemes as being a standard part of health and social services. The committee further recommended that people with a mental disorder should be cared for:

> *"- with regard to the quality of care and proper attention to the needs of individuals*
>
> - *as far as possible, in the community, rather than in institutional settings*
> - *under conditions of no greater security than is justified by the degree of danger they present to themselves or to others*
> - *in such a way as to maximise rehabilitation and their chances of sustaining an independent life*
> - *as near as possible to their own homes or families if they have them. "* (Home Office, 1992, vol. 6, p.8).

Guite and Field (1997) suggest that service developments have been targeted on services for those with the most pressing need due to the combination of a high level of demand and the low levels of resources. It is perhaps for this reason that although the Reed Report stated that there must

> *"..be access to a range of supported and non-supported accommodation, as well as day care, social security, and other services, and a co-ordinated approach to care fostered by a multi-professional, multi agency team responsible for mentally disordered offenders,"*

that much of the debate has focused on the availability of secure places. Special Hospitals have been recognised as not always appropriate and so the debate has been around the number of available beds in medium secure units. The Butler Committee recommended 2,000 beds nationally and the Reed Report recommended 1,500 beds. By the end of 1997 there were 1,504 beds (Laing, 1999, p.196). However demand still outstrips supply. James (1996) describes the lack of beds leading to a "bed fixation" and a consequent distortion of what a community provision might entail outside of buildings and beds. The development of secure units has also been described as the recreation of the asylum in a different guise (Mason and Mercer, 2000).

The need for a range of provision with different levels of security was identified by the Wessex study (Vaughan, 1999). This study focused on the security and accommodation needs of mentally disordered offenders placed in Special Hospitals, regional secure units and in specialist placements through extra-contractual referrals. The study concluded that there was no appropriate "in – Wessex" provision for people with mental health needs requiring long-term secure care and no secure care for people with learning difficulties and personality disorder with severe challenging behaviour. People with learning difficulties were mainly dealt with through extra-contractual referrals when secure accommodation was required.

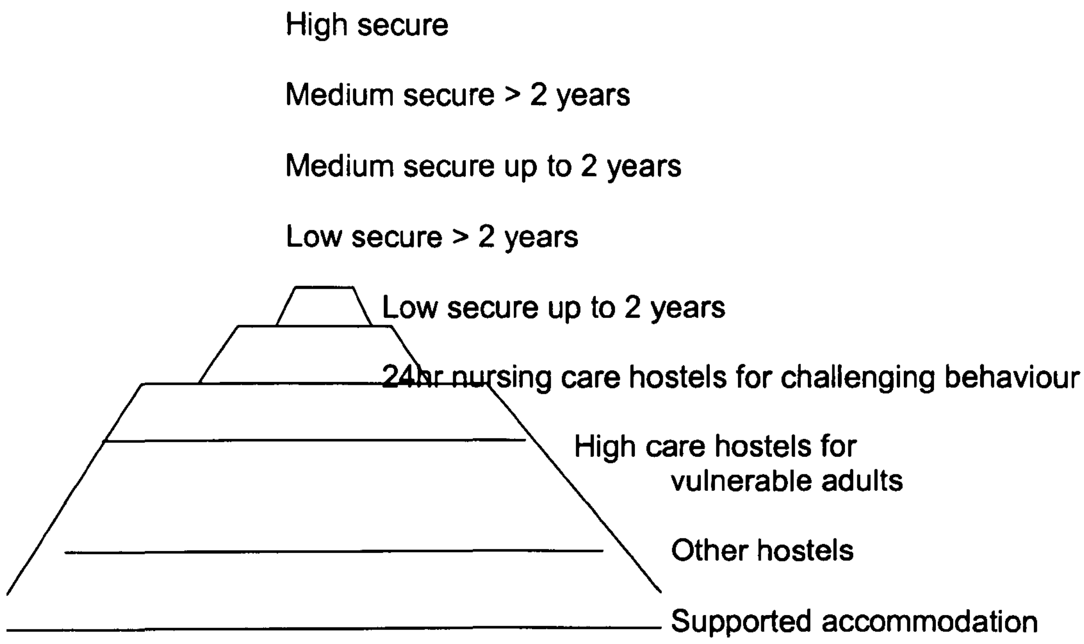

Figure 2.1: Availability of beds for people with learning disabilities from Wessex (From Vaughan, 1999, p. 84)

This local study accurately reflects the national picture, with people remaining in Special Hospitals and high secure provision because of the lack of appropriate move on accommodation (SHSA, 1995). A needs assessment exercise in 1994 in Mersey (quoted in SHSA 1995) also identified gaps in the provision of long-term secure care. People with borderline learning difficulties and women form a significant section of this group. The different needs of people with learning difficulties has been recognised by the SHSA[3] with the development of specialist services at Rampton Hospital. In addition a number of specialist secure units, usually based on the sites of old learning difficulties hospitals, provide a service to people with learning difficulties and severe challenging behaviour and many of the residents are potential or actual offenders. However, these units are subject to the same problems as hospitals with little or no move on provision.

Just as there are no national statistics on "mentally disordered offenders" there are also no national evaluations of the institutional or community based forms of support for people who are diverted. There have been a number of more local studies on psychiatric care provided in a hospital setting which do show an

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[3] The SHSA was replaced by the High Security Psychiatric Services Commissioning Board in 1995. This aims to integrate special hospitals with mainstream mental health services.

improvement, in terms of mental health for mentally disordered offenders, but the outcomes vary widely according to definitions and methodology (e.g. Dell and Robertson, 1998 which is based upon self report, and Joseph and Potter, 1993 which is based upon clinical evaluation). Local studies have shown also that specialist units can be effective in reducing people's levels of challenging behaviour but their effectiveness may be decreased by lack of continuing support in the community following discharge (e.g. Murphy and Clare, 1990; Clare and Murphy, 1993; Murphy et al, 1996).

One major consequence of the fixation on beds has been the lack of attention and commitment to inter-agency working in general, and the provision of community based services in particular. No extra funding or resources have been made available to develop community based services to meet the needs of mentally disordered offenders. Instead, it appears to have been the view of the government that good inter-agency working and more creative use of existing resources will address the issue (e.g. HOC23/90, LASSL (90)11, HOC29/93, LASSL (93)11, HOC12/95, HOC52/97, "Building Bridges,"1995, "Mentally Disordered Offenders: Inter-Agency Working", 1995). The government's exhortations and guidance on joint working between health and social services with particular reference to meeting the needs of people with mental health needs and on joint working between criminal justice agencies and health and social services have had extremely limited success.

"Building Bridges" (1995) stressed that it was important that the care programme approach and care management were effectively co-ordinated to provide a sound framework for service delivery for people with mental health problems. It emphasised that the care programme approach was not intended as a bureaucratic system to sit alongside or on top of existing systems. It was designed to ensure that people in the community received the treatment, care support and monitoring they needed to stay as well as they could, and to remain safe. Each agency has a specific role; the health authority with the social services department to develop the strategy; the trust and social services department to plan and develop the full range of services; the social services department with the trust to work with other providers including housing in the independent sector, to provide these services." (SSI, 1999). "Mentally

Disordered Offenders" (1995) described the work of 3 pilot projects funded by the Home Office and the Mental Health Foundation which aimed to encourage effective co-operation between the criminal justice system and health and social services to ensure that the health and social care needs of mentally disordered offenders were met. A key finding of the project was the need for inter-agency groups at a senior level to monitor and drive developments. Agencies are still struggling to put findings and guidance into practice, despite the need for inter-agency working, sharing of information and developing strategies to reduce crime now being a statutory responsibility for the police and local authorities under the Crime and Disorder Act 1998.

The SSI carried out an inspection of services for mentally disordered offenders in the community (SSI, 1997). Although there were some examples of good joint working, in general the SSI reported poor inter-agency working on definitive issues such as the integration of care management and the care programme approach. The concept of diversion was understood, but there were limited resources to put it into effect. There was evidence of difficulty for all agencies in dealing with high levels of occupancy of acute psychiatric beds, problems of substance misuse and mental illness and in achieving maximum throughput of patients from forensic mental health services into mainstream. Prisoners with mental health problems were often not connected up with health and social services after their release. They concluded that

> *".sometimes the needs of mentally disordered offender were a low priority or overlooked altogether "* (SSI, 1997, p.1).

In order to meet the needs of mentally disordered offenders, the SSI made a number of recommendations which focused on the need for strategic planning – identifying numbers and needs, planning developing and reviewing services and including the identified needs of mentally disordered offenders and service developments into existing plans, such as community care plans.

However, some 2 years later, the situation had not changed significantly. The DOH (1999) carried out a survey into services for people with learning difficulties in 24 local authority and partner health authorities. This survey established that there was still a significant gap between needs and services:

- specialist community forensic services appeared to be adequate in only half of the authorities
- in-patient specialist services, including forensic and mental health services were reported to be adequate in only a third of authorities
- a significant increase was expected in the volume of NHS secure accommodation in order to meet need.

In North Yorkshire there was growing pressure to support people with moderate/mild learning difficulties who had offended or might offend if they were not properly supervised (DOH, 1999). Sex offenders posed a particular problem for services who did not have the required expertise resulting in buying in packages of care costing between £60,000 to £100,000 per year. In addition, the local specialist in-patient forensic service was fully utilised and there were no move on facilities, highlighting the need for the development of a range of community based services for people who are at risk of offending and for people who are returning to the community.

The lack of expertise in dealing with mentally disordered offenders is not an issue which is confined to Yorkshire. A survey of community teams for people with learning difficulties and people with mental health needs as well as the probation service in Wessex (Vaughan et al, 2000) examined the capacity of teams to support mentally disordered offenders in the community. This study also identified a lack of proficiency in dealing with this particular group of people. Furthermore, the lack of inter-agency working led to people not being able to access much needed services. This together with a lack of services such as accommodation and day services led to a reluctance of services to work with mentally disordered offenders. Due to the lack of formal probation orders, the majority of mentally disordered offenders were on the caseloads of the learning disability teams, possibly reflecting the reluctance of the police to prosecute.

This picture of compartmentalised and often inadequate services delivered by staff who have limited expertise in working with a small minority of people who nevertheless attract a great deal of attention because of past or possible future behaviours, raises the issue of risk . “Still Building Bridges” (1999) found that there had been some positive development in joint working in delivering services for people with mental health problems in the 15 authorities that were surveyed. However only 3 out of the 15 authorities had agreed and implemented comprehensive inter-agency risk assessments. The concept of risk in relation to mentally disordered offenders, usually considers the risk assessment/management function within service provision, and it is here that the increasing emphasis on control is apparent. In addition there is the wider risk of the constant failure to provide adequate services to a group of vulnerable people, a group of people who are made vulnerable through exclusion and discrimination.

2.3 Risk assessment and management in the community

(i) From risk-taking to risk minimalisation

The literature relating to risk and mentally disordered offenders is rapidly expanding, reflecting the increasing focus within services, particularly community based services, on public safety. Risk-taking has always been a concept which has formed an essential part of good practice despite the difficulties in developing good policies and practices in terms of its implementation (Alaszewski et al, 1999; Tindall, 1997). In this context, the focus primarily has been upon enabling service users to develop new skills and new experiences without being harmed or inflicting harm on others, particularly when working with groups of people who have been disempowered such as people with learning difficulties. The emphasis now in work with people who have offended is on ensuring that the activities which any ex-offender undertakes does not represent any harm or potential harm to members of the public, regardless of the restrictions which that may place upon the person's life (Lawrie, 1997). Davis (1995) describes this as risk minimalisation.

This explicit focusing on the issue of public safety may be seen to be the result of a moral panic which has been spearheaded by the tabloid press and some organisations such as SANE, which have linked the development of community care with an alleged increase in homicides at the hands of people with a diagnosis of mental illness (Beresford, 1999). This has resulted in a common perception that all people who have mental health needs are potential murderers and that we are all potential victims of an attack by crazed knifemen. Central to this particular analysis is the concept of dangerous people who cannot be "cured" and the ineptitude of professionals. This perception has been fuelled by the "name and blame " strategy which has been adopted by the government, together with the sensationalisation of the inquiries into those homicides which have been carried out by people with mental illness. The public's fear of crime is not based upon actual crime rates as the British Crime Survey shows (Kershaw et al, 2000). This survey found that 1/3rd of the people surveyed thought that crime had risen "a lot" when in fact it had fallen by 10%. However, public pressure is largely responsible for the government passing a number of pieces of legislation (Criminal Justice Act, 1991, Criminal Justice Act 1993, Criminal Justice and Public Order Act 1994) and directives (e.g. LAC (92)15, LASSL (94)4) which aim to reduce risk through the identification of public protection as paramount and the increased use of strict supervision of ex-offenders in the community as a distinct methodology to achieve this protection. Current proposals for a new Mental Health Act recommend even more restrictions for people who have the diagnosis of personality disorder regardless of any offending behaviour. Psychiatry, in particular, and professionals in the social care arena in general, who were once seen as abusing power and being over-controlling, are now often criticised for not being enough in control.

The fact of the matter is that the number of homicides committed by people with a diagnosis of mental illness has not increased since the inception of community care. Indeed an analysis of the figures of people admitted to Special Hospitals from 1972 to 1995 for crimes of homicide shows a decrease of about 3% over the last few years (Bennet, 1999; Langham and Lindow, 2000). Gunn and Taylor (1999) compared the average annual figure of 40 homicides committed by mentally disordered offenders to that committed by others, i.e. 600 – 700 each year, and other studies have shown that in those cases where homicides were committed by people with mental illness, only 13% involved strangers as victims. The most likely people to be victims were family members and involved professionals (Taylor and Gunn, 1999). People with mental illness are in fact 25 times more likely to kill themselves than someone else (Munro and Rungay, 2000).

Regardless of the numbers of people involved, professionals clearly have both a legal and a moral duty to minimise harm – to members of the public, people known to the service user, professionals working with the service user and to the service user themselves. However, this duty needs to be realistically framed with a recognition of the complexities of the issues and based upon achievable outcomes. This process is only possible where there are robust risk assessment tools, good practice guidelines in risk management and access to adequate and appropriate resources.

(ii) Identifying risk

In order to identify risk, it is necessary to firstly define what is meant by risk. Kinaler (1990) suggests that "risk is a course of action or inaction, taken under conditions of uncertainty, which exposes one to possible loss in order to reach a desired outcome." This definition is favoured because it includes the impact of action as well as inaction and by its very simplicity exposes a number of complexities which must be addressed, in particular, the lack of certainty in a changing environment, the fact that minimising one risk may increase another and the possibility of there being a number of desired outcomes which conflict. The National Standards for the Probation Service, for example include maintaining public safety as well as rehabilitating the offender as goals (Shaw, 1996).

Risk assessment tools fall into two main categories: actuarial and clinical. Briefly, actuarial tools are those that are based on statistical evidence, and reflect the view that there are a number of predictive factors e.g. previous court appearances (Turner, 1998). Clinical tools are those that are based upon clinical judgement. There has been much discussion in the literature about the effectiveness of both kinds of tools, with some commentators favouring actuarial models (Cooke and Michie, 1996), whilst other favour clinical models (e.g. Walker, 1991) and of course many favour a combination of both (Munro and Macpherson, 1998). This approach to risk has strong links with the positivist school of criminology and is subject to the same criticisms.

With respect to actuarial tools there are questions about the definitions of risk factors which are taken into account, as some factors may be seen to overlap. There are also issues of relevance to that particular offender and offending situation. In addition, factors need to be sensitive to changes in either the offender or the environment. The concept of static and dynamic risk factors are of particular importance here (Andrews et al, 1990). Static risk factors are those which cannot be changed (e.g. gender or the age of the first offence), whilst dynamic risk factors are those such as employment, friends etc. which if changed may reduce the risk of reoffending.

Shaw (1996) suggests that in order for a "damaging incident" to take place there must be three essential elements : - the offender, the circumstance and the victim. Offending is therefore a dynamic interplay of different elements, and thus a focus purely on the offender or a conceptualisation of all offenders as inherently dangerous is unhelpful. Walker (1991) suggests that there are four different kinds of offenders which he called a typology of dangerousness, The likelihood of the offender reoffending depends upon the category into which he/she may fall:

1. The individual who harms others only when sheer chance brings him/her into a situation of extreme provocation or sexual temptation
2. The individual who gets into such situations by chance, but following inclinations
3. Individuals who constantly look out for opportunities
4. Individuals who create opportunities.

Walker suggests that the last two kinds of people are unconditionally dangerous and it is in making decisions about which category that people fall into that clinical judgement and an analysis of motives comes to the fore. The problem with such an approach is that "dangerousness" is a particularly pejorative word, which is used frequently but has never been clearly defined, and like all labels runs the risk of being attached to someone when no longer relevant. It is for these reasons that it probably should never be used, but rather judgement confined to a regular analysis of risk and its management (for a fuller discussion, see Crighton 1999). Clinical tools, also, may fall foul of biases (Strachan and Tallant, 1997), misperceptions or just plain bad judgement on the part of the clinician.

Many of the tools that have been developed are not particularly relevant to people with learning difficulties as the majority focus on people with mental health needs. Turner (2000) suggests that part of the reason for this is the difficulty in identifying prevalence rates and characteristics of people with learning difficulties who offend which may mean that it is difficult to identify the factors to be used in predicting likely reoccurrences. There are an increasing number of checklists which are currently in use, e.g. the RAMAS checklist is being used by Sandwell Social Services in order to assess people with learning difficulties leaving secure facilities; an adapted version of the MacArthur Foundation checklist is being used in a Devon open forensic unit for people with mild/moderate learning difficulties (Turner 1998), and the HRC–20 was found to be in current use in the North-west of England (Turner 2000).

Problems with the accuracy of risk assessment have led some writers such as Carson to suggest that the focus should be on risk management rather than risk assessment, and it is certainly the case that the controversy around risk assessment and accuracy of actuarial factors and clinical judgements could lead one to suppose that risk assessment is an end in itself rather than the beginning of the provision of individually tailored support packages. An analysis of 40 public inquiries which took place into homicides committed by people with a diagnosis of mental illness between 1988 and 1997 concluded that in 11 out of the 40 cases it would have been possible to predict the violence, whilst in 17 out of 40 cases the violence could have been averted by better levels of care (Munro and Rungay, 2000). The authors conclude that it is better to focus resources on providing good levels of care than trying to identify high-risk patients.

Another danger of the focus on risk assessment is that it does not look at the whole picture, but merely the offending behaviour, with the possibility of restricting the lives of a number of people who have been falsely identified as a potential risk and never given the opportunity to disprove it. Gunn and Monahan (1993) suggest that out of every three mentally disordered offenders likely to be detained because they are viewed as potentially violent, only one would be violent if discharged.

(iii) Managing risk : risk minimalisation vs. risk taking

Conflicts between risk minimalisation and risk taking become particularly evident when looking at issues of multi-agency working. The focus of the criminal justice system is on risk minimalisation whilst that of the social and health care services is on risk taking, as encapsulated in such philosophies as normalisation and user empowerment. The tensions of such approaches have been usefully summarised by Turner (2000) in the following table:

Factor	Risk-taking	Risk minimalisation
1	Risk assessment takes place within general care plan	Risk assessment is a comprehensive investigation within a framework of forensic process
2	Adopted as good practice for all clients	Specific to a few high-risk individuals
3	Attempt to balance risk minimalisation with risk taking	Public/staff safety primary consideration
4	Also applied to other risks (e.g.challenging behaviour or health and safety)	Emphasis on a limited number of risks (i.e. violence, sex offences and arson)
5	Assessment not specific to one profession	Centred on forensic psychiatric expertise
6	Community based	Institution based e.g. secure unit, prison, hospital

Table 2.5 : Risk taking and risk minimalisation
Turner (2000) p.253.

The differentiation shown in this table has however become increasingly blurred as mainstream social and health care services take on more responsibility for offenders, e.g. with the development of assertive outreach teams (George, 1999). Responsibility for risk assessment and risk management may be held by any number of agencies at any point in the process e.g. a risk assessment may be carried out by one agency and risk management may be carried out by another agency or agencies in the case of someone discharged from an institution to the community. Good risk management requires good communication between a number of involved agencies. Unfortunately as has been previously described, there has been a lack of commitment to inter-agency working with many diversion schemes relying on the appointment of a specially created post in order to facilitate liaison. As Kershaw (2000) states, the chaos which typifies many disordered offenders' lives is second only to the chaos which typifies services which are supposed to meet their needs. Given the failure of services to date, she recommends the creation of keyworker posts who have responsibility for co-ordinating services for mentally disordered offenders (Thames Valley Partnership, 1999).

Despite the fact that there is a conflict in terms of approach in managing risk, many see philosophies which are currently in use in social care services as good practice in service provision for mentally disordered offenders (e.g. Clegg et al,1999; Vaughan, 2000). It is indeed possible to develop a risk assessment/management model with user participation, for example. Strachan and Tallant (1997) suggests that this is a necessity given that one cannot constantly supervise someone, and people must be encouraged to take responsibility for their own actions. They outline a process by which the service user and the professional jointly identify risk factors and triggers, and the service user is given a copy of the trigger factors. Where there is conflict, issues should be re-visited until agreement is reached. Strachan and Tallant do not make any recommendations for situations in which there is no agreement. This model of identification of losses and gains could be easily incorporated with Tindall's model of risk management in which activities are jointly evaluated in terms of risks and benefits, strategies are developed, clearly stated and owned and activities are regularly reviewed and monitored (Tindall, 1997). The processes are not difficult, it is more the issues of resources, skills, the conflict between different agencies' perceptions and the lack of ownership for a group of vulnerable people that prevent them being put into practice.

2.4 Assertive Outreach Teams

Over the last 10 years, assertive outreach teams have become recognised as the most effective way of meeting the needs of people with severe and enduring mental illness who do not engage with statutory social and health services. Assertive outreach teams began their life in America as a response to enabling people with severe and enduring mental illness to manage, not only the transition from hospital to the community, but also to remain living in the community. Research had highlighted that people with severe mental health needs found it difficult to access the kind of support that was needed, partly because of the fragmented nature of the way in which services were structured. Two ways of enabling people to access the service they needed were identified and developed:

- care management, in which a paid worker would co-ordinate the services that the person needed, often providing services themselves. This model forms the basis of the Care Programme Approach.

- a team which included all the professionals who had relevant skills and who shared responsibility for service users. This model was developed further by Stein and Test (1980) and forms the basis of assertive community treatment (Drake, 1998).

In Britain, following a number of homicides by psychiatric patients in the 1990's and the ensuing debate about community care and public safety, the care programme approach (CPA) was developed. This appears to have coincided with a growing concern that people with severe and enduring mental illness were not always receiving the services that they needed. Following the demand for ring –fenced services in the early nineties, the government produced policy which supported this approach e.g. King, 2001. Assertive outreach teams appeared to offer an answer to supporting a complex group of people with severe mental illness, many of whom were also perceived as violent. Tulip, a voluntary sector organisation set up one of the first assertive outreach teams in 1995.

"Assertive community treatment" has now become a positive buzz-word in mental health circles and is being actively promoted by central government for people with severe and enduring mental health need. In 2000, the government declared their intention to develop 220 assertive outreach teams by 2003 serving an estimated 20,000 people (DOH, 2000), and developing assertive outreach teams now forms one of the performance indicators that NHS trusts are required to report on. Projects, and even individual workers, were often described as being "assertive outreach" when they bore little resemblance to the assertive community treatment model. Assertive outreach, as an approach, has necessarily undergone some changes in order to develop a model which is appropriate for Britain. The model that was developed in America was developed within a different legal framework which allows for punitive action to be taken for non-compliance with services. The service framework is also very different, with health, social housing and employment services being organised separately in Britain. The development of a model of service which is appropriate for Britain is more than an academic exercise in purity, as research has shown that where the model does not contain essential core components, it is less effective (Ford and Ryan, 1997). In order to ensure that appropriate service models were developed, in 2001 the DOH produced guidance upon an assertive outreach service model which was based upon the following research and lessons learnt from practice (DOH, 2001).

(i) Core components of assertive outreach teams

The Sainsbury Centre for Mental Health, together with four assertive outreach teams based in London and Birmingham drew up a framework which listed the essential components of assertive outreach teams. They defined assertive outreach as

> *"a flexible and creative client-centred approach to engaging service users in a practical delivery of a wide range of services to meet complex health and social needs and wants. It is a strategy that requires the service providers to take an active role, working with the service users, to secure resources and choices in treatment, rehabilitation, psychosocial support, functional and practical help, and advocacy ...in equal priorities."* (Morgan et al, 1999).

- one point of access
- working on the service user's own territory
- a team approach
- manageable caseloads
- a comprehensive range of interventions
- a no-close policy.

Table 2.6: Core components of assertive outreach teams (Morgan et al 1999)

- " The team targets those with severe and enduring mental health problems, and this is strictly adhered to
- Each service user must have a key worker nominated who is known to the user
- The case load ratio of key worker to service user is about 1 : 10
- The team consists of a multi-disciplinary staff mix who operate using a team approach
- The service should meet the basic needs of service users and include assistance with practical everyday tasks

- The importance of developing trusting working relationships with individual service users is stressed
- The services offered should be on-going and not time-limited
- Offer specific evidence-based interventions
- Assertive Outreach Teams should be properly integrated into a wider system of comprehensive mental health care
- Provide community based crisis intervention or have access and established links to crisis intervention services. "

Table 2.7 : Service characteristics of assertive outreach teams (Hemming et al, p. 142, 1999)

These core components and service characteristics have been widely promoted but have not always led to the same model and there have often been differences in the team composition, operating hours and links with mainstream services, for example (see Burns and Guest 1999; Tasker 1998). The guidance produced by the DOH in 2001 attempted to regulate this, by specifying operating hours, team composition, the role of the care co-ordinator and essential policies and procedures. This guidance also specified who the teams should work with and people with a history of violence or offending now form one of the key target groups.

(ii) Effectiveness of assertive outreach teams

Assertive outreach teams have become extremely popular in Britain as a result of many studies from America, Australia and Britain which show that assertive outreach teams are more effective in engaging and maintain engagement with service users (e.g. Henrinckx et al, 1997; Gauntlett et al, 1996). Studies have also shown positive outcomes in developing life skills (McGrew et al, 1995; Hambridge and Rosen, 1994) and in preventing readmission to hospitals (Dincin et al, 1993). Many studies have reviewed assertive outreach from an economic perspective and found them to be cost-effective because of their ability to maintain people in the community, develop independent living skills and reduce hospital admissions (Essock et al, 1998; Johnston et al, 1998; Latimer et al, 1999). Latimer (1999) found that hospital admissions were the main source of cost-effectiveness and that assertive community treatment reduced hospital admissions by 58% a year when compared to other forms of case management.

To date studies have not focused on reoffending rates although many of the service users of assertive outreach teams have committed offending behaviours or have a forensic history.

Minghella et al (2002) in an evaluation of two assertive outreach teams in the voluntary sector (Tulip and Impact) found that there were significant differences between the teams and a lack of fidelity to the assertive outreach model. The main differences were in the lack of psychiatry input, frequency of contact and the lack of targeting of people who had a history of frequent hospital admissions. They concluded that although there were disappointing outcomes in terms of the lack of improvement in social and daily living skills, reported quality of life and reduction in hospital bed use, there were positive outcomes in user satisfaction and engagement.

There has been also some suggestion from Ryrie et al (2001) that the focus on teams which are based upon the treatment and management of illness such as assertive outreach, crisis management and home treatment teams have effectively left a gap in terms of the provision of psychosocial interventions which support community integration, the development of daily living skills, educational and employment support. Some teams do provide this kind of support but have increasing difficulty in fitting into the current picture of services.

(iii) Assertive outreach teams : care versus control

There has been some concern about the potentially authoritarian and aggressive nature of assertive outreach teams in the models developed in America, and the possible transfer of coercive measures to Britain. In America workers are able to use a range of coercive measures if service users fail to co-operate such as taking control of service users' money. Assertive outreach has been criticised for

> *"..the common justification for any intervention being that it works.."*
> (Heath and Nicholson,1999, p.52).

Alternative models have been developed such as the active client engagement model (Heath and Nicholson, 1999). This model bears a strong resemblance to assertive outreach – there is a team approach, holistic support is provided flexibly, trusting relationships are developed with service users and links are developed with other agencies. The active client engagement model shows similar outcomes in terms of user engagement (100%), high service user satisfaction, and reductions in hospital admissions (45%). The main difference from Heath and Nicholson's perspective seems to be that

> *"..we hold the people we work with in high regard, respecting their rights, need for self-determination and autonomy to the furthest degree possible within the limitations imposed by their illness."* (p.52, Heath and Nicholson, 1999).

Hand in hand with this approach is an emphasis on working with rather than doing to. They do not produce any evidence that assertive outreach teams cannot work in an empowering way except to say that assertive outreach teams In America have coercive powers and that they do not claim to reduce violence or suicide. Heath and Nicholson also fail to show that their way of working reduces either of these behaviours.

- **Collaboration: -** emphasis on establishing qualitative relationships with clients, based on co-operation to produce a partnership in care. Working with rather than doing to.
- **Comprehensiveness:** - A holistic approach to the clients needs and aspirations. It is important that the clients should perceive contact with the team as meaningful to them.
- **Flexibility:** - Interventions and intensity of contacts adapt to the changing needs of the client over time.
- **Continuity:-** The partnership in care between the client and members of the team is maintained throughout all phases of their illness including times of hospitalisation
- **Teamworking:**- A small, committed, highly motivated team facilitates good communication and high clinical standards.
- **Networking:**- High quality care in the community necessitates establishing effective links with other agencies, professionals and community resources along with developing appropriate and sensible links with the clients own personal network.

Table 2.8 : Key elements of ACE approach (Hayes and Nicholson, 1999, p.53).

Assertive outreach teams are still in their infancy and so far they seem to have the critical support of most professionals. There is a fear amongst professionals that limited resources may go to assertive outreach teams rather than other kinds of services or that assertive outreach teams may be assertive in name only and consist of repackaged already existing services (e.g. Gould 2003), but as yet there does not appear to be orchestrated concern coming from the user movement. In fact, in a survey of the views of mentally disordered offenders, Vaughan and Stevenson (2002) found that 88% of interviewees said that they would be glad to receive such a service. There may be high levels of user satisfaction with the service or it may be difficult to criticise a model which is so disparate. It may also be that like many professionals, service users are waiting for the proof of effectiveness from their perspective.

2.5 Conclusion

The structures which have been put into place to ameliorate the possibly damaging effects of the criminal justice system on mentally disordered offenders appear to have a somewhat limited impact. Peay (200) suggests that there will always be mentally disordered offenders in the legal system because of contradictions within the way the system operates and our perceptions of who offends and why, issues of treatability and sometimes the seriousness of the crime. There are also real issues about the difficulties of both identifying vulnerable people and offering appropriate services. Where vulnerable people are identified, they may not be offered an Appropriate Adult for instance, because it is not felt necessary. They may also be diverted either formally or informally to inadequate services where people are subjected to different forms of control or no services at all. Where vulnerable people are not identified which seems to be remarkably common, they may end up making false confessions and being sent to penal institutions where they are victimised because of their vulnerabilities or where their health deteriorates through lack of treatment. The attempts to make the criminal justice system work fairly for people with learning difficulties, mental health needs and Asperger's have frequently failed.

However, it is not just the criminal justice system which has failed mentally disordered offenders. Diversion schemes have proved better at identifying a new "criminal" population, by widening the net, than in enabling people to access much needed support. To put it plainly, health and social care services do not want to deal with this group of people. They are not seen as a high priority (Newham, 1994), there are no additional resources to provide new services, existing services often lack the necessary key skills and people frequently do not meet eligibility criteria for access to services. Moreover the service users are often hard to engage with and may have behaviours which create high levels of anxiety should services fail to support them adequately. The service response appears to have been through the creation of new asylums, i.e. the secure units, and more invasive community based services such as assertive outreach teams. One of the problems with the way that services are constructed is that access is based upon diagnostic criteria, administered by experts, not on levels of need identified by potential service users. Thus people who are extremely vulnerable but do not fit easily into a service may be batted about from one service to another with neither wanting to take responsibility. Inter-agency co-ordination is indeed poor, and this contributes to a lack of services for mentally disordered offenders, as responsibility for this group is denied on an individual and a joint-working basis. Although diversion schemes should provide a combination of treatment and social control, the focus is very much on control within the community. Thus hard options are well financed, and there is an increasing technology in areas such as electronic monitoring, in enforcing medication and in risk management. Where people require good housing, an adequate level of income and access to support when they need it, these options are frequently not available.

The increasing emphasis on risk minimalisation highlights a number of themes. Firstly there is the conceptualisation of the mentally disordered offender as irrational and unable to take responsibility for his/her actions. Secondly, given that diversion means diversion to health and social care agencies which are acting as an informal part of the criminal justice system, it then becomes the responsibility of those agencies and the community to manage risk resulting in conflict between traditional service philosophies and new objectives. Thirdly, the emphasis on public safety, which is explicit in the criminal justice system, e.g. section 2 of the Crime Sentences Act 1997, has lead to a reconceptualisation of those people who are in contact with health and social care services as potentially dangerous. Risk, and its identification and management then, brings a new edge to the debate on care and control. It is perhaps because of the issue of public safety and risk, that although there has been considerable blurring between populations of offenders and potential offenders and the criminal justice system and the welfare state, social and health care agencies have not embraced this new population whole-heartedly, preferring instead to use institutional rather than community based options.

Finally, the Crime and Disorder Act 1998 section 17 requires local authorities and police authorities to consider the community safety implications of their activities and states that they should do all that they can to reasonably prevent crime and disorder in their area. The lack of services provided to people who are potential offenders, "para-offenders" (people who commit offences but are not sentenced) and actual offenders could have clear implications for community safety, and raises the issue of clearly identifying the population who are the remit of these authorities. This is recognised by most authorities in their youth strategies, but has not yet been extended to mentally disordered offenders, although there are ring fenced monies which could possibly be used to fund such initiatives, if seen as a priority. The next challenge will be to develop services which minimise control and maximise support and opportunities for people with learning difficulties, mental health needs and Asperger's syndrome.

Chapter 3
Evaluating Services

3.1 Inputs, processes and outcomes

Services may be described as being composed of three elements: inputs, processes and outcomes. Until the 1990's, service evaluations focused upon on inputs and processes, with the end result of producing limited information (Jenkins, 1996; Thornicroft and Tansella, 1996; Beaile and Warden, 1996). An evaluation of inputs looks at the resources which make up the service, such as type of staff, number of beds. Whilst this information is essential for assessing a service, this focus lacks an analysis of whether services are actually doing what they are supposed to do. Similarly an examination of processes such as staffing levels, number of staff/service user contacts are important in terms of understanding how a service operates, but limited in terms of evaluating the service as a whole.

An evaluation of outcomes essentially measures the impact of the service on the lives of the recipients – central to outcomes are the perceptions of service users. A lack of effective psychometric measures probably contributed to a limited view of outcomes – those that existed commonly measured morbidity and mortality (Biggeri et al, 1996). More sophisticated outcome measures have now been developed which include measures of service user satisfaction, quality of life and global functioning and outcome measures are now being seen as the most important measure (Jenkins, 1996) focusing as they do on the effectiveness of the service and providing information with which to improve services.

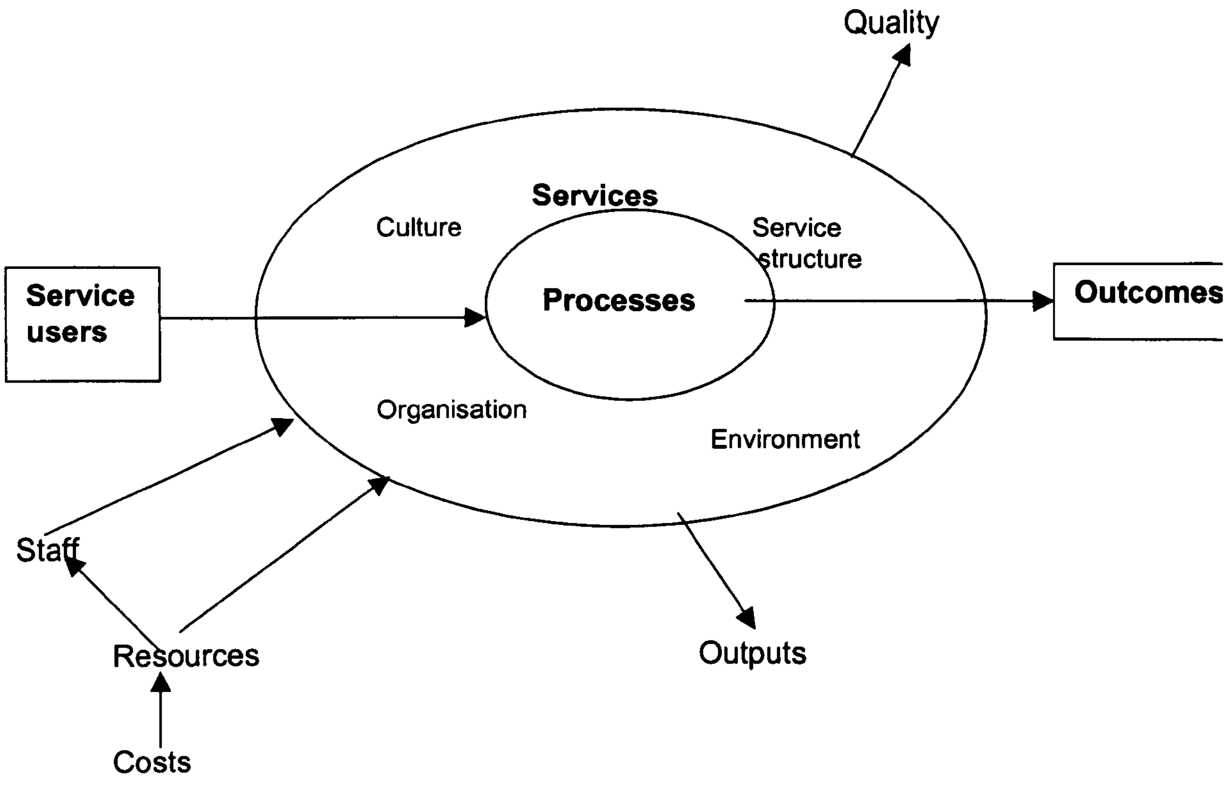


Figure 3.1 : The relationship between inputs, processes and outcomes. (Lindsey and Gralton, 1999, p.415).

Biggeri et al (1996) recommend a multi-dimensional assessment of outcome which somewhat widens the concept of outcome to include inputs and processes where appropriate. They suggest that in order for outcome measures to usefully inform practice, they should be comprehensive and combine optimal measures at both the service level and the patient level, including input and process measures where appropriate. Process indicators, such as the number and profession of staff do have value at the service level when combined with outcome measures, such as the ability to meet referrals to the service as they will inform good service planning. At the patient level, measures should explore the impact of the service on a number of different dimensions of patient well-being, including the severity of symptoms, social variables such as quality of life and the users' interaction with service, including satisfaction. It is generally accepted that measures should also include professionals' and relatives' views as these add to the evaluation of the service. Clearly, as figure 3.1 illustrates, an effective evaluation of any service must look at all aspects of its functioning, and any attempt to delineate and discard inputs, processes or outcomes would distort the final result.

Strathdee et al (1997) state that service effectiveness can be assessed by measuring the following outcomes:

- Clinical status e.g. symptom presence and severity
- Social functioning e.g. daily living skills, ability to participate in day care, work and leisure opportunities
- Quality of Life e.g. users' ability to participate in activities of their choice, level of access to appropriate social and domestic support
- User satisfaction e.g. if users are satisfied with the level and types of treatment and the service as a whole
- Service utilisation e.g. the amount of hospital/community services, caseload/case mix
- Carer support e.g. the extent of carer involvement in individual care planning and how much information they receive about their relatives
- Staff morale and burn-out, e.g. rates of sickness amongst staff, staff motivation.

Key features of this framework that will be used for measuring the effectiveness of both residential and community services in part 2.

3.2 Choosing Outcome Measures

There are a range of outcome measures, both qualitative and quantitative, that may be used. Factors taken into consideration when choosing a particular tool include not only validity, reliability and sensitivity to change, but also the relevance of the content of the measure to the area studied, in this case, services for people with Asperger's or autism, mild/borderline learning difficulties, mental health needs or a combination of conditions. One of the difficulties in identifying appropriate measures is that most measures focus on people with learning difficulties or people with mental health needs but not both. Another issue is that measures are changing and becoming increasingly sophisticated as the focus of service evaluation changes. This is particularly the case with evaluating residential services as much of this research has been undertaken within the framework of evaluating the impact of changing policy reforms. This means that the range of comparable data will also be limited.

The following section discusses the tools developed to measure these areas of services with particular reference to the selected outcome measures.

3.2.1 Measuring changes in symptoms or functional skills

There are many measures of global functioning scales for both people with learning disabilities and people with mental health needs. Scales which look to assess global functioning suffer from the same difficulties as quality of life schedules in trying to identify a range of abilities which accurately reflect functioning and behaviour whilst remaining objective and non-judgemental. Some schedules focus on impaired behaviours whilst other will focus on impaired performance in social roles and living skills. It is also difficult not to include value-laden and culturally influenced judgements as to what is "normal functioning" in the development of such scales. However despite the difficulty in assessing functioning, it is particularly vital to do so, given that the level of functioning may indicate the level of support that someone needs (Phelan et al, 1996). There are a number of measures which have been developed for service users with learning difficulties, but only one which was developed with them – the HONOS-LD. There is also one scale, the Avon Mental Health Measure (AMHM), which has been developed by service users with a diagnosis of mental health needs.

The AMHM enables people to take an active approach in their own support and looks holistically at the person's strengths and support needs (www.mind.org.uk). It allows people to state what they would like to happen if they had a crisis. The measure has been piloted and evaluated by Bristol University. The AMHM enables people to examine 25 aspects of their lives including:

- Housing
- Ability to self care
- Effects of medication
- Social support

- Daily routine
- Experience of discrimination
- Community involvement
- Risk to self
- Anger
- Substance misuse
- Mood swings
- Experience of a number of mental health symptoms
- Income
- Communication skills and opportunities
- Money management
- Sleep disturbance.

(i) Global functioning measures in people with learning disabilities

The HONOS-LD for people with learning difficulties and mental health needs was designed in order to provide an easy-to-use tool for use by clinicians to measure changes in symptoms and functioning (see Appendix 3). The scale was designed by many different groups of interested professionals, including the Royal College of Psychiatrists and the British Psychological Society's Centre for Clinical Outcomes, and in consultation with People First, the national self-advocacy group for people with learning difficulties. Over the last 3 years, it has been tested in field trials in 16 trusts and now has a scale of 18 items. Tests indicated that the scale was acceptable to practitioners, had good inter-rater reliability and was sensitive to change. It also had good correlation with well established instruments such as the Aberrant Behaviour Checklist and can be used in conjunction with other scales (Roy et al, undated). Although Roy et al claim that the scales are appropriate for use with people with all levels of learning difficulties, Lindsey and Gralton (1999) argue that they are more suited to use with people with mild learning difficulties.

The HONOS-LD is used to rate 18 items on a 5 point scale (from 0, no problem to 4, severe problem) on a 4 weekly basis. Descriptions of behaviours are provided to assist accurate rating. Items rated fall into 4 sub-scales - behaviour, impairment, symptoms and social issues. The HONOS-LD scale does cover some aspects of social functioning but not in as much detail as the Life Skills

Profile (Rosen and Parker, 1989). The scale can be used by any trained professional who is conversant with learning difficulties and one of its advantages is that it can be completed in a relatively short timescale as opposed to more complex scales like the Vineland Adaptive Behaviour Scale. The scale is used to measure changes in individual functioning on individual items, global and sub-scale scores, although a factor analysis of sub-scales carried out on the generic HONOS suggests that a rearrangement of the items to different sub-scales provides a more accurate measurement of behaviour, impairment and symptoms. The same study concluded that global measurements should not be relied upon as the same total scores could mean a variety of different things (Trauer, 1999).

The most widely used global functioning scales for people with learning disabilities are the Vineland Adaptive Behaviour Scales (Sparrow et al, 1984) and the Adaptive Behaviour Scale (Nihira et al, 1974). These scales do take time to complete and are often used for identifying areas which require intervention.

The Vineland Scale is an interviewer administered questionnaire which requests information, not from the person themselves but from someone who knows the person well. The interviewer must be a professional with a degree who has received specific training in assessment and test interpretation. It aims to measure adaptive behaviour which in this case is defined as

> *"..the performance of the daily activities required for personal and social sufficiency."* (Sparrow et al, 1984, p.6).

Three key principles are central to this definition:

1. adaptive behaviour is age related
2. adaptive behaviour is defined by the expectations or standards of other people
3. adaptive behaviour is defined by typical performance not ability.

Unfortunately the normative data provided for the scales may not reflect these principles. Whilst variables such as gender, race, community size, region and parents education are taken into account, the scales were based upon a population sample of children aged under 19 years. When standardising the scales, an additional sample of 2,300 people with learning disabilities aged 18 and over were included. It appears that non-disabled people in this age group were not included in developing the norms or scales.

There are three versions of the scale – all have domains in communication, daily living skills, socialisation and motor skills. A further domain – maladaptive behaviour is contained in two versions. The survey form has 97 items, takes 20 – 60 minutes to complete and is recommended for a general assessment. The expanded version has 577 items and takes 60 to 90 minutes to complete. This version is recommended when a treatment programme is required. Items within the scales were refined through years of research using the stratified samples identified above. The scales have good test-retest reliability (intra-class coefficients of.95 to .99) and interrater reliability (intraclass correlation coefficients of .93 to .99) for each of the adaptive behaviour domains and their sub-domains. There is also high validity as evidenced by the interpretation of the finding of the scales (e.g. children with hearing impairments scoring lower on the communication domain) and their comparison with scores from other measures of behaviour, social functioning and intelligence.

The Adaptive Behaviour Scale (ABS) can be used as either an administered schedule or a tool for self-completion (see Appendix 4). The scale can be completed by any trained person who has direct knowledge of the person being evaluated or is able to get that information from someone else. The ABS aims to measure adaptive behaviour – in this instance adaptive behaviour is defined as

> *"..the manner in which people cope with the natural and social demands of their environments."* (Nihira et al, 1993, p.1).

The ABS is divided into two parts. The first part focuses on personal independence and has ten domains – independent functioning, physical development, economic activity language development, numbers and time, domestic activity, prevocational/vocational activity, self direction, responsibility and socialisation. The second part is concerned with social behaviour and has eight domains – social behaviour, conformity, trustworthiness, sterotyped and hyperactive behaviour, sexual behaviour, self-abusive behaviour, social engagement and disturbing interpersonal behaviour. It is used to help develop service or treatment plans for people with learning disabilities to monitor progress.

The ABS was standardised with a sample of 4,103 people with learning difficulties aged 18 and over. Variables taken into account included race, ethnicity, gender, whether someone lived in an urban or rural environment, employment, place of residence, geographic region, other disabilities and IQ. Additional sampling with non-disabled children and children with learning difficulties was used to develop age related norms. No non-disabled adults were included in the standardisation. Test – retest reliability scores were between .85 and .99 across all domains and factors. Inter-rater reliability scores were between .96 and .99 across all domains and factors. Construct and content validity were tested in the same way as the Vineland scale.

(ii) Global functioning and symptom measures for people with mental health needs

There are many different measures of symptom presence and severity for people with mental health needs, for example Sartorius and Janca (1996) list 5 different measures developed by the World Health Organisation. A literature search undertaken by the Royal College of Psychiatrists in October 1997 identified 107 references to measures of mental illness for use in the general population and 24 references to measurements used specifically with people with learning difficulties (Roy et al, undated). In 1993, the DOH commissioned the Royal College of Psychiatrists to develop standardised assessment scales to measure the health and social functioning of people with severe mental illness - the Health of the Nation Scale (HONOS). HONOS has many variations including one for mentally disordered offenders which has just been piloted in Regional Secure Units in the South Thames Region.

The generic tool for people with a diagnosis of mental health is scored as the HONOS-LD and has gone through an equally rigorous evaluation. It comprises the following 12 scales:

- overactive, aggressive, disruptive or agitated behaviour
- non-accidental self-injury
- problem drinking or drug taking
- cognitive problems
- physical illness or disability problems

- problems associated with hallucinations and delusions
- problems with depressed mood
- other mental and behavioural problems
- problems with relationships
- problems with activities of daily living
- problems with living conditions
- problems with occupation and activities.

The HONOS-MDO has evolved somewhat and has been redeveloped as the HONOS-secure, a scale which assesses the need for secure care for all users of secure services (www.rcpsych.ac.uk.).The scale is in two part and measures seven dimensions of security.

- potential harm to other
- potential for self-harm or self-neglect
- need for buildings security to prevent physical escape
- need for a safely staffed living environment
- need for escort on leave
- potential harm to individuals from other
- need for specialist clinical procedures

The administrator then has the choice of using the second part - the generic HONOS or one of the specialist scales.

The government, in its Mental Health Information Strategy, has made the implementation of Minimum Data Sets obligatory by April 2003. This includes all members of the HONOS family (Honos, 2001).

Phelan et al (1996) suggest that scales which focus on social functioning are concerned with 3 broad areas of life: social attainment, social role performance and instrumental behaviour. In a review of such measures for people with a mental health need, they identified a total of 10 scales, including the Life Skills Profile, and concluded that there was no such thing as the perfect scale because of difficulty of design etc. The Life Skills Profile is a measure of impairment and social function which was designed specifically for people with schizophrenia, but has been used more widely for people with a diagnosis of mental illness, for example in measuring the effectiveness of assertive outreach teams and case management (Hambridge and Rosen, 1994; Johnston, 1998; Issakidis et al, 1999) (see Appendix 5). The profile is a 39 item measure divided into 5 sub-scales -self-care, non-turbulence (a measure of anti-social behaviour), social contact, communication and responsibility which are each rated on a 4 point scale. Scores can be compared on a sub-scale and a global basis. It is designed to measure aspects of functioning in the community (Rosen et al, 1989). The scale has good internal consistency and high inter-rater reliability (Phelan et al, 1995), and has been shown to have good psychometric properties (Parker et al, 1992). It can be administered by any professional. Further work has identified the capacity of the Life Skills Profile in terms of sensitivity and in identifying clinically significant improvements in functioning (Trauer et al, 1997). Other studies have identified the capacity of the scale to predict re-hospitalisation (Parker et al, 1995) and survival in the community (Preston, 2000). The scale is perhaps more widely used in Australia.

The Life Skills Profile has been exclusively used with people with mental health needs. Whilst as a measure it would have applicability to people with learning difficulties and mental health needs in identifying changes in functional ability, it may have limited applicability in terms of its capacity to predict rehospitalisation as the outcomes for people with learning difficulties in accessing psychiatric hospitals are different. There are different care pathways and limited "specialist" facilities for people with learning difficulties who are experiencing acute mental distress and need treatment in a hospital facility.

3.2.2 Quality of Life

Quality of life measures are now frequently used in the evaluation of the impact of treatment methods and different ways of providing services. This is a relatively recent phenomenon. Angermyer and Kilian (1995), in their examination of the interest in the quality of life in the field of psychiatry, for example, found an increase in journal articles of nearly fourfold when comparing publications in the 1980s and the early 1990s. Muldoon et al, in their examination of literature across medical disciplines, found that "although quality of life assessment was almost unknown 15 years ago, it has rapidly become an integral variable of outcome in clinical research; over 1000 new articles each year are indexed under the "quality of life."" (Muldoon et al 1998 p.542).

The concept of "quality of life" is not a new concept. Philosophers from as early as Aristotle have attempted to define the concept of quality of life from a variety of value perspectives. However, in recent times the concept has been used in order to determine the allocation of limited resources, e.g. in the health care services. The notion of the quality of life is therefore not just a theoretical issue, but one which now has clear practical application and importance (Borthwick-Duffy, 1996). Researchers who seek to measure the quality of life do not always attempt to overtly define the concept, but seek instead to identify which areas of life are of understood importance within a particular culture. Concepts such as the quality of life are rarely used for examining the life-styles and well-being of the general population as a whole.

> *"We do not have an agreed upon standard for determining anyone's quality of life. In fact, we seldom make enquiries into the quality of life of people who are not disabled or disadvantaged in some way"* (Taylor and Bogden,1996).

This has changed recently with the Audit Commission developing broad performance indicators which relate specifically to the quality of life for general populations, but the thrust of quality of life measures which focus on individual's lives in quite intrusive ways is still on disabled and disadvantaged populations.

As with measures of social functioning and challenging behaviour, there are real issues about including value judgements in quality of life measures. The debate has ranged around whether quality of life measures for disabled people should include the same measures as non-disabled people given that the discriminatory nature of society means that the quality of life achievable for disabled people is not the same as that for non-disabled people (Rosen, 1986). However, the majority view is that, by using the same measures, areas which need improving can be identified and therefore quality of life measures are seen as tools to improve service delivery in particular, and life opportunities, in general (Schalock, 1996). The problem with this strategy is that the values encompassed in such a measure could reflect culturally inappropriate values and those of non-disabled people resulting not so much in an improvement in life, but rather a “normalisation” of life. Because of these considerations Felce and Perry (1995) argue that a 3-factor model should influence any measure in which life conditions, personal satisfaction and personal values all interact to determine quality of life.

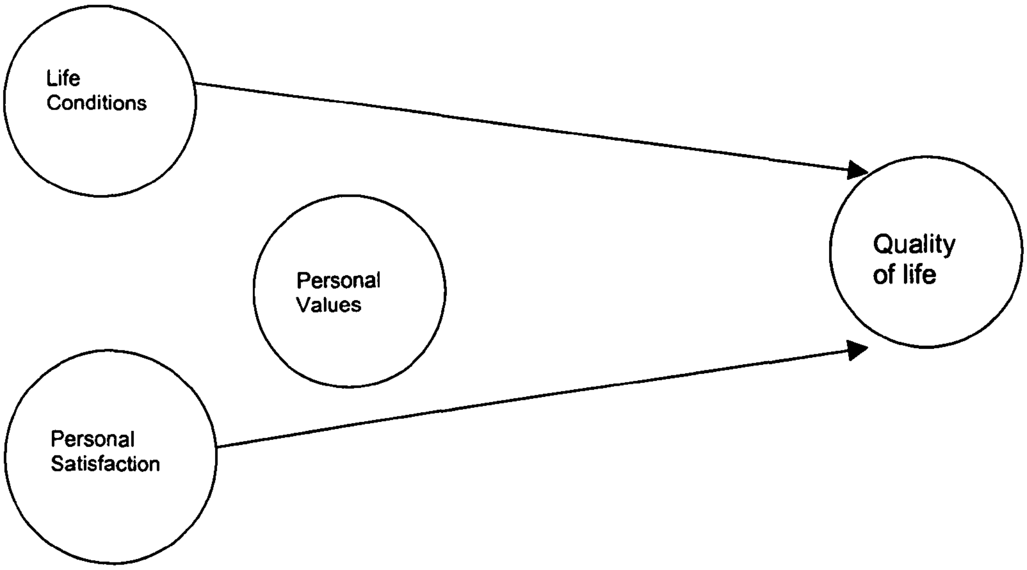


Figure 3.2 : Quality of Life as defined as a combination of Life Conditions and Satisfaction weighted by Scale of Importance
(Felce and Perry, 1995, p.55).

Despite the wide variety of definitions of quality of life and its measurement, there appears to be some consensus on the relevant domains, with most quality of life measures including physical well-being, material well-being, social well-being, development and activity, and emotional well-being (Felce and Perry, 1995). Subjective quality of life has emerged as a key variable by which to measure people’s perceived well-being. Often called life satisfaction, this aspect of quality of life measures has been found to depend upon close relationships and other factors such as religious faith rather than age, gender or income (Myers, 2000). However there has been some debate between Ager and Cummins, who have designed two of the most popular scales to measure quality of life on what constitutes the most effective way of measuring quality of life.

In a review of 13 scales designed to measure the quality of life for people with learning difficulties, Cummins (1997) suggested that 9 were too limited in terms of their scope, e.g. Ager's Life Experience Checklist , Heal et al's Life Satisfaction Scale. Of the remaining four, one did not have an adequate scoring system, one was lengthy to administer and required a 2 day training programme, which left only two measures with an adequate and equal range of items and domains and acceptable psychometric properties – the Schalock Quality of Life Questionnaire (QOLQ) (Schalock and Keith, 1993) and the Cummins Comprehensive Quality of Life Scales (ComQol) (Cummins, 1997). This position has subsequently been criticised by Ager and Hatton (1999, 2002) as one might expect. In particular Ager and Hatton dispute the need for only subjective measures of life given that people with learning difficulties may rate services highly due to their lack of experience of alternative forms of provision where more objective measures would highlight those service deficits. They further suggest that quality of life measures may be used to justify service developments which do not contribute to the empowerment and independence of people with learning difficulties. Cummins (2001, 2002) responded by confirming his view that the Ager LEC did not encompass a sufficiently wide range of objective and subjective measures or domains to adequately reflect quality of life citing the opinions of other renowned bodies such as IASSID to back him up. By 2002, Cummins had decided to abandon his Com-Qol in favour of developing a Personal Wellbeing Index. Clearly this discussion will carry on.

Ager's Life Experience Checklist is popular for measuring issues related to services, but does not cover the range of topics and views that other checklists do. The five sections cover the domains of home, leisure, relationships, freedom and opportunities. Under each heading, there are ten statements with which the respondent agrees or disagrees, and indicates the frequency of activity. Goble (2000) criticises the approach which both Ager and other people have taken in suggesting that more activity is better, without ascertaining anything about the service user's wishes or the quality of the experience. He also notes that there are significant gaps in the domains, e.g. questions about work. The reliability and validity of the tool seem to be limited by standard scores which do not take into account age, gender or race, and the consequent restrictions that people with these characteristics experience.

Cummin's Com-Qol was created in 1997 following 5 years developmental work. It aims to measure both objective and subjective quality of life in 7 domains: material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being. There is a separate pre-testing tool for people with learning difficulties. The pre-testing tool and the full scale take about 45 minutes to complete. The scale is described as reasonably valid, reliable and sensitive to change. The objective scale shows higher levels of internal reliability than the subjective scales (Cummins, 1997).

The Schalock and Keith QOL-Q (1993) is a 40 item questionnaire which looks at four domains – satisfaction; competence/productivity; empowerment/independence; and social belonging/community integration. Each domain has 10 items which can be scored between 1 and 3. The scale was designed in America for verbal adults and was tested on 552 people. Initial evaluations found good internal consistency and test-retest applicability. Rapley and Beyer (1996) determined that it was applicable to adults in Britain but questioned the validity of the scale if used with staff as a proxy measure (Rapley et al 1997). Staff tended to report much more positively – however this is likely to be a feature of all proxy measures, not just the QOL-Q.

In a review of 10 quality of life measures for people with mental health needs, Lehman (1995) concluded that there was considerable variety in the domains examined and that the selection of a measure should depend upon the purpose and needs of the research. Three measures were recommended as being comprehensive and having good psychometric properties – the Oregon Quality of Life Profile, the Lehman Quality of Life Interview and the Lancashire Quality of Life Profile (QOL-P).

The Oregon QLP has 141 items relating to services, responsibilities, performances and satisfaction of peoples' needs in each domain. The scales measure satisfaction with home, structure and support at home, self and home maintenance, adequacy of income, physical health, meaningful use of time, psychological distress, well-being, inter-personal relations, housing services, home management services, education services, employment services, social recreational services, physical health, mental health, nutritional services, transportation and protective services. Originally developed to measure the quality of life of people with mental health needs and the impact of case management, the Oregon QOLP was validated in one study of 62 people which also included 50 people with learning difficulties. Although overall inter-rater reliability was found to be satisfactory, the internal consistency was below 0.5 for seven of the 17 subscales (Turner, 1997 in Riemsma et al, 2001).

Of all the measures in learning difficulties and mental health needs, only 2 – the Lehman Quality of Life Interview and the Lancashire QOL-P included crime and safety. Of these, only the QOL-P has been designed with specific reference to Britain. No reference could be found in any literature to either measures developed with service users or by service users.

The Lehman QOLI consists of eight objective and subjective scales examining living situation, frequency of family contacts, frequency of social contacts, number of leisure activities, work, frequency of religious activities, finances, safety and health. The QOLI was evaluated on a population of 1,200 people with mental health needs in America – 232 of these people also had a learning difficulty (Lehman et al 1986, Lehman, 1998). These studies found that the QOLI had good internal consistency (0.5 – 0.956) and test-retest reliability (0.5 to 0.9).

The Lancashire QOL-P is based upon the Lehman Quality of Life Measure, but has been modified to reflect cultural variations between America and Britain, and to produce information that is particularly relevant for service evaluation, e.g. the living situation domain would be affected by the provision of accommodation services. It combines objective and subjective measures of recent and current experiences in the areas of living situation, family relations, social relations, leisure activities, finances, safety and legal problems, work, school, religion and health. In addition, there are measures of general well-being and self-concept. Life satisfaction ratings are on a 7-point Likert scale, ranging from "couldn't be worse" to "couldn't be better". There are 100 items in all, and the profile can take up to 1 hour to administer (see Appendix 6). The psychometric properties of the QOL-P have been evaluated, and test-retest reliability, internal consistency, reliability, content, construct and criterion validity were also assessed and found to be adequate (Oliver et al, 1996). The QOL-P has been used in a number of community based surveys such as the PRISM study (Clarkson and McCrone, 1998) and the UK 700 group (Burns et al, 1999).Both of these studies examined the needs of psychotic patients, some of whom have mild learning difficulties (Hassiotis, 1999). The scale however has not been used extensively with people with learning difficulties.

3.2.3 Team Assessment Tools

Multi-disciplinary teams are a relatively recent phenomenon in service provision, emanating from government documents such as "Caring for People" and "Building Bridges" which emphasised, firstly, effective collaboration between services, particularly health and social care services, and later multi-disciplinary teams as a way of working. The creation of multi-disciplinary teams has led to the development of tools to assess how well team members cope and perform in such settings and latterly how effective those teams are in achieving their aims and objectives. Scales have been developed or adapted to assess such issues as innovation (Anderson and West, 1994), job satisfaction (Weiss, 1967), role clarity (Onyett, 1997), professional identification (Onyett, 1997) and burnout (Maslach and Jackson, 1986).

The Team Climate Inventory Scale (Anderson and West, 1994) examines team members' perceptions of the teamwork environment in which they work and in particular the extent to which innovation is encouraged and supported in their team. The Team Climate Inventory consists of four factors that contribute to the team climate for innovation and measures five aspects of internal team climate - 'participate safety' (do members feel safe to share new ideas in the team), 'vision' (do members share objectives and vision of the team's work), 'support for innovation' (the degree of practical support for innovation) and 'task orientation' (commitment of the team to achieve high standards of work performance).

The Job Satisfaction Scale (Weiss, 1967) measures job satisfaction, using two themes – intrinsic and extrinsic satisfaction. Intrinsic satisfaction is the amount of contentment that the worker gains from the performance of the work itself – e.g. recognition or responsibility. Extrinsic satisfaction is the degree of contentment with extrinsic factors which are integral to the work environment – e.g. salary, status, security and supervision. Scores can range from 20 to 100 with high scores indicating high job satisfaction.

The personal/team role clarity scale was developed by Rizzo et al (1970) and adapted by Onyett et al for use in multi-disciplinary teams (1997). The personal role clarity scale assesses the extent to which an individual is clear about his/her responsibilities, who she /he will be accountable to and how his/her work will be evaluated. Team role clarity refers to the extent to which the team is seen as having clear aims and priorities, including clarity about who the team is working with. The scales are completed by participants themselves, rating 7 statements for each scale from 0 (strongly disagree) to 4 (strongly agree) (see Appendix 7). Reliability and validity has been established (Boakes, 1998; Onyett et al, 1997).

The team/professional identification scale was developed by Brown et al (1986) and also adapted by Onyett et al (1997). The scale is a self-completion scale which rates a total of 16 items, 8 of which confirm and 8 of which deny team and professional identification, from 0 (strongly disagree) to 4 (strongly agree) (see Appendix 8). The scale has established adequate reliability and validity (Boakes, 1998).

The Maslach Burnout Inventory (Maslach and Jackson, 1986) measures staff burnout using three different dimensions of burnout – emotional exhaustion (the long-term emotional effects of stress, resulting in a lack of capacity to offer psychological support to others); depersonalisation (how well or poorly workers relate to service users and colleagues) and personal accomplishment (feelings of competence and achievement). The tool was developed from extensive research involving over 1052 people working in the "human service" field. This research highlighted the dangerous consequences of burnout for both staff and service users. The MBI consists of a 22 item scale which takes about 15 minutes to complete, and respondents rate how they feel using a scale of 0 – 6. Scores are then rated as representing high, moderate or low levels of burnout. Previous studies have indicated that there is a relationship between burnout, case load levels and length of time in a particular job (e.g. Vachon, 1987; Miller, 1995). Edwards and Miltenberger (1991) and Alexander and Hegarty (2000) established that different kinds of burnout are experienced at different points in the managerial structure. The Alexander and Hegarty study into burnout in a learning disabilities residential and respite centre found higher levels of burnout in senior rather than junior staff. Chung et al (1996), Chung and Corbett (1998) and Hayter (2000) suggests that there may instead be a relationship between burnout and management issues, and that supportive models of supervision may reduce burnout.

In addition to tools which measure various aspects of team and professional life, there are some documents which aim to give practice guidance on both setting up teams to meet particular needs and on improving team performance. Ovretveit(1993) extracted guidance for community multi-disciplinary teams based upon action research over 10 years with such teams. Ovretveit concluded that;

> *"Teams need to develop structures and organisation which are not dependent on individuals and which provide an environment which survive the inevitable changes of membership."* (Ovretveit, 1993, p.4).

Central to this structure and organisation were the way in which teams were managed and formed and the role of the team leader. Ovretveit was clear that there was no such thing as a "best practice" model, but rather that the type of team should be the most effective in meeting the aims and objectives of the team and the needs of service users. Within the framework of the team, Overtveit felt team members should be clear about their roles and should be supported to ensure that there is no overload or deskilling. This is one of the key functions of the team leader who fulfils, in Ovretveit's view, the most important role. Another function of the team leader is to ensure that teams works effectively and that "democractic ideals" do not destroy a team.

Ovretveit stated that there were six models of multi-disciplinary teams. He distinguished between "core" and "associate" membership of teams. Core membership is where team members are:

- Full time in the team
- Governed by team policy

- Managed by the team leader
- Have formal voting rights on team decisions

Associate membership is where team members are:

- Part-time in the team
- Not governed by team policy
- Have managers outside the team
- No voting rights on team decisions.

Type 1 : **Fully managed multi-disciplinary team**

- One team manager manages all the different professions in the team, and is accountable for each member and has managerial responsibility for them.
- The team manager decides team policies and procedures for cooperation, and directs team members
- Usually all team members are full-time.

Type 2: **Managed core and coordinated-associate team**

- One team leader manages core full-time members
- The team leader co-ordinates part-time associate team members in agreements with each associate's manager
- Professional superiors manage associate members.

Type 3: **Managed core and contracted associate team**

- As type 2, but associates may be full or part-time and are contracted to work in the team.
- Management of associated members takes place outside of the team

Type 4: **The managed and coordinated-core and contracted associate team**

- The team leader manages core members of staff.
- The team leader co-ordinates associate members and manages the contracts for contracted members of staff.

Type 5 : **The leader co-ordinated team**

- The team leader co-ordinates both core and associate members under agreements with their managers and employers.

Type 6 : **The leader contracted team**

- Most team members work under a contractual relationship to the team leader and are formally managed elsewhere.
- Membership is determined by perceptions of service users' needs
- Members are usually semi-permanent and may be full or part-time.

Table 3.1 : Types of multi-disciplinary teams

Ovretveit (1993) also looked at the internal functioning of teams and identified key areas, e.g. operational policy, role of team leader, team members' roles, supervision, etc., which determine whether a team succeeds or fails. Cutler (1998) has produced a "checklist" of reasons why multi-disciplinary teams may fail based upon an analysis of evidence from Overetveit (1986), Adair (1986) and Whitmore (1994).

Issues related to team members' own perceptions

- A lack of shared philosophy
- Conflict between profession-based clinical and team responsibilities
- Perceived loss of professional identity
- Loss of clinical autonomy
- Uncertainty and fear of change
- Formation of internal cliques, usually profession based
- Covert power struggles

Planning and development

- Poorly defined objectives, no coherent development plan
- Service lacks a clear identity
- Unclear lines of accountability
- Poor mechanisms for making decisions or resolving disputes
- Lack of leadership
- Unequal distribution of power among professionals

- No mechanism for evaluation of services or feedback from service users

External management and resources

- Political expectations and ideological intrusions
- Conflicting cultures between participating agencies
- Lack of awareness or commitment to multi-disciplinary team at a senior level
- Team members coerced into team
- Attempts by external managers to control team members for whom they have responsibility
- Lack of support from external managers who assume team leader has responsibility
- Multidisciplinary team seen as a threat to those outside it or seen to be elite
- Inadequate funding
- Resources withheld from outside
- Failure to recognise resources or important relationships outside of the team
- Poor training opportunities for team members

Table 3.2 : Obstacles to multi-disciplinary team working (from Cutler (1998) p. 40).

There has been little research on the internal functioning of teams which support people with learning disabilities. The majority of research comes from looking at teams in the private sector and the need to develop effective organisations within business. Clearly some of this is translatable into the social and health care world. Over the last 15 years there has been a growing body of research into the internal functioning of the Community Mental Health Team, and to a lesser degree, assertive outreach teams (e.g. Onyett et al (1997), Moss (1994), (Onyett and Ford(1996), Norman and Peck (1999)). These studies have developed and used some of the scales mentioned earlier and looked at internal functioning and team structures of CHMTs using similar concepts in their analysis to that of Overtveit and Cutler. Some of the findings of this research will be discussed later.

3.2.4 Evaluating Residential Homes

Tools which evaluate the quality of support provided in residential homes have increased in number and sophistication over the years. This is particularly evident when looking at longitudinal studies such as the Twelve Years On study (Cambridge et al, 2001). Heller (2002) suggests that research on residential settings for people with learning difficulties has developed through several stages. Before the deinstitutionalisation movement in the 1970's, research concentrated on environmental characteristics of both family homes and larger institutions. Studies such as the King et al (1972) survey of institutions for disabled and deprived children were instrumental in fundamentally challenging the way in which services were delivered by developing tools which measured institutional practice and the quality of support provided in the different settings. The type and size of provision were examined and attempts to ascertain the impact of the residential model on behaviour, skills, health and community integration were made. More recently, user satisfaction, quality of life and social networks have been included in evaluations of residential provision as in the Emerson et al study (1999) of quality and costs of residential models for people with learning difficulties and Becher et al (2000) in the EPSILON study of people with a diagnosis of schizophrenia. More than in any other area, studies into residential provision both describe and influence the nature of services. It is therefore no surprise that each successive study appears to either redesign existing tools or create new tools from scratch. It is thus exceptionally difficult to summarise measures in this area. This section briefly traces the development of quality measurements and summarises the key themes of tools which have been used for the larger studies.

King et al (1972) discovered that there were wide variations in practice within institutions for both deprived children and children with learning difficulties. They described practice as ranging from institutionally oriented to child oriented practice, and as these differences could not be attributed to characteristics of the children looked for other explanations, namely the sociological characteristics of the institution. They developed a tool which measured key concepts of institutionalisation based upon Goffman's (1961) analysis of institutions and looked at rigidity of routine, block treatment, depersonalisation and social distance. Although the study focused on children with learning difficulties, King et al felt that the measures could be used with other groups of people in other residential establishments.

King et al found that the features of institutionalisation were not linked to the size of the facility, although smaller homes had clear advantages, but rather to the training and philosophy of key management staff and the way in which staff were organised and carried out their duties. They also recognised that their belief that child-oriented practices were more desirable was a value judgement rather than a scientific one –

> *“..kindliness and consideration, an environment in which children are respected as persons, treated as individuals, and given variety of experience, seem to us important in our society and at this time, whether or not they benefit children in measurable terms. ..we think in as much as other children are treated in a manner which is impersonal and institutional, not only do they suffer but the community loses something of its respect for human dignity and human happiness”* (King et al, 1972, p. 199).

Future studies aimed to show that child/adult management practices could also be justified from a “scientific” basis.

“Rigidity of routine: Management practices are institutionally-oriented when they are inflexible from one day to the next and from one inmate to another . Individuals in different situations are treated as though they were in the same situation, and changes in circumstances are not taken into account. Management practices are child-oriented when they are flexible, being adapted to take into account individual differences among the children or different circumstances.”

“Block treatment: Child management practices are institutionally-oriented if the children are regimented – that is, dealt with as a group – before during and after any specific activity. Management practices may be described as child-oriented where the organisation of activity is such that residents are allowed to participate or not, as they please, and when they are allowed to do things at their own pace.”

“**Depersonalisation:** Child management practices may be seen as institutionally-oriented when there are no opportunities for residents to have personal possessions or personal privacy. Depersonalisation is also shown when there is an absence of opportunities for self-expression, or, of situations in which initiative on the part of the children may be shown.” “**Social distance:** Management practices are institutionally-oriented when there is a sharp separation between staff and inmate worlds. This may be because separate areas of accommodation are kept for the exclusive use of staff, or because interaction between staff and children is limited to formal and functionally specific activities.”

Table 3.3 : Key Concepts of Institutionalisation (King et al, 1972, pp 106 –7).

The Wessex experiment arose as the result of the need to accommodate significant numbers of children and adults with learning difficulties following the creation of the Wessex Regional Hospital Board. Kushlick argued strongly that there was no reason why children and adults should be accommodated in small home-like living units, and that there were many reasons why they should (Kushlick, 1974). This experiment aimed to study the impact of different forms of institutional care (the hospitals and the new living units) on residents and their families and evaluated the progress made by residents, the quality of care and the costs. The new units were based upon the philosophy that residents required care rather than treatment and needed to remain part of their community and so were more homely, smaller (20 – 25 places) and based in local residential areas so as to encourage visiting from family members etc. A control group was established from children and adults in existing hospital care.

Felce et al (1981) developed a range of measures to assess progress in the development of key skills and engagement in activities in the Wessex experiment. They found that although both children and adults in the Wessex experiment units had higher levels of impairments they all progressed significantly more in gaining a range of practical skills e.g. mobility, dressing and interpersonal skills e.g. social behaviour, than the control groups. Engagement in activity levels were also between 9 and 10% higher in the experimental groups than in the control groups and family contact was also more frequent in the experimental group. The experimental units were no more expensive than local hospitals and cheaper than new campus style hospitals.

Following the Wessex experiment, two model demonstration services were set up by Felce, Mansell and Jenkins (Felce, 1998) in Andover in 1981. Each house was for 6 residents with severe/profound learning difficulties. Again the houses were located in ordinary streets and different philosophies of care or support were employed – this time staff were trained in normalisation and the goals of normalisation were encapsulated in operational policies and procedures. Higher staffing ratios were in operation.

A series of studies evaluated the impact of this model of residential care on the lives of the residents using a variety of measures which focused on

- the impact of the physical environment and the ability of residents to access all areas of the home
- the role of staff and the nature of their interaction with residents
- staff:resident ratio, staff:resident interaction and resident engagement

The studies concluded that firstly the small size and the internal design of the home contributed to positive outcomes for the residents. Secondly, the way that the staff were organised impacted positively on the way that staff worked with residents enabling them to focus on activities and increase the levels of engagements with individuals or small groups of staff. This was a factor of the organisation of staff rather than the staff:resident ratio. The residents particpated well over half of the social and community activities included in the Index of Community Integration (Raynes et al, 1994).

The All Wales Strategy led to the provision of housing in much smaller homes – usually with less than 4 residents. The quality of the support in some of these houses (15 services, 57 residents) was evaluated over 2 years (Felce et al, 1998, Felce, 1998) using similar measures to the Andover project. The majority of the homes were homelike and well-furnished, but people with a higher level of impairment lived in less homelike settings. Staff: resident ratios were higher than in larger institutions, but contact levels varied between homes were the staff:resident ratios were the same and it was found that people with low levels of impairment received greater levels of interaction from staff, than people with higher levels of impairment. Levels of staff contact and interaction were low and often inappropriate, focusing on verbal instruction rather than practical assistance. Staff indicated that there were high levels of choice and autonomy for residents. Resident activity varied, but was generally very low including engagement in domestic activities and active leisure pursuits. Using the Index of Community Integration (Raynes et al, 1994) it was found that residents had variable integration into the local community but that all residents participated in some activities.

When levels of staff:resident contact and interaction from the Wales studies were compared with those from the Andover studies, it was found that despite having higher levels of staff, there were lower levels of interaction in the Welsh homes than the Andover project. Participation in domestic activities was also considerably higher in the Andover homes. Felce (1998) concluded that "structural reform has to be complemented by procedural organisation, with working methods allied to aims and values" (Felce, 1998, p. 110). This led to the development of a range of measures which could record levels of "active support" given to residents in the organisations polices, procedures and practices (Emerson and Hatton, 1994).

The history of residential research and development has created a set of tools which measure

- architectural features
- working practices, including institutionalisation, active support, choices and risks
- community participation and social networks
- activity and engagement.

The most common measures are briefly described below:

- Residential Services Setting Questionnaire (Emerson et al, 1995)

This collects information on the size and location of the setting; the age and gender of residents and the number and qualification of staff employed within the setting.

- Residential Services Working Practices Scale (Felce et al, 1995)

This scale collects information on procedures implemented within the setting regarding individual planning, assessment and teaching, the planning of daily and weekly activity, arranging staff support for resident activity and the training and supervision of staff.

Other scales in common use are the:

- Architectural Features Scale

This collects information on aspects of the physical environment including homeliness of the setting. The scale has been shown to be reliable and has acceptable internal consistency (Cronbach's [alpha] = 0.68] (Thompson et al, 1990)

- Group Home Management Interview

This schedule collects information which is used to rate the level of institutionalisation in four domains – block treatment, depersonalisation, rigidity of routines and social distance. High internal consistency was reported in previous research (Chronbach's [alpha] > 0.8) (Raynes et al. 1994).

- Index of Community Involvement

This index collects information about residents' use of community and leisure activities in the last four weeks. It has acceptable internal consistency (Chronbach's [alpha] = 0.7, (Raynes et al, 1994)) and is sensitive enough to discriminate between the activity patterns of residents from different settings (Gregory et al, 2001).

- Client Service Receipt Inventory

This schedule collects information on income, including benefits and a description of services used in the past 3 months, including day time activities, in order to examine the cost-effectiveness of services (Knapp, 1995).

- Social Network Map

This collects information about the size of people's social networks, the density or ratio of people known to each other, the membership and the frequency of interaction between members. No information is available about the psychometric properties of this tool. (Forrester-Jones et al, 2001).

- Choice and Risks Scale

The Choice scale looks at the extent to which people can exercise choice over key aspects of their lives. The Risks scale looks at the level of exposure to risk as conceptualised by accidents, abuse and exploitation. Excellent internal consistency was found in a previous study (Chronbach's [alpha] = 0.95) (Gregory, et al, 2001).

In addition to scales, semi-structured interviews are also used to elicit as much information as possible from residents. Interview schedules are usually designed by professionals, e.g. Emerson et al (1999). However, the Twelve Years On study used an interview schedule based upon the findings of focus groups of residents with learning disabilities and mental health needs.

- Likes and dislikes about the home
- Daytime activities
- Social and recreational activities
- Friendships and Relationships
- Support that is received from Services
- Choices
- Risks and safety

Table 3.4 : Areas covered by semi-structured interview designed by professionals (Gregory et al, 2001).

- What are the main things you like about living here?
- Is there anything you don't like about living here?
- What do you like most about things that you do during the day?
- What do you dislike most about the things you do during the day?
- What would you like to do in the future?

Table 3.5: Areas in semi-structured interview from focus groups of residents (Cambridge et al, 2001)

In conclusion, the choice of measure for use in residential homes seems to be dictated by the area of investigation and the primary diagnosis of the service user or resident. Thus there is a range of similar measures which have been used to evaluate the support of people discharged from psychiatric hospitals (see Leff and Trieman, 2000).

3.3 The Social Model of Disability and Service Evaluation

Health and social care services exist within a changing philosophy in which notions of disability as individual pathology are challenged and existing inbalances in society which are experienced by disabled people are allegedly rectified through normalisation. The view that is held here is that unless service provision and evaluation are informed by the social model of disability, the locus of oppression and discrimination will be wrongly identified as being due to individual characteristics, such as cognitive impairment, rather than the organisation of society. This argument extends to research methodology used in evaluating services and the disability movement has been virulent in criticising non-disabled researchers for interpreting the experience of disability using the individual or medical model. In addition, the main involvement of disabled people has been as passive objects of analysis using tools which have been designed with no reference to the real experiences of disabled people. Abberley (1992) argues that the OPCS surveys are an example of oppressive research into the experiences of disabled people. The terms of the research were heavily based upon an individual or medical model of disability, which is itself oppressive as it locates the source of social exclusion in the individual's impairment rather than in the way in which society is structured. Disability in the OPCS surveys was seen as synonymous with functional ability. The OPCS survey of 1984, for example, was based upon

> *"..a ten-point severity scale denoting the extent of disability,..[and] ..a complex set of individualising and oppressive questions with which to decide who was and who was not disabled."* (Oliver and Barnes, 1998 p.20).

Both Abberley and Oliver argue that disability is actually the result of a dynamic between somebody's impairment and the environment within which one finds oneself, not something which is located within the individual.

In this way research can be seen to reinforce the interests of powerful groups within society through the continual reinforcement of a particular perception of a group of people as pathological and unable to survive without help from others. This depiction of research as a tool which reinforces the interests of powerful groups in society is not new. Feminists have explored this in great detail and at length (e.g. Roberts, 1985). This led to the development of non-hierarchical ways of conducting research, such as participatory interviewing techniques (Oakley, 1985). Equally there have been many criticisms of the dangers of carrying out research for funders with particular ideological stances. All of these analyses highlight the fact that research is not a neutral activity nor value-free.

This has led disabled researchers to summarise non-oppressive research as that which must be rooted in the social model of disability, encompass different relationships between the researcher and participants and impact upon the real world (Barnes and Mercer, 1997). Where any researchers, but particularly non-disabled researchers, are researching disability issues, the recognition and challenging of oppressive methods which reinforce existing power relationships must be an on-going process. Only in this way can research be construed as potentially non-oppressive. Zarb (1997) argues that research by non-disabled people can never be emancipatory but only participatory. In order for research to be emancipatory the research must be controlled by disabled people "...as part of a broader process of empowerment." (Zarb, 1997 p.51).

The social model of disability has been mainly developed and promoted by people with physical impairments who are well able to take control of their intellectual environment and there are questions about the relevance of models of participatory or emancipatory research to people with learning difficulties. There are also issues about the relationship and the identification of people with different impairments within the disability movement and their allegiances and the nature of allegiances, if any, between disabled and non-disabled people. There are differences of opinion amongst people within the disability movement about all of these issues. These issues have not been resolved but it may be that the problem is located in the concepts of control and power used by people with physical impairments. Power and control is seen as intellectual power and control over physical environments that are difficult to manipulate because of physical impairments. For people with learning difficulties power and control may have to be defined differently, or for the social model to apply to all groups, they may need to be defined at a more global level. A reworking of such concepts would have to take into account definitions of identity and concepts of interdependence.

Until such a discussion has taken place, using the participatory model of research, what would amount to good practice in service evaluation? Goodley (2000) suggests that it is not whether or not someone has the right kind of label, but rather whether one understands the real nature of oppression that enables practice to be non-discriminatory. Thus an evaluation should be located in a social model of disability. It should also seek to work in partnership with people who are being studied, on their own terms, in the proposal, the methodology and the dissemination of any findings. It is recognised that this is rather a simplistic overview, and that it does not address issues such as what would happen if there was a disagreement. In addition this description does not reflect what happens in the real world – service evaluations are not undertaken out of choice but are often a funding requirement and must use outcome measures which are seen to be discriminatory by disabled people but required by commissioners. However, evaluations like any other form of practice require the practitioner to be constantly aware of the contradictions and difficulties which surround any piece of work and to critically evaluate them.

3.4 Conclusion

Service evaluation initially concentrated upon inputs and processes in order to establish their effectiveness, possibly because of the lack of effective tools which measured outcomes. This has now changed and there have been significant developments in the number of tools which measure outcomes, some of which have been discussed. However, although there has been a proliferation in the number of tools there are still problems with the tools themselves as many are limited in scope and although they have the appearance of objectivity may contain implicit value judgements. This is particularly the case for tools which relate to behaviour, social functioning and quality of life. However, research into institutional and residential care has challenged existing pre-conceptions and resulted in less oppressive models of care.

Overall there is little user involvement in the design of tools, leading to valid criticisms about tools being used to measure impairment by non-disabled people in order to perpetuate the myth of dependency. It is therefore vitally important to include user views on an equal footing.

Most tools have adequate reliability and validity and have been tested for psychometric factors. However the choice of tool does depend very much on the subject matter to be investigated.

A concentration on any one element of service provision to the exclusion of all others when evaluating services gives a distorted picture, and although outcomes are important, consideration must be also be given to inputs and processes. To ensure that research does not contribute to the oppression of disabled people, the real locus of oppression must be borne in mind and a critical evaluation of tools and practice which contribute to individual pathological descriptions of disabled people must be carried out.

PART TWO

Chapter 4

Study 1: Methodology

4.1 Background to Study 1

Chapters 1 and 2 have outlined the numbers of people with mental health needs and learning difficulties who come into contact with the criminal justice system, and the problems encountered by professionals who attempt to divert vulnerable people from the criminal justice system to health and social care services who often either refuse to accept this group of people or are unable to provide an appropriate service. Chapter 3 outlines theories and methods of evaluating services, particularly focusing on people with learning difficulties and mental health needs. Study 1 is an evaluation of a pilot community based service which was set up to meet the needs of people with learning difficulties, and/or mental health needs and /or Asperger's syndrome at risk of offending or reoffending. Study 2 explores the quality of residential provision for the same group of people when community services fail to meet their needs.

There was a recognition amongst both commissioners and service providers in a London NHS trust/health authority which was co-partnered with two boroughs, that people with mild/borderline learning difficulties and mental health needs who were at risk of offending were not receiving services that they may need in order to support or maintain independent living in the community. There was also an awareness that this particularly applied to people with mild/borderline learning difficulties and severe challenging behaviour, and that once people came to the attention of services, the response was usually to refer people to some form of residential care outside the borough, given that the specialist skills needed for this particular group of people were not present within the trust. People with severe/profound learning disabilities and challenging behaviour were catered for within the borough. This reactive approach to the needs of people with mild/borderline learning difficulties neither encapsulated good practice nor good financial management.

In 1996, a survey was commissioned by the health authority and carried out by the Tizard Centre (Murphy and Fernando, 1999). This survey used an agreed definition of severe challenging behaviour to screen all service users with learning difficulties and/or mental health needs which facilitated the identification of a group of people with common behaviours (see Appendix 9). 140 people were identified in the two London boroughs, all of whom had learning difficulties, severe challenging behaviour and/or mental illness. 71% of this group had a learning difficulty and 29% had a mental health need. The most common mental health diagnoses were schizophrenia and personality disorder. Of those with learning difficulties, over half had a severe or profound disability. A high proportion of people with learning difficulties were also reported as having autism or autistic features (22% for the inner-London borough and 52% for the outer-London borough). Very low numbers of people from ethnic minorities were reported. The most frequent type of challenging behaviour reported was aggression, followed by sexually inappropriate behaviour and self-harm.

When looking at the service provision for people in this group, the survey concluded that people with moderate or severe learning difficulties received relatively good services from the local CLDTs, but those with mild/borderline learning difficulties often only received a service when they were in crisis. The usual response was some kind of residential placement or admission to an institution, often out of borough. Where people were placed in out-of-borough placements, their short-term needs were met, but their long term prospects were less positive. On the mental health side, Murphy and Fernando found that challenging or offending behaviour was often linked to personality disorder rather than mental illness and there appeared to be a lack of psychological support, crisis intervention, outreach support and supported accommodation for this group.

The Tizard survey considered that services were failing both the most able people with learning difficulties and the least able people with mental health needs, all of whom were at risk of offending. They suggested that these people were falling into a gap between the CLDT services and the CMHT services, and they recommended that a range of service provision should be developed including a small registered nursing home, staffed housing provision, community based houses and flats, and a team with expertise in mild learning disability, mental health and offending/challenging behaviour in order to provide community based crisis intervention and outreach work, and thus bridge the gaps between existing services.

In 1997-8, a review of the needs and the service response to people with challenging behaviour in the two London boroughs was carried out by the NHS trust itself (Wolfson et al, 1998). An adapted version of the definition of challenging behaviour used in the Tizard survey was used for this review. This definition was used to screen all people with learning difficulties or mental health needs and identified 97 people, including people with severe and moderate learning difficulties. It is likely that the difference in numbers of people identified is due to the addition of an extra paragraph to the definition by Wolfson which excluded people who did not need restraining. The researchers not only looked at the current needs, service responses and behaviour profiles of the 97 individuals, using a range of questionnaires completed by keyworkers and with service users themselves, but also asked consultants involved in their care to rate the severity of their behaviours on a scale of 1- 4 and to predict the levels of support which those people would need over the next two years.

The review established that the people falling within the revised definition in the two boroughs were mainly male (76%), white (84%), single (90%) people aged between 19 and 68 years. The most common primary diagnosis was learning difficulties (51%), followed by schizophrenia (32%). Where people had a secondary diagnosis, 8% had a secondary diagnosis of learning difficulties. 61% of the learning disability clients also had a secondary psychiatric diagnosis. 68.5% of the sample had shown some form of autistic behaviour. 38% of people were formally detained under section 3 and section 37/41 of the Mental Health Act 1983. The most common form of challenging behaviour reported was aggression, with only 6% of the sample never having shown any aggression at any time. For 57% of the sample, their condition or illness had a severe impact on their quality of life. For 7% it had an overwhelming impact. Unmet needs were reported for a range of residential provision and supported living options in borough, in general, and in particular, a significant number of people with learning difficulties were thought to have unmet mental health needs.

Based on this information this review recommended that :

1) there should be a development of a range of residential provision with different levels of support, as respondents considered that one third of the sample were inappropriately placed
2) a "Challenging Behaviour Support Team" should be established in order to support existing residential placements through the provision of specialist knowledge and skills and the prevention of placement breakdown. The team would also have a role in supporting people who were moving into less secure placements with lower levels of support.
3) A multi-disciplinary team should be established which would provide direct support to people with severe challenging behaviour, mild/borderline learning difficulties and poor social functioning in order to prevent the escalation of behaviour. It was expected that this team would directly meet the needs of 8 – 10 people already known to services who were identified by the review.

Following the surveys and discussion with key stakeholders a comprehensive range of developments were proposed in order to better meet the needs of people with severe challenging behaviour within the boroughs and reduce the level of expenditure on out-of-borough expensive placements. These recommendations were remarkably similar to those produced by Murphy and Fernando (1999) in 1996 :-

- ☐ A community outreach team (the pilot team – this team was to fulfil the brief of 2 and 3 above)
- ☐ A secure assessment/treatment/rehabilitation service
- ☐ A range of residential and day provision (still to be developed).

A successful bid was made to the NHS Partnership Fund to part-fund the development of the team for two years, as a pilot project. The remainder of the costs were made up from the local NHS Trust and Social Services from boroughs A and B.

The aim of the pilot multi-disciplinary team was to provide an innovative service for people with low social functioning and severe challenging behaviour which would reduce the incidence of challenging/offending behaviour. The objectives of the service were to:

- Provide a comprehensive service broadly based on an assertive outreach model
- Provide a service to people who have traditionally fallen between existing mental health and learning difficulties services
- Target services on those with the most enduring, complex and challenging behaviour
- Reduce challenging/offending behaviour through drawing on specialist knowledge from a range of disciplines across client groups
- Improve the quality of life of service users
- Divert people away from secure provision
- Increase local competencies to enable people to manage risk safely within communities and existing resources
- Prevent out of borough specialist placements (Harris, 1999).

It was expected that the service would initially work with 8 –10 service users already identified by the NHS Trust challenging behaviour survey, and provide a service to at least 25 people over the first 18 months. It was further anticipated that there would be local developments in terms of housing provision which would enable the team to work with service users who were returning from out-of-borough placements.

The service was set up from April 1999, although not with a full team membership. Referrals were received from May and the service proper began in June 1999. The evaluation started in April 2000.

4.2 Aims of Study 1

The aim of the study was to give an informed view on the effectiveness of this model of service in supporting people with mild/borderline learning difficulties and/or mental health needs, at risk of offending, who are living in the community.

Study 1 was essentially an exploratory piece of research which aimed to assess the impact of the pilot team in a number of areas:

- Meeting service users' needs more effectively than other previous services

- Improving service users' levels of social functioning and reducing levels of challenging/offending behaviour
- Improving service users' quality of life
- Supporting informal carers

In order to accurately assess these factors, a number of different methodologies were used, including those which look at inputs and processes as well as outcomes.

4.3 Method

Study 1 had already gained the support of the relevant trust managers and social services managers, some of whom had been involved in the bid for funding for the evaluation.

Permission was sought, and granted, from the Tizard Centre ethics committee and the two NHS ethics committees of the relevant health authorities. These submissions included a description of the measures and the methodology to be undertaken, together with:

- A copy of the service user's consent form (for service users to be personally interviewed) (Appendix 10)
- A copy of the form giving the service user's consent for the carer to be interviewed (Appendix 11)
- An information sheet on the research (Appendix 12)
- A copy of the complaints' procedure (Appendix 13)
- Copies of measures together with indications as to their reliability and validity.

4.3.1 Participants

Participants in the study were service users of the pilot team, informal and formal carers, team members and other professionals who were not part of the team.

(i) <u>Service users</u>

All service users who had received some form of intervention from the team by October 2000 were asked if they would like to participate in the evaluation (n =22). These people were identified through discussion with the team manager and team members in order to ensure that the research did not intrude on the therapeutic process. If service users agreed, a team member would introduce the researcher, who would briefly describe the research and a further appointment would be arranged if the service user was happy with this. At this meeting the content of the evaluation was described, service users were told about the payment for their work and consent was obtained if possible. Before any research, or indeed intervention of any kind, is undertaken, informed consent must be obtained. To give informed consent, a person must:

- Be capable of taking that particular decision ("competent")
- Have appropriate and sufficient information
- Have the capacity to understand consequences and
- Give their consent voluntarily.

In this study, service users had mild or borderline learning difficulties and would have been seen as legally competent under the law. Information was given in an accessible form for participants to read and discuss with people outside of the research process. Understanding of the information was checked through the methods outlined in the DoH guidance on seeking consent (2001) such as repeating and rewording explanations and exploring the participants' ability to explain the content and process of the research. Time was allowed for people to consider their participation and the research began when participants gave consent. It was made clear both at the beginning of the research and at every stage that participants could withdraw and/or complain about the process. Interviews used an accessible format and data was adapted to ensure that participants could understand the questions fully (e.g. the adaptation of the Likert scale which accompanied the QOL interview). One participant initially agreed and then did not make any future meetings.

Care was taken to ensure that potential participants were aware that the researcher had no influence in any of their cases and that non-participation would not have any impact on the services they received due to the possible perception of people with learning difficulties of professionals as being powerful. It was also made clear to service users that they did not have to take part in the study. Service users were also reassured that if they agreed to take part in the study, they could withdraw at any time. 4 people refused in total.

One person subsequently became unwell, was admitted to psychiatric hospital and was omitted from the study as he was deemed to no longer have capacity to consent by the team.

Informed consent should be seen as a process and not a one-off event and so tapes of interviews were returned to participants checking once data had been transcribed and participants were able to withdraw all or part of their data if wished. Copies of completed schedules were also offered to participants.

(ii) Carers

No. of Carers	Outcome
12	Interviewed (one carer withdrew and one carer was only interviewed after the closure of the service).
3	Service users did not give permission to interview
1	Team advised inappropriate

Table 4.1 : Carers

Service users were asked if they had someone like a carer who made sure that they were alright, for example their Dad or Mum. If they said yes, then they were asked for their permission to contact that person. Initially, this elicited a very low response. Service users were contacted again and asked directly if the researcher could speak to their Mum or Dad. All service users who agreed were asked to complete a consent form confirming this. Three service users refused. The team also advised that it was not appropriate for carers to be contacted in two cases because of concerns about abuse within those relationships; one person was subsequently moved from living at home to an adult placement scheme and the paid carer there was interviewed instead. Most carers were parents, and in all but two cases, the main carer was the mother. All the carers contacted agreed to be interviewed, although one withdrew from the study part way through. A total of twelve carers, including two paid carers were interviewed. Results are reported for eleven carers due to one carer withdrawing from the study and refusing permission for the data to be used.

(iii) External professionals

External professionals were identified using referral information. An analysis of referrals, both successful and unsuccessful, was used to draw up a sample of professionals from both groups who had referred to the team. This was supplemented with team managers from mental health teams, learning disability teams and generic social services teams from both boroughs. To ensure that the list reflected all professionals whose work may have been affected by the pilot services, professionals were asked if they felt that the list should include other services. This led to one other person being identified. A total of 20 professionals were identified, and of these 19 were interviewed. The last person was unavailable due to sickness.

(iv) Team members

All team members of the pilot team took part in the study. The team was a multi-disciplinary team which has changed its composition over the two years of its existence.

4.3.2 Measures

The following table identifies those measures used :

Area	Outcome Measure	Method of data collection
Clinical status	HONOS LD	Completion by team member
Social functioning	Rosen & Parker's Life Skills Profile	Completion by team member
Quality of Life	Lancashire QOL-P	Interview with service user
User satisfaction	Semi-structured interview	Interview with service user
Service utilisation	Interviews, plus file analysis	Interview with service users and carers Researcher to analyse files
Carer support	Semi-structured interview	Interview with carers
Staff perceptions	Semi-structured interview Team/Professional identity scales Team/Personal role clarity scales	Interview with staff and external professionals Scales to be completed by team members

Table 4.2: Outcome Measures Used in Study 1

Because of the lack of involvement of service users in constructing the quality of life schedule, a focus group was held to check that the quality of life profile included all of the constructs that service users felt were important to them.

(i) Semi-structured interviews

Semi-structured interviews were designed for use with service users, carers, team members and external professionals to explore issues around the team and its work. These were piloted and adapted before their use. The interviews with service users were designed in consultation with a focus group of service users.

The interviews with service users looked at (Appendix 14):

- who they see from the team and what they do with that person
- if they find the team helpful
- any other services they might receive and how they compare with those from the pilot team
- what help they have received before
- how they would cope if the team was not there to help them.

The interviews with carers looked at (Appendix 15):

- what kind of support the team offered their son/daughter and themselves
- whether that support was helpful or not
- how the team compared to any other service their son/daughter might have received
- what would happen if the team was not in existence.

The interviews with external professionals explored (Appendix 16):

- the clarity of the team's eligibility criteria, policies and procedures
- operational issues through contact with the team
- views on the role of the team
- whether the team targeted people most in need
- who they thought was the priority group/s of service users
- areas of unmet need.

The interviews with team members looked at (Appendix 17):

- the individual's perception of their role in the team
- agreement around policy and procedures including eligibility criteria, referral process, assessment and intervention

- the nature and function of team meetings
- co-working and liaison within and outside of the team
- supervision structure and accountability
- theoretical models used by themselves and the team
- the future of the team.

(iii) Team Composition and Functioning

The model of team, its management, internal membership and functioning was compared to models and principles developed by Ovretveit (1993) and Hannigan (1999) in terms of multi-disciplinary teams, and to those developed by Hemmings et al (1999) and Morgan et al (1999) which describe the model of assertive outreach teams. Briefly, multi-disciplinary teams are evaluated in terms of management; the nature of, and barriers to communication and joint working; and the importance of clear operational policies. The model of assertive outreach predominantly operating in Britain has clear prescriptions about roles, methods of communication and the importance of team working. This drives both the internal operation of the team and its external relationships.

(iii) File analysis

Service users were asked for their written permission to access their files. A thematic analysis of files held both by the pilot team and other services was undertaken in order to provide information on the impact of the service (see Appendix 18) and to check the accuracy of the data for validation and reliability purposes. The frequency of contact was also analysed using file information in order to ascertain any links between identified needs or outcomes and frequency of contact.

(iv) Control Group

A number of different methods were employed to identify a control group in order to ascertain whether any changes were as a probable consequence of receiving the pilot team's service as opposed to any other factor.

It was anticipated that a control group of similar people might be identified in a neighbouring borough. However, there was no database that could be used to identify individuals to form a control group. The alternative was to rely upon professionals' knowledge. However, this could have identified an unrepresentative group, and there was little guarantee that the individuals so identified could have been matched with the group of service users from the pilot team. There were also added complications in using a different borough in that the existing service structures were slightly different.

Another way of identifying a control group would have been to use the waiting list for the pilot team. This would have the advantage of identifying a control group in the same boroughs with the same structures, but the possible disadvantage of not being able to match key characteristics of people on the waiting list with those who had been prioritised and were currently receiving a service. Unfortunately, the team did not have a waiting list.

A third possibility was therefore explored. It was hoped that similar individuals could be identified from the data collected by Wolfson et al in their review. Eight possible people were identified, but on further exploration, all but one person had more significant levels of learning difficulty.

A fourth alternative was then considered. Some of the current service users from the pilot team had been part of the Wolfson et al survey. Perhaps these people could form a "retrospective" control group and the information previously collected on their predicted future level of support needs, type of accommodation and severity of challenging behaviour levels, could be used for comparison purposes with the same schedules being used to collect information on people receiving a service from the pilot team. Unfortunately, on examination, the data was completed by different consultants who had interpreted the scales quite differently. The data proved to be too subjective to use for comparison purposes.

Although it proved to be impossible to set up a control group throughout the life of the pilot team, in fact, the service users who took part in the study became a control group by default when the pilot team closed down due to cessation of funding. The service users were followed up at approximately 6 months after the end of the service and key factors – quality of life, accommodation, incidences of offending behaviour were recorded at that point.

4.3.3 Procedures

(i) Focus group

A focus group was held in order to elicit the views of service users on what was important to them and to create an opportunity for them to inform the research process by saying what should be included in their interviews. All service users who had been taking part in the study were invited and 5 people (4 men and 1 woman) attended. The focus group was co-run with an assistant psychologist who was a white man, as the majority of service users were white men. Service users identified the areas of their lives which were most important for them, commented on proposed questions and added some of their own to the interview schedule.

(ii) Service Users

Because many of the service users had a history of challenging/offending behaviour which may or may not have involved violence against others, team members gave an indication to the researcher regarding where the interview should take place. Interviews took place with service users in their own homes, in an interview room near to the team's office, and in an interview room in one of the trust's offices.

Before each interview, it was explained what would happen and that the service user could terminate the interview at any point. The semi-structured interviews were taped and the tapes returned to the service users with the researcher keeping a transcript. Service users were asked to listen to the tape and leave a message for the researcher if they wished to change anything they said. Interviews lasted for a maximum of 15 minutes.

The QOL-P is in a written questionnaire format. The QOL-P was filled in by the researcher with the service user. All service users were offered the opportunity to complete the questionnaire themselves. The 7 point Likert scale was thought to be quite difficult for people to understand, and so simple faces were added to help people identify the phrases used in the scale. Respondents used all 7 points of the scale, usually giving a verbal answer and then, through prompting, identifying one of the points. It was recommended that one hour be allowed for the QOL-P, but most people completed it in well under one hour, the average time being around 30 minutes (Oliver et al, 1996). This could be because the previous respondents had severe and enduring mental illness and they may have been heavily medicated. Despite the fact that the QOL-P had not been used extensively with people with mild/borderline learning difficulties before, people appeared to have no difficulty understanding the questions. Only one misunderstanding occurred when one person misinterpreted the question about close friends, interpreting this to mean geographically close as opposed to emotionally close. This was easily explained. Service users were offered copies of the completed QOL-P but most people declined.

All service users were paid £5 every time they completed a piece of research.

(iii) Carers

Carers were interviewed in their own homes. Interviews, which were taped, lasted between 10 minutes and 1 hour, with some carers becoming quite distressed during the interview. The tapes were transcribed and returned to the carer for checking. One carer subsequently withdrew from the study because he said that the tape did not reflect what he had said in the interview.

(iv) External professionals

External professionals were interviewed at their place of work. Interviews lasted between 5 minutes and one hour, with the average being thirty minutes. All interviews were taped, with transcripts being returned for checking.

(v) Team members

Team members were interviewed in an interview room either near to the team's offices or near their own office, if they were part-time members of staff. Interviews lasted between 20 minutes and 1 hour. Interviews were taped, transcribed and returned to staff members for checking.

Team members were also given the identity and role clarity scales at the end of the interview and asked to complete them immediately. This took approximately 10 minutes.

(vi) HONOS-LD / Life Skills Profile (LSP)

Copies were made of the HONOS-LD and the LSP scales and given to team members in May 2000, following a team meeting where the scales were explained together with the rational behind using them. Team members were asked to complete them on a monthly basis for the people for whom they were the case co-ordinator. One team member did so for the first month. Team members were frequently reminded about completion and apologised for not completing them, but finally in September 2000 it was decided to abandon this method as team members were still proving unable to complete the scales.

(vii) File Analyses

Number of people	**File location**
3	Learning difficulties team
3	Generic social work team
2	Mental health team (within catchment area)
1	Mental health team (another borough)
2	Probation
1	Children's Services
3	Psychology and psychiatry only

Table 4. 3 : Breakdown of file analysis

Analyses were undertaken of files held by other service providers for six months prior to, and throughout the time that the service user received a service from the pilot team (Appendix 18). As well as providing information on key aspects such as incidences of challenging behaviour in the absence of the pilot team failing to carry out any baseline assessments, this analysis also provided validating information on such aspects as contact with the team whilst the service user received a service. Although negotiations proved to be quite complex on some occasions, access was gained to all relevant files, except one. This file was held by Probation.

Analyses were also carried out of the files held by the pilot team, and files held by psychology and psychiatry. The psychiatry and psychology files were located separately although the professionals concerned were part-time members of the team.

(viii) Analysis of Intervention

It was originally intended to carry out an analysis of interventions provided by the pilot team using data entered into PIMS (a computerised database for recording activity of healthcare interventions). This did not prove possible due to the lack of data entered into PIMS by the staff.

(ix) Analysis of qualitative data

The framework analysis approach was used to analyse the data obtained from the semi-structured interviews (Richie and Spencer, 1994; Pope at al, 2000). This analysis is particularly appropriate for research in which there is a predetermined question to be answered (in the case how effective was the service in supporting people), and may be contrasted with approaches such as grounded theory in which questions are determined though data analysis. For both studies, there is a body of literature and research which can partially inform and structure the research.

In this study, the following steps of framework analysis were undertaken:

- Familiarisation with the information
- Identification of a thematic framework
- Coding/ indexing of data
- Thematic charting of the information
- Interpretation

Initial analysis of the data was undertaken using the questions in the semi-structured interview as an initial thematic framework. Given that many respondents addressed different topics at different points in the interview, this involved familiarisation with the entire interview and constantly revisiting the data. The thematic framework was then revised with the identification of further themes and sub-themes. Data was then re-coded. The relationships between respondents' perceptions of the service were then further explored with particular reference to cases which appeared to be different or offer a different explanation. The interpretation phase required both descriptions of participants' responses by topic, together with suggested explanations.

4.3.4 Discussion

A combination of off the shelf measures and specifically designed instruments were used in evaluating all aspects of the service. Whilst it has been possible to obtain a wide variety of views on the impact of the service, it has proved difficult to gain more "objective" measures of changes in service user's behaviour because of team members being unable to complete HONOS and LSP scales and the lack of baseline measures. Service users had some involvement in designing the methodology somewhat late in the day, partly due to the problems of identifying a co-facilitator for the focus group.

Chapter 5

Study 1 : Results

5.1 Introduction

The results are presented in two sections – those identified through team member and external professional interviews and measures, and those identified through service user and carer interviews and measures. Given that the service was set up as a result of a gap in service and identified unmet need by professionals, the aims and objectives of the service will set the framework within which professional, users and carers views are explored. Although professionals views are presented first in order to discuss the mechanics of the service, it is the views of users and carers which most effectively reflect the impact of the service and its subsequent withdrawal.

5.2 Team members and external professionals interviews

5.2.1 Background

Interviews with 9 members of the team and 19 professionals who were potential referrers to the team took place from April to July 2000.

External professionals

The views of the external professionals were elicited using semi-structured interviews. External professionals were identified by using lists of all those organisations who had previously referred to the team and comprised a mixture of team leaders and social workers.

Discipline	**Total no. of people**	**No. of people who were team leaders**
Mental health	9	8
Learning disabilities	4	3
Psychiatry of learning disabilities	1	1
Generic social work	5	2

Table 5.1 : Analysis of professionals by discipline

No. of professionals	**Borough**
6	Borough A
12	Borough B
1	Both boroughs

Table 5.2 : Analysis of professionals according to borough

More professionals were interviewed from Borough B than Borough A because of the different service structure. In Borough A people with learning difficulties were served by one team. In Borough B people with severe learning difficulties were served by one team and people with moderate/borderline learning difficulties could come into contact with one of two teams of social workers and one of two teams of case managers.

Team members

The views of all nine team members were elicited using a semi-structured interview, the Role Clarity scale and the Team/Professional Identity scale.

The team was essentially a multi-disciplinary team with specialist skills and a range of professional backgrounds. The team had been in existence since May 1999 and fully operational from June 1999, nearly a year before the interviews with team members took place. Two of the team members were relatively new having been in post for approximately 6 months at the time of the interview.

No. of team members	Post	Background
1	Administrative Officer	
1	Challenging Behaviour Specialist	Learning Disabilities
1	Occupational therapist	Forensic Learning Disabilities
1	Outreach worker	Mental Health
1	Psychiatrist	Learning Disabilities
2	Psychologists	Learning Disabilities
1	Social Worker	Learning Disabilities
1	Team Leader	Mental Health Social Worker

Table 5.3 : Breakdown of team members according to current post and professional background.

5.2.2 Aims and objectives of the service: eligibility criteria

Views of External Professionals

External professionals stated that the aim of the multi-disciplinary team was to bridge the gap between already existing services.

> *"It bridges the gap. Where there are service users with a multi-diagnosis or non-diagnosis as is often the case, where they fall between the services, where services themselves have tight criteria, its quite easy to say no, they don't meet that specification – hopefully [this team] would provide assessments in order to look at where that person should receive a service from and perhaps receive a direct service from them."*

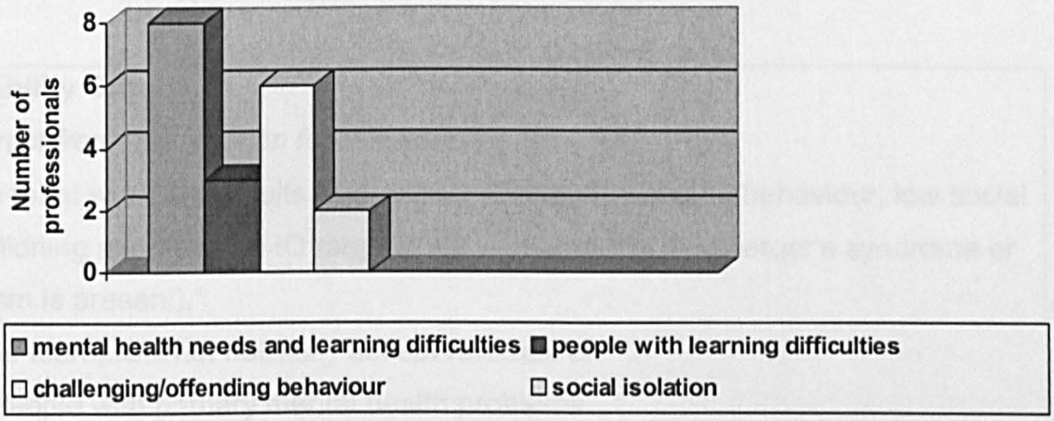


Figure 5.1: Who does the team work with?

However, external professionals did not agree as to the nature of the service users that the team would work with. Professionals usually identified a combination of factors - 8 respondents referred to the team being set up to work with people with mental health needs and learning difficulties, 3 respondents thought that it was set up to work only with people with learning difficulties and 6 respondents thought that it was set up to work with people with challenging or offending behaviour. Two respondents felt that the target group was people who were socially isolated.

> *"Its for people without a learning disability or mental health. People who are suffering from social isolation. That's their main criteria – social isolation."*

The eligibility criteria listed in the box below are those which were encapsulated in the information leaflet for referrers which was issued in June 2000, one year after the service became operational. It is possible that the lack of clear written criteria during the set-up period and the first year of operation led to different interpretations of the work that the pilot team would do.

Of the 18 professionals (n = 19) who were aware of the team, only two people felt that the eligibility criteria were very unclear: one because of limited contact with the service, and one because of his/her experience in making referrals. Both of these professionals were from mental health teams.

> *"I'm not very clear about that. I think its to do with people with mild learning difficulties, but we haven't been very successful in making referrals. So its not very clear."*

Eligibility Criteria

(Extract from "Information for referrers.")

"The team work with adults who exhibit severe challenging behaviour, low social functioning and have an IQ range of 60 – 85, (except if Asperger's syndrome or Autism is present)."

" [The team]..will not normally accept referrals of:

- People with primary mental health problems
- People with primary addiction problems
- People with an IQ outside of 60 – 85 range (except where Asperger's Syndrome or Autism is present)
- People with acquired brain injury obtained after 18 years with no evidence of difficulties during the developmental period
- People currently placed in a 24-hour unit or in a specialised challenging behaviour unit (consideration will be given to individuals who are about to move into less supported accommodation or back into the borough)
- People currently living outside the boundaries of Bexley and Greenwich boroughs."

Table 5.4 : Eligibility Criteria

After being shown a copy of the eligibility criteria contained in the leaflet, "Information for referrers", the respondent continued:

> *"The criteria are quite clearly laid out, but the reality does not relate to this I have to say and people are very disappointed with the service and very critical of it. We've had some clients who do need help from [the team], but we can't even get assessments."*

Views of professionals	No. of professionals (Professionals may have had more than one view)
Eligibility criteria are unclear	2
Eligibility criteria can be described	11
Have requested formal clarification on eligibility criteria	2
Feel interpretation of eligibility criteria have changed since the team began	8
Did not recognise eligibility criteria	1
Eligibility criteria are deliberately vague	1
Why are the eligibility criteria constructed this way?	3

Table 5.5 : Views on the Eligibility Criteria

Of the sixteen professionals who felt that the eligibility criteria were clear, eleven professionals could describe the criteria as listed in the leaflet, with a fair degree of accuracy.

> *"....IQ, some mental health need, some social need. I think the social need is quite a big factor. I think the team is interested in people whose social functioning isn't achieving the optimum or maximum and its very much about providing a service to help people achieve a better quality of life. And often supporting carers and other people who are working with people. There is often a degree of social isolation there. "*

Where the confusion arose for some professionals was in the interpretation of the criteria and a feeling that the criteria had changed during the life of the service.

> *"Whilst the eligibility criteria are very clear, I would say that criteria are always difficult to interpret, and that one always interprets them in the way that one would like them to be interpreted."*

Two professionals, one from a generic Social Services team and one from a mental health team, had requested more clarity from the team in how the criteria might be interpreted:

> *"..I felt that I wasn't clear about the criteria and that was my rationale for going back to [the team leader] and asking him to send me more broken down criteria and I think that was helpful."*

One teams' experience was not so helpful. When the team manager of the new service visited the team, the team were very dissatisfied with his response.

> *"..what was understood by the criteria was certainly not what the manager was saying. He was saying that the criteria had not been agreed by him and therefore it was changing... my feeling was that the person had been asked difficult questions and had changed the goalposts on what they were looking for."*

One professional from a Social Services generic team thought that the eligibility criteria might be deliberately vague in order to accommodate people who fell through the gap of traditional services.

> *"I think that the criteria are okay. It leaves in it a somewhat grey area because that's what people falling thorough the gap experience. No-one really wants them, no-one knows where they should go. So, actual criteria wouldn't really work."*

Three professionals, two from learning disabilities and one from mental health services, questioned why the eligibility criteria had been constructed in the way that they had.

> *"..what are they tailored for? Why are they tailored in this direction? That's what I don't understand. The issue for me was that a service was being provided that would look at people who didn't meet peoples' criteria, so why are we tailoring it down?"*

>> *"I think for me, working in a mental health team, where you see at the top of the list of things that they will not normally accept, people with mental health needs then you think well that's that then. Its debatable of course when you're talking about dual diagnosis, mental health need and learning disability..... Which*

> *came first and which is primary? I think we can get hooked on that as professionals and what does it matter? They have got these needs and they need to be met."*

One professional, who had been working closely with the team for over a year, did not recognise the eligibility criteria when they were shown to him. This seems to indicate that there has been a change in either the eligibility criteria or the interpretation of the criteria. This was supported by the views of four other professionals, two from mental health, one from learning disability and one from a generic Social Services teams.

> *"I don't remember them quite that specifically. Its interesting. I don't know when that leaflet was actually issued, but we've been working with [the team] for quite a long time."*

> *"I think they've [the eligibility criteria] shifted slightly. I thought they were slightly more open at the beginning and I think that they've tightened up around severe challenging behaviour. I haven't actually seen the revised criteria."*

> *"..it has become more difficult to refer to them, in as much as they seemed to have tightened up .... It could be resources, it could be caseload I don't know. I'm not saying that they have tightened up the eligibility criteria – it just feels like it... People who we would have said oh yes, they'll get there, they're not getting there. "*

For some professionals this meant that when they referred someone to the team, they were unclear as to the possible outcome, because of the way that the eligibility criteria might be interpreted.

> *"..I think that historically what happened was it was a case of us identifying a case and seeing what happened, whether it was accepted or not."*

External professionals were also asked if the team targeted the group of people most in need. Two people were unable to answer this question because of their limited contact with the team.

Does the team target the people most in need?	No. of respondents
No	12
Yes	3
Yes, but there are other groups in equal need	2
Not able to answer	2
Total	19

Table 5.6: Does the team target the people most in need?

Number of professionals who thought that the team targeted those most in need	Discipline
1	Generic social services
2	Learning disabilities
2	Mental health

Table 5.7: Analysis of professionals who thought that the team targeted those most in need.

Number of professionals who did not feel that the team targeted those most in need	Discipline
3	Generic social services
3	Learning disabilities
6	Mental health

Table 5.8 : Analysis of professionals who thought that the team did not target those most in need.

Twelve professionals felt that the team did not target people most in need. Of these twelve, six respondents were from a mental health background.

- Young people leaving care/residential school
- 16-18 year olds with Asperger's/autism
- People with mild/moderate learning disabilities who have additional emotional needs/sensory needs/challenging behaviour/autism **
- Vulnerable people who are at risk and/or socially isolated *
- Parents with learning disabilities*
- People with substance/alcohol abuse
- Homeless people
- People with a mental health diagnosis*
- People with a personality disorder*
- People with anti-social, psychopathic traits who are isolated*
- Working with people at risk of going into residential provision or more secure accommodation (a preventative role)*
- Working with people in residential provision (a rehabilitative role)
- Training/consultancy function around challenging behaviour
- Developing comprehensive support packages

Table 5.9: Identified areas of unmet need

(N.B. areas of need marked * were covered by the team if they had challenging/offending behaviour and mild/borderline learning difficulties: ** refers to areas which were included in the eligibility criteria).

Professionals were asked which priority groups the team should have targeted (table 5.9). The groups that respondents identified varied according to which service they worked for. Some of these groups identified as being an unmet need were clearly within the pilot team's remit – e.g. people with a mental health diagnosis and people with mild learning difficulties, challenging behaviour and additional needs. In general professionals wanted the team to target a range of people who did not have challenging behaviour but whom appeared not to receive an appropriate service – however this does seem to be rather an unfair criticism when the pilot team was set up specifically to deal with people with challenging behaviour.

Professionals from a mental health background identified people with complex needs which included mental health needs amongst others as being a priority group which the team did not target. However, people with mental health needs were not excluded as long as they met other criteria, namely mild learning difficulties and severe challenging/offending behaviour.

> *"Because of the exclusion criteria, they do exclude people who have high needs and are very difficult to work with. People whose main issue is a mental health diagnosis or a personality disorder and who take drugs. That's a huge group, and they are often people who are hard to place and hard to house, whose housing situations often break down, who sabotage their mental health through their substance misuse, and a lot of those people have behaviours which are quite hard to manage in the community and often they will be people who wouldn't go into a hostel or residential resource even if you had one to offer."*

People from non-mental health backgrounds identified people with multiple problems, people who were vulnerable and at risk, and people in residential care. Many of these people were within the remit of the team.

> *"I can't actually say that they deal with the priority group because I can only think of 2 or 3 cases that they are actually involved with. The one group of people that they might miss are the people who need outreach,*

> *I don't know if they do that. I am aware of several people out there who come sometimes and say I have got this problem ... they usually have a multitude of problems – drinking problems, physical health problems, mental health problems, disability, a whole combination of things. I'm not working, I'm not accessing any activity or leisure, I have a drink or drug problem. Those people actually float near us, they find it very difficult to engage themselves and I don't know whether those people should be outreached by a service and I don't know whether [the team] actually touch them. .. These people get into trouble with the police, they're socially isolated and often homeless ... The other type of people are people who are in residential services, where they are in the wrong place or are out growing the place...These people are very complex, and when they come out I can see [the team] having an important role to play there."*
>
> *"Those of us that make the assessment and then refer would say that the people with less need are getting the service. .. I would certainly say that there are people out there that would be seen as potential offenders or possibly falling into some sort of social decline and other people that would be far more vulnerable in terms of their potential to be exploited or to be used or to be targeted in some inappropriate way. They would be regarded as having most need and they haven't been taken up."*

Whilst two professionals thought that the team targeted a priority group, they also felt that there were other groups of equally high need.

> *"I would say that they probably target people who are most in need of a service. They are certainly people who cause anxiety amongst other professionals or carers. They are the people who are most at risk from getting in difficult circumstances and being at risk. I think there is probably another group of people who could equally benefit from a similar service, but wouldn't necessarily be such a high priority because the risk factors aren't so obvious, but their needs are probably as great. We've got younger people coming through the system now. Younger people leaving care or who've been in boarding school – they're possibly disadvantaged in the sense that they leave school at 18 and they're not really prepared for living independently. If they had a severe learning*

> *disability they would be eligible for residential care, but there's nowhere for the mild or moderate learning disabilities people with additional needs. It might be something to do with vulnerability, for social reasons, that they're not really prepared for social life because of their social history. They may have had problems with their family while they were in boarding school. There's a group of people whose additional needs are to do with their sensory needs, who are deaf and blind... and we've got a group of people coming through next year from a school where they deal with people with autism."*

> *"I think that the other group that tends to surface in terms of most need, is the vulnerability factor, and working with a milder group of people and people at risk from abuse from others, assault from other. A group of people, again with low social functioning, but it tends to be risks to themselves as opposed to risks to others..... The other group of people... is people with parenting needs .."*

Five professionals thought that the team did target the people who were most in need of a service. Of these five professionals, three had successfully referred. One person spoke from his experience of trying to obtain services.

> *"I think that most of the other people get some sort of a service. They are targeting the people who haven't always been getting a good service. "*

Views of the team

This description of the aims and objectives of the service overlapped with that of the team who were actually providing the service. Just over half of the team members (5 out of 9) saw the service as not only working with people who had fallen into the gaps between services and eligibility criteria but also people for whom appropriate services did not exist because of the lack of appropriate skills in the established range of services.

> *"..the main aim of the team is to provide community support to people who have been difficult to engage with in the past, who a lot of have been through CLDT and learning disability services and maybe forensic services and other teams have struggled to contain them or manage them."*

One team member felt that although there was clarity at a broad level about the aims and objectives of the team there was a lack of clarity about how these were put into practice.

> *"The main aims and objectives of the team are fairly clearly set – on the one hand ....to provide a service which isn't otherwise provided. What isn't very clear though is how it does that within the remit, particularly around prioritising."*

5.2.3 Referral patterns

The team received 88 referrals over the two years. Of these 58 were for people originating from or living in Borough A and 30 were for people from Borough B. 29% of referrals from Borough A were accepted and 31% of referrals from Borough B were accepted. These referrals came from a wide variety of agencies including some which were not represented as part of the research such as GPs and the probation service. Referrals from mental health were less successful than referrals from learning difficulty services, particularly those from borough A with a success rate of 20%. Referrals from Social Services and the Community Learning Disability teams tended to have a success rate of around 50%. The most successful referrers were the probation service from Borough A and the group "other" (GPs and the Adolescent Resource Centre from Borough B).

The 88 referrals came in 2 main waves with a minority of referrals being made on an ad hoc basis. The first wave came from a trawl of services before the team was set up. The majority of these referrals were rejected. The rejection letter that was sent out was not specific and merely stated that the people referred did not meet the eligibility criteria. However an analysis of supporting documentation which came with the referral identified the reason for rejection in 24 cases as living in a 24 hour residential facility, either in or out of the borough – one of the exclusion criteria.

Borough	Agency	No.of referrals	Successful Referrals	Unsuccessful referrals
Borough A	CMHT	18	3	15
	CLDT	15	7	8
	Probation Service	6	4	2
	Psychiatry	8	4	4
	Other	11	3	8
	Total	**58**	**21**	**37**
Borough B	CMHT	6	2	4
	Learning Disability Team	5	2	3
	Community Social Work Team	8	5	3
	Probation	0	0	0
	Psychiatry	3	0	3
	Other	8	6	2
	Total	**30**	**15**	**15**
Total		**88**	**36**	**52**

Table 5.10 : Source and outcome of referrals by agency and borough.

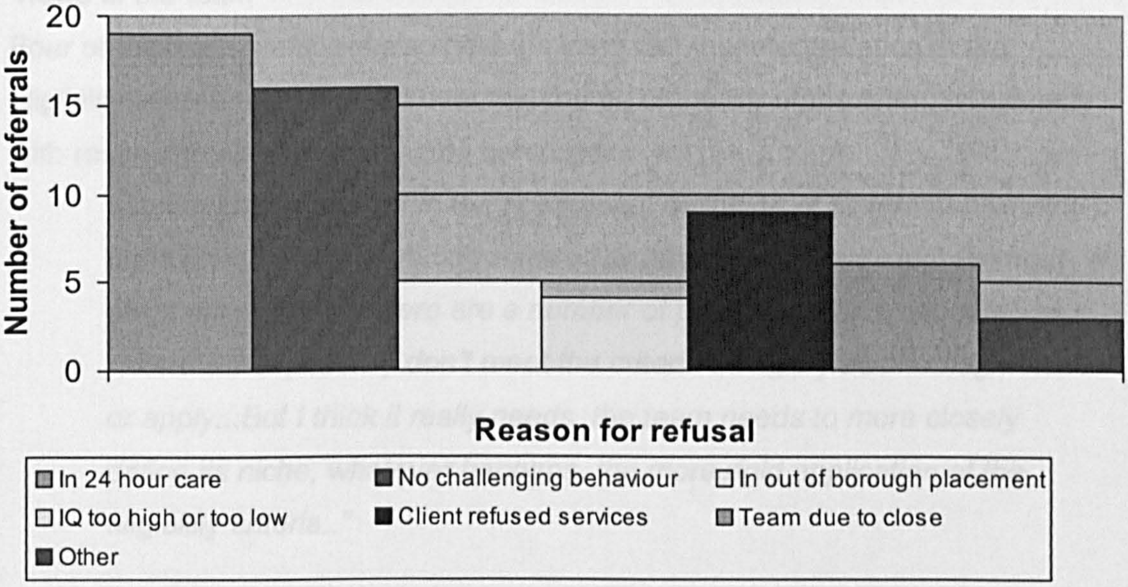


Figure 5.2: Reason for refusal

The second wave came in the summer of 2000 at a time when the research was being conducted and team members were visiting a number of services. Both of these activities raised the profile of the team. The majority of these referrals (16) were deemed to be inappropriate because of a lack of severe challenging behaviour. Other reasons for refusal included an IQ outside of the eligibility criteria (4), being too young (1), not having the appropriate primary diagnosis (2) and from January 2001, the team being about to close (6). In addition nine people who did meet the eligibility criteria for access to the service refused to engage with the team.

Reasons for refusals were spread across the referring agencies. Referrals from mental health teams were commonly refused because of the lack of challenging behaviour, being in an out of borough placement (including prison) and being in residential care. Referrals were commonly rejected from the Community Learning Disability Team and Social Services teams for the same reasons. This would suggest a widely held view of the eligibility criteria by external referrers which did not match that held by those within the team. As many referrals were made before the team was set up, it would also suggest that there was an established picture of whom the team would accept that was somewhat misleading, and that subsequent attempts by the team to clarify this were interpreted negatively.

Views of the team

Four of the team members also held the view that the interpretation of the eligibility criteria had changed over the course of the life of the team, particularly with respect to severe challenging behaviour.

> *"I'm not convinced within the operational definition of severe challenging behaviour that we have had referred or have on our caseload, the right client group. I think there are a number of people we have accepted as referrals that possibly don't meet the criteria as rigidly as one might hope or apply...But I think it really needs, the team needs to more closely define its niche, whatever happens, the more rigid application of the eligibility criteria.."*

There was a feeling from the team that other services, because of the pressure that they work under and the difficult nature of some of the service users that they work with, were trying to fudge the eligibility criteria so that they could "off load" some people.

> *"..I think that happens to all sorts of other teams where either they don't know what to do with that person, they don't know what that person's needs are, they don't know whether they've got a learning disability or mental health problem or they're really so stretched that they search madly for something other than themselves to deal with the problem, and*

> *they give us the person to take them off their hands. So some of that is about saying in a helpful way, come on this is one person too far, you need to meet with this person first off so you might get a sense of what the person is. So it's a bit of a buffer or container or something like that."*

There was also a perception from team members that poor communication of the team's aims and objectives had led to inappropriate referrals.

> *"I think there's a sense in which there was a clearly defined target group of people that the team was supposed to work with when it was set up..I think what may have happened is that insufficient communication or poor quality communication with referring agencies has led to misunderstandings about what type of client group we are working with. The problem is that variability within our client group in terms of mental health, learning disabilities and challenging behaviour has added to that confusion. On what basis are we accepting people and there needs to be a clear understanding from the varying agencies of what the priority criteria are that needs to be met, and that we will accept, and I think that's not there at the moment. There are also issues around, at least in a couple of referrals that we have had, where the agency has made other referrals to different services. ... I don't think that this is very helpful in terms of trying to identify and be specific about who we should work with. They're just saying will some other agency take this person off my caseload or get involved because I need help."*

5.2.4 Communicating the work of the team

Views of external professionals: making a referral

No. of successful referrers	No. of unsuccessful referrers	Total no. of professionals who had referred to team	Total no. of professionals interviewed
7	8	15	19

Table 5.11 : Numbers of professionals interviewed who had referred successfully to the team.

Referrers by Care Group	Successful referrers	Unsuccessful referrers
Learning disabilities teams	2	1
Mental health teams	1	4
Generic social services teams	3	1
Others	1	2

Table 5.12 : Breakdown of successful and unsuccessful referrers who were interviewed.

Seven professionals had referred successfully to the team. These professionals came from across the range of referrers and reflect the difficulty that mental health teams had in successfully referring. There was considerable concern amongst all of these about the lack of feedback on the referral and any subsequent intervention. One respondent from a mental health team expressed the following view:

> *"To find out what happened ..in the process was incredibly difficult, and given that our team has only one success in making this, despite making something like ten or twelve referrals, causes one to be worried about the whole thing. Certainly we have never had adequate feedback, or any feedback, on why these people were rejected. We also did invite two members of [the team] to come down and they gave a talk, but the team felt that the answers given by the team manager were so unconvincing that they had serious qualms about making use of them again given the difficulties before and the outlay involved in terms of time and effort making the referral."*

> *"I would have liked a lot more information on the process, the assessment process, who was doing assessments, how they were doing it what information they were gathering from the case-notes etc., and also what stage those assessments were at, and I've repeatedly made my views known to ...the team. I don't think that they've been nearly as clear with people, 1. What the assessment process consists of, 2. How long it takes, 3. What assessments are actually going on and 4. What happens to the assessment reports. That's been my major bugbear."*

> *"I think some of the assessment materials were mis-interpreted through lack of communication in two cases at least."*

Views of professionals: is the service the best way of meeting peoples' needs?

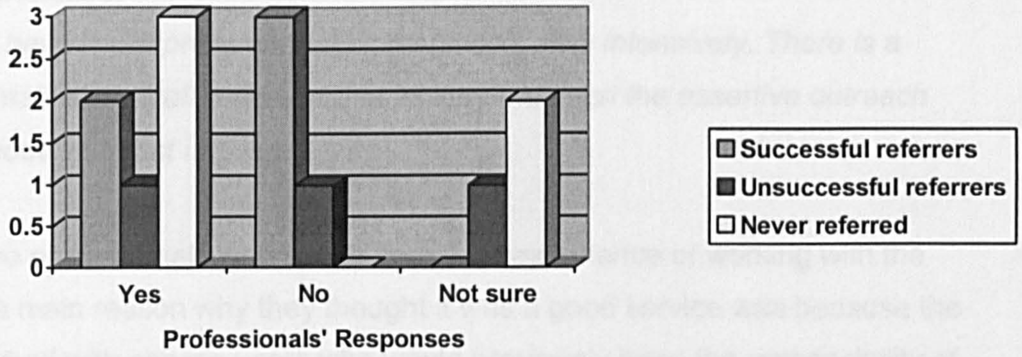


Figure 5.3 : Is the team the best way of meeting peoples' needs?

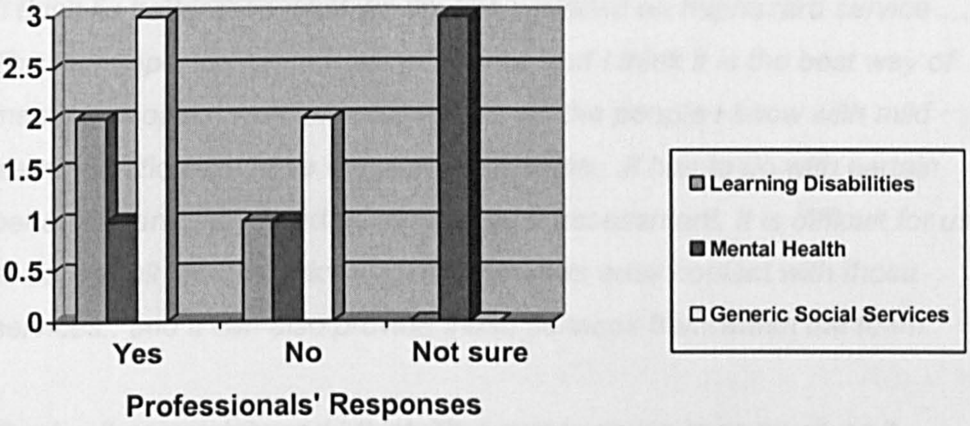


Figure 5.4: Is the team the best way of meeting peoples' needs?

Five people felt unable to comment on whether the team provided a service that was the best way of meeting peoples' needs because of their lack of knowledge and or contact with the service. Three of these were from the mental health teams.

Of the remaining thirteen people, six people thought the team was providing a good service. Only one of the six people came from a mental health team. Of this six, two people had successfully referred. Of the remaining four who thought that the team provided a good service, only one person had made any referrals to the service. This referral was unsuccessful and therefore all four professionals had limited contact with the service. Their reasons for giving a positive answer was based upon their perception of the service, rather than any direct experience.

> *"I have the impression that workers work very intensively. There is a small client-staff ratio and that its very much on the assertive outreach model. So that is good.."*

Of the two professionals who spoke from their experience of working with the team, the main reason why they thought it was a good service was because the team worked with service users who would previously been the responsibility of their teams and had taken up a lot of the team's resources. These professionals were from Social Services learning disability teams and felt that they did not have the same access to a similar level of resources. However, they differed in whether they thought it was the best way of meeting the service users' needs.

> *"I think its better than what we do. We provided an haphazard service .... The team operate a much better service and I think it is the best way of meeting peoples' very complex needs. All the people I know with mild learning difficulties have emotional problems...It has to do with certain behaviour and they need a psychological assessment. It is difficult for us to access all those services... The team has easy contact with those services.. and it can also provide those services from within the team."*

> *"I value it completely and I think it's a good service in so much as it actually takes some of the pressure, and the resource issue, if you like from us, and from me, in respect of the people I'm working with, because I don't have all the time and the means to be able to respond to their needs as I'd like. I think its great. In terms of whether it's the most ideal and the most suitable, I don't think its been set up to do a role whereby the outreach side of it in terms of practical support isn't quite as significant as it needs to be. From the point of view of that's what they need, the people I'm involved with need more regular outreach support. But having said that I don't think that's what the team was set up to do."*

Three professionals were more mixed in their views as they had no or limited experience of the service:

> *"Its difficult to answer that because the team is a new service and I think that we're still learning whether or not its an appropriate one. I think for a long time, when the idea of the team was around, we felt, in this team, that it was a good one, meeting a gap in the service."*

> *"Initially I would have thought it was a very appropriate and much needed service, yes. A team set up and designated to work with those hard to place and difficult to engage clients. At the outset I would have said yes, [the team] is fine and its much needed. At the moment I'm not sure."*

Four people thought that the team was not the best way of meeting its service users' needs. Of these one was an unsuccessful referrer (from mental health) and three (from learning disabilities/ Social Services) had worked closely with the team. Their views were that creating a separate team was not the best way of bridging the gap.

> *"..what should have happened is that they should have said why is there a gap and stopped it from happening, not accepted that there was a gap and trying to fill the gap."*
>
> *"I don't think that a specialist team who creams off that group of people is a useful way of doing it, after the experience we've had. My concern would be that because we've never seen them in operation, its difficult to know what they could or couldn't have done ."*

Views of the team

This perception of the team by external professionals as an organisation which does not communicate or liase with referrers was certainly not held by the team. Out of the nine team members the only team member who did not say that they actively liased, and in some cases co-worked with referrers, was the administrator who did not feel that it was part of her role. Seven out of eight team members mentioned the Community Learning Difficulty Teams, the Community Mental Health Teams and other referrers in particular as teams that they liased with. Some team members certainly felt that there was poor communication on the part of other teams with the new service.

> *"I've found the communication there [at the CLDT] very good. I couldn't really generalise that across to anyone else unfortunately. There are varying levels of input from referring agencies."*

It is evident from the interviews held with external professionals that team members were visiting other teams to explain the work of the team. However, evidence from the files of both successful referring agencies and the pilot team themselves show very little documented evidence of inter-agency communication. The mean for both time periods, the first and the last 6 months, is less than one contact with involved services for each service user during time periods which presumably would require a considerable degree of communication in terms of enabling full assessments and clear handovers. Given that the information was extrapolated from all agency files that the service users had contact with it is unlikely that this data is affected by under-recording.

Number of interagency contacts	**Number of service users**	**Minimum**	**Maximum**	**Mean**	**Std. Deviation**
during the first 6 months of receiving a service	16	.00	2.00	.8750	.5000
during the last 6 months of receiving a service	16	.00	3.00	.9375	.7719

Table 5.13 : Number of inter-agency contacts recorded in service users files

It may also be that it was the quality and clarity of information that led external professionals to feel that there was inadequate communication on the part of the team. Some of this may have come from confusion within the team about how it operated as it established its own operational policies and some of this may have arisen from the split of roles and responsibilities between the new team and the existing service.

5.2.5 Roles and Responsibilities of the Team

Views of professionals

Early on in the life of the team, a decision was made that only people who had named keyworkers in the referring agency would be accepted. The rationale for this was that as the team was time-limited, there needed to be a service who would pick up that person following the closure of the service. Clearly, however, if the aim of the service is to work with people who do not meet the existing eligibility criteria of already existing services, then this is confusing from the outset, and proved to be a source of frustration to referrers as it led to a lack of clarity around the roles of the new service and the referring agency.

For both successful and unsuccessful referrers there were issues about still having to retain responsibility for some aspects of work, such as accommodation issues and CPA responsibility. This appears to be due to perceptions that the team operated as a tertiary service. There were also differences in perceptions of whether service users were jointly worked with and to what degree the referrer continued to work with the service user.

> *"..as people rightly said, if they're inappropriately placed in a mental health team, why can't they be appropriately placed with your team, and then if funding does become an issue you can have the potential to refer them to the least worst option which would be us. But if we have been identified as not being an option for these people then why are we still involved.. "*

Two successful referrers, who were from a non-mental health background agreed with this position.

> *"I would say that there is an issue about case responsibility. [The team] say they will take the case and we will do the assessments, but we require a named person to remain in contact for reviews, but its actually been a lot more than that. With this case there are fears that the case responsibility remains with the team because of adult abuse investigation and adult placement issues. I can see the logic behind that. But it does seem to us that we've done a whole section of work which has got us nowhere because of the complexities of the case, and which we were going over again… which was extremely time consuming… The roles weren't clearly defined enough. We had a lot put back onto us because the individual was difficult to engage with and we had already built up a good relationship with her. So we became involved with some joint work with the social worker."*

For two successful referrers, who felt that they had co-worked with the team, they described their experience as positive, after an initial period of uncertainty.

> *"I'm beginning to think now that there is a mutual understanding of people's roles. I think in the early days, that took a while for us to sort out."*
>
> *"My experience has been really positive. I was concerned that it might be fraught with all kinds of problems from a point of view of what people classically struggle with in terms of different expectations, duplication of roles, the conflicts that exist in multi-agency working, in actual fact its been quite refreshing."*

Views of the team

In contrast, team members were clear about how they worked with teams and what the areas of responsibility were. They were very keen to co-work where that was appropriate and felt that the roles and responsibilities should be negotiated on an individual basis according to the needs of that individual service user.

> *"We try to differentiate at the beginning stage about what the client's needs were and how we work around that negotiation."*
>
> *"..it seems to me that the care managers are doing the care management role that they were doing before. What we hope to do is take on a more therapeutic and developmental role, developing the person's life to fit in more with what they want it to be. The care manager is there for things like, housing and especially anything with budgets attached. Maybe around other sorts of services, like day services or social work tasks. But quite a lot of those would be carried out by the social worker in the team. What the team tends to do is to separate off the key tasks of care management."*

Successful and potential referrers were certainly clear about the value of accessing services such as psychology and challenging behaviour expertise which they could not ordinarily easily access. The difficulty for both referrers and team members seemed to lie primarily in where there was overlap in the team's membership and their profession, particularly around the role of social work, and where a piece of work necessitated accessing budgets for placements which was outside the sphere of the team.

5.2.6 Roles and Responsibilities : Team Members

Team members were also asked to complete two scales which examine the clarity of their roles and the strength of the individual's identification with the team or their profession. The personal/team role clarity scale (Rizzo et al, 1970) assesses the extent to which an individual is clear about his/her responsibilities, who he or she is accountable to and how his/her work will be evaluated. The team role clarity refers to the extent that the team is seen as having clear aims and priorities, including clarity about whom the team is trying to support. A higher score indicates more clarity. Professionals may be clear about both roles, either or none.

	Number	Minimum	Maximum	Mean	Std. Deviation
Personal role clarity	9	15.00	23.00	19.22	2.99
Team role clarity	9	12.00	26.00	18.11	4.93

Table 5.14 : Personal role clarity and team role clarity scores for the pilot team.

Team members also completed the team/professional identification scale (Onyett et al 1997). Again higher scores indicate higher levels of identification.

	Number	Minimum	Maximum	Mean	Std. Deviation
Team identity	9	23.00	32.00	27.22	2.94
Professional identity	9	10.00	32.00	25.88	7.60

Table 5.15 : Team and professional identity for the pilot team.

The scores from the scales indicate a stronger allegiance to the team than to ones' professional group, and a low level of clarity of individual roles and the purpose of the team. Generally speaking these scores are lower than those identified in other studies (see pp. 290 – 296). The professional identity score could be explained by the difficulty in being in a multi-disciplinary team rather than in a uni-professional team and the problems of professional isolation. The lack of clarity of roles and purpose is explored further in the following findings from the semi-structured interviews.

All of the team members saw themselves as forming an integral part of the team and playing an important role in enabling the team to achieve its aims and objectives. Those team members with a distinct professional function were much clearer about their role than those with more generic briefs. This clarity, however, may be something which has developed over time. One worker, whose role was constantly being negotiated, described a period of "norming and storming" (Tuckman, 1965) before the team formed and roles became clear.

> *"It [my role] has changed, because I wanted to do a lot more at the start, and was kind of told, oh no. Other people also weren't sure what their roles would be too. The dynamics in the team were quite difficult, and because there was no team leader, there was no-one reigning anybody in.... But at the moment I feel quite happy with my role."*

All team members were aware of the need to contribute towards the smooth functioning of the team and often used their existing professional skills to do this.

> *"I also think there's a bit of – this hasn't been negotiated quite so clearly – an element of me sticking my oar in and saying, something about team development....it extends to bringing psychological principles to bear around the dynamics, the way the service is organised, the effectiveness .. about the sorts of interventions we are doing."*

Some felt that they needed to develop new skills in order to fulfil their role as a team member.

> *"I come from a team where ...[my] role is very clearly defined, so my coming into a team where there has been an expectation of doing a bit more generic work has been a learning curve in terms of my work."*

One saw being a team member as an opportunity to take on different, and often, more stimulating areas of work.

> *"..I would describe my role as the client stuff, but that's half of what I do, and the other half is kind of more interesting and challenging..."*

Team members generally felt that they worked closely with all of the other team members. However, team members rarely co-worked and only one person referred to joint work.

> *"..[we] are involved with the same client, but we do discreet pieces of work, we don't do any joint work. We have a core group and get together and think about things. [Another team member] and I are actually doing a joint piece of work around potential .... abuse."*
>
> *"I do bits and bobs with most of the team to be honest. I don't co-work in terms of joint visits as such, but with . [a team member], I will delegate bits of work..."*

Only one team member felt that the different disciplines may raise issues in terms of working closely.

> *"I feel more comfortable with the social aspects of the work. So that's the occupational therapy, the support worker, and the social worker. I feel very unconfident working with the psychologist because I don't have that professional background, not anywhere near it. And also their approach to problem solving is very different to mine. So I feel quite challenged by them and by the challenging behaviour specialist. I feel less challenged by the medics because I've worked with them in the past."*

Where team members had a professional background, usually they identified their own professional background as providing a theoretical framework for their own practice. One person did not use a theoretical model to understand practice.

> *"I don't, but I can't talk about the rest of them. Obviously, when they underwent training they must, but I haven't given it a lot of thought."*

Team members found it difficult to identify a team approach. Only one person identified their own approach and that of the team as being identical.

> *"Its engagement. Its about having the flexibility and sophistication to operate intervention models alongside the service user, but at the same time addressing the carer's needs because of the carers – they are particularly important to people with a degree of learning disability. Its both my and the team approach, and it is one I would encourage and*

> *develop. I think with certain members of the team in the past it hasn't been quite so clear, but those people aren't around."*

This feeling of a shift in the theoretical locus of the team was echoed by another longstanding member of the team.

> *"There was an idea that the team was going to work quite behaviourally, and it has to some extent. It is less strong now that ..[two team members]..have left. There has also been a very strong approach or discourse even, of a sort of social worky approach, drawing from social work practice. It feels more than that.. Sometimes it feels more like that than a health team."*

One team member felt that there was a lack of a team theoretical approach but that practically speaking, assertive outreach described where the team was now.

> *"I guess the assertive outreach model.... where there is a whole team approach, everybody is involved with everybody. This thing about being assertive with people, so if they don't turn up or engage, they'll go out of their way to be assertive, but ... I wouldn't say that there is anything that holds the team together theoretically."*

Two team members, with quite different theoretical frameworks, felt that their own theoretical approach was not held across the team.

> *"I think my approach is ...I'm very respectful of people, very caring. I suppose it would be sort of Rogers' "positive regard.." Its hard for me to speak for the rest of the team, collectively. I think some members of the team are like that and very respectful, and I think that maybe some others aren't."*

Throughout the interviews, reference was made by all of the team members to problems relating to team dynamics and the problems caused by not having a stable membership, in particular, the lack of a manager. The team manager did not come into post until August 1999, two months after the team started to provide a service. Some team members felt that the team had not been properly supported and that to some degree this situation continued.

> *"A few months ago, I was desperate to leave and looking for other work.. it was horrible..We didn't have a manager full time at the beginning. We didn't know where we were. We came in, we had to write our own operational policy and forms and everything, from our contact sheets to quite detailed assessments. There wasn't even paper in the office or pens.. I think because there wasn't a manager, personalities were allowed to dominate."*
>
> *"I think for me the issues surrounding professional concerns integrated with personal dynamics within the team have been seriously disruptive. I think it has retarded the development of the team as a professional unit. I think the support for the team hasn't been in place, especially for the team manager and I think that this has had a serious impact on his ability to lead effectively. The internal problems about team dynamics and personal issues or professional role issues have compounded the lack of support and resources. There may be issues for some members of the team about whether some of the personal issues are resolvable...I don't think that some of these issues for some people, will ever be fully successfully resolved for them personally.."*

The team manager began to plan a team building day in late 2001, but this did not materialise. Two team members felt that it may be too late in the day to revisit and address the issues of team dynamics.

> *"The team is a lot more stable now, but sometimes when the damage has been done.."*

All team members saw themselves as accountable to the team manager. In addition members saw themselves as being accountable to a professional/clinical supervisor who was usually external to the team. For three people, the team manager was the sole supervisor. One team member was unhappy with having the team manager as the sole supervisor and was currently negotiating clinical supervision from another member of the team. This move was felt to be more in keeping with that person's needs and role within the team.

Team members found clinical/professional supervision very useful. Its emphasis was practice led and focused very much on service users.

> *"Clinical supervision is useful for discussing client related issues and formulating our understanding of client related issues."*

Meetings with the team manager outside of clinical supervision tended to be very infrequent and less clear in terms of content.

> *"I think the supervision I have with the team manager hasn't really been very useful in terms of developing a greater understanding of the expectations of my role within the team. I think its been useful for addressing personal need in terms of training courses or training goals. But maybe that's something the whole team is struggling with really – how we all fit in and work together as members of the team."*
>
> *"Supervision with [the team manager] tends to be on a 3 monthly basis and it tends to be more about issues to do with team development and team issues.."*

The team manager had not received consistent supervision throughout the first 9 months of his employment, and in the absence of a named supervisor, saw himself as being accountable to the steering group for the project.

5.2.7 Developing Operational Policy and Procedures

At the time that the interviews took place with the team there were no operational policies and procedures. These were not developed until August 2000, over one year after the team began to provide a service. Even then the policies were not comprehensive and there were significant gaps such as risk assessment and management.

At this point (April–May 2000) however, there was considerable agreement amongst the team as to how referrals were dealt with, who carried out the assessment and how this process happens and the team aimed to follow the process outlined in Figure 5.5. The initial assessment included a brief history, an overview of needs and risks, a personal skills checklist and identified the areas for in-depth assessment. These in-depth specialist assessments were carried out following agreement at the team meeting that the referral was accepted.

> *"..the team manager will acknowledge the referral....and then, its agreed that two people will make the initial assessment and they should be from different professional backgrounds, and then we bring it back to the full team meeting, and establish an agreement to continue with the assessment. And then the assessment concludes with the initial review in which we bring in the referrer's and the service user's and carers' views."*

The main areas of disagreement were around which professionals carry out initial assessments.

> *"I think its very haphazard really."*

Opinion was divided between allocation on the basis of the clients' perceived needs and allocation on the basis of available time. Allocation of cases took place at the team meeting.

Type of assessment	First 6 months of service	Last 6 months of service
Initial needs assessment	16	0
Challenging behaviour	10	1
Occupational therapy	7	3
DISCO	1	1
Vineland ABS	1	0
IQ test	2	1
Psychological	1	0
Risk	2	2
EEG	0	0

Table 5.16 : Number of service users receiving an assessment during the first and last 6 months of receiving a service.

An analysis of service users' files focusing on the first 6 months of receiving a service and the last 6 months shows that whilst everyone received initial assessments during the first 6 months, the receipt of other assessments varied.

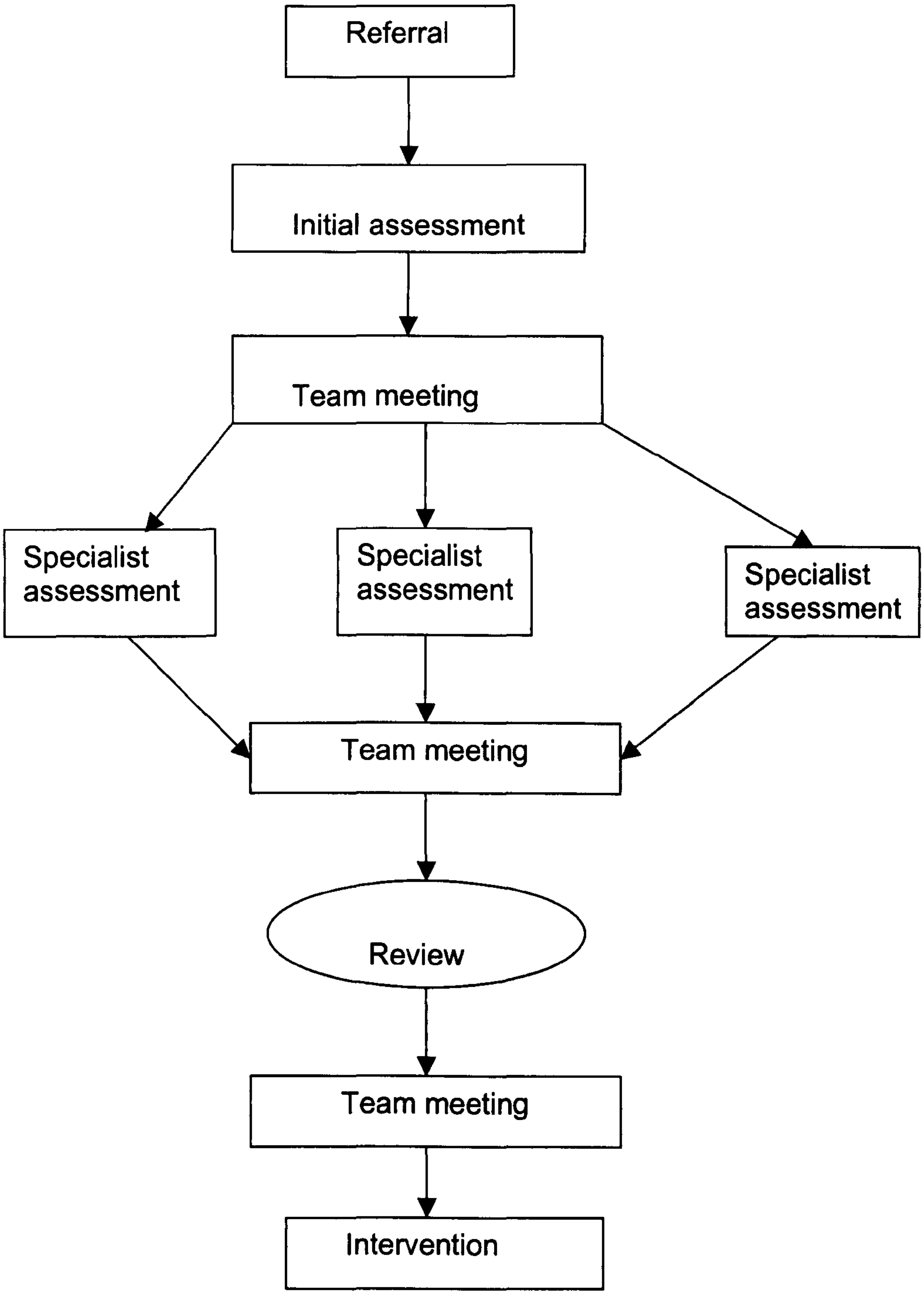


Figure 5.5 : Service User Pathway

Assessments received were only marginally related to the initial needs assessment – one young man was assessed as requiring a risk assessment, a psychological assessment and a behavioural assessment. He received no further assessments. One woman was assessed as requiring an activities of daily living assessment, a behavioural assessment and an occupational therapy assessment. She received a risk assessment, a cognitive assessment, an IQ (WAIS-R) test and a functional assessment. Another man was assessed as requiring a psychological assessment, a risk assessment, a psycho-sexual assessment, a behavioural assessment, a psychological assessment and an occupational therapy assessment. He received an occupational therapy and a challenging behaviour assessment. This reflects the constant negotiation which happened within the team.

Team members were clear that discussion at the team meeting about the assessments, together with the initial review identified which areas of work should be focused upon, and who should provide the identified service.

> *"Once we've done all the more in-depth assessments, we're much clearer on treatment and needs. So that would come out of the initial review that we should have and identify who the best people are in the team, be it skills, professional background etc., whether its going to be joint working or separate working, and its done according to assessed need. The frequency and intensity of that work will be led to some extent by the client and to some extent by what the intervention is to be and what the timescales are that have been worked on. Some examples are that we've offered it to a client on a more frequent basis than they can obviously sustain and its trying to enable them to tell us that, so again its about flexibility."*

The file analysis contradicted these views. The nature of the individual interventions were not clear from the files as there were no explicit care/treatment plans for most people. There were also no contracts between service user and the team. Reviews happened infrequently, were often not minuted and certainly did not take place in the way described by the team. The work was mainly co-ordinated through "case co-ordination" meetings which were internal to the team. Of the five people who did not receive a review or case-co-ordination meeting in the first 6 months of receiving a service, three people also did not have a review or case-coordination meeting within the last 6 months of receiving a service (see Appendix 19).

Team members saw the ability of the team to respond in a flexible way as being advantageous. However concerns were also expressed about confusion arising from the informal way that decisions were made and enacted upon, particularly in terms of measuring their effectiveness.

> *"The one thing that we are doing more is ... trying to get measures of outcomes, particularly around things like if we are agreeing that these are the interventions we are going to make with people, how are we going to measure them?"*

For example, half of the team members referred to the quality standards of the team – that all assessments should be carried out within 6 weeks. Most were unclear as to whether these standards were being met. Not one referrer to the team mentioned this quality standard, and there was no evidence that it existed or was monitored.

In the absence of clear guidelines, then, decisions appear to have been made at the team meetings. This was felt to be beneficial by one team member:

> *"The most useful thing about team meetings is, I think, the decision making, although the buck rests with the team manager, decision making is allowed to happen within that setting and .. there's ownership as a result of that.."*

The least useful aspect of the team meeting as a decision making forum was unanimously felt to be both the content and length of the team meeting. Clearly these two aspects are closely related. The length of the meeting was unpredictable, often lasting in excess of 4 hours and taking up a disproportionate amount of part-time workers' time. Team meetings were increased to twice weekly for four months in order to shorten the length of the team meeting and enable more part-time workers to attend. This did not work. Both team meetings together continued to take in excess of four hours.

The content of the meeting was also not felt to be sufficiently structured enough. It was used for both discussing individual clients and also looking at team/service development issues. There was a lack of both decision making and actions resulting from the meetings. Inconsistent attendance by team members (due to the part-time nature of some team members, other commitments, holidays, sickness and staff changes) often meant that issues would be revisited.

> *"..[T]here's the temptation to talk endlessly about the person that you're working with, its very difficult to boundary, and everybody does that. I think that everybody's got at least two people working with them and some people have got 4 or 5 people working with them and there's the potential to go on for ever and ever and for it to emphasise off-loading rather than identifying the person's needs, formulating based on assessments and looking at how well we're doing at sticking to that formulation and the objectives that we've set...Also team meetings aren't that good at helping us review the team as a whole. I think we do little bits of tinkering, sometimes quite important bits but translating that into action is particularly.., its hard to keep the big picture in mind at those meetings."*

> *"Sometimes, I feel that things get lost in team meetings too, key ideas about how we're going to develop the service. It doesn't always feel like these get implemented or put into practice. They get lost or sidelined for a while, and then they'll come back on to the agenda a few weeks later ... which can be a little frustrating."*

> *"I think that there's not enough time to really think about some of the work that we're doing, there 's a lot of clients to get through, if you try to get through every client at every team meeting, basically what you're going to do is be quite succinct around this happened and that happened and not think about interventions and where we're going with people. So I think they're quite impulsive and they're not a great forum for thinking. We spend time getting people's ideas on stuff and it tends to be quite impulsive and quite reactive and so you come out thinking you haven't*

> *really discussed that person at length or really we haven't moved on with that person, but everyone knows where we're at with that person. "*

One team member felt that the lack of structure had impeded the team's development.

> *"..[I]t is difficult to chair the meeting because people have their own agenda and don't allow enough time for other people to talk, and in the past it has been used by some individuals to keep others quiet, who have less professional clout and that isn't on."*

The forum then, that was used for making decisions about accepting referrals and determining interventions, was, according to the team members, not an ideal way of doing this. The inclusive decision making approach that the team used meant that issues were not always finally decided if not everyone had been included in that decision. Team members felt frustrated by revisiting the same issue, so it is not perhaps surprising that referrers also felt frustrated by apparent inconsistency.

In order to ensure that the interventions were properly managed, and because of the failure of the team meeting to address the issues in depth, the role of a case co-ordinator was created. There were no guidelines or job description for this role. Because of this there was a lack of clarity about the process for allocating a case co-ordinator, the role of the case co-ordinator and even whether service users had one or two!!

> *"[T]here's been no discussion about what criteria we should use to decide how we choose a case co-ordinator, but again if it is an issue where social needs were primary, it would be the social worker or OT. If there were significant psychological deficits, or psychological problems, or obsessional fixations particularly with people with autism, then it would be the challenging behaviour specialist or psychologist. But its often related to the availability of those individuals, because the medical input is very limited and so is the psychology input. And the role of the case co-ordinator is to be available at all times. That's not possible. So we introduce partnership, where two people would act as a case co-ordinator. "*

Just over half of the team (5) saw the case co-ordinator as having responsibility for reviews and liaison, both internally and externally. So there may have been an issue about who was responsible for liasing with external professionals. Team members also differed in whether they thought that the co-ordinator should be actively involved in interventions with service users or whether they should be solely responsible for co-ordinating.

> *"I think primarily it's a liaison role, and a monitoring role. You don't necessarily need to be the person who does everything. I think its liaison with the different members of the team who are working with clients, ensuring that they've got an overview of what's happening in the team, but also liasing with external teams and services that may be involved, and referring agencies. The allocation of clients is generally based on whose doing the initial work with somebody and the sense we're getting from the information we're gathering as to who is going to be most involved or the key player in that person's care – .. [that's] usually the most suitable person to be the case co-ordinator.. more often than not it's the person most involved."*
>
> *"I see the case co-ordinator role as certainly not providing all the work, but just making sure that things are ticking over, and that other people are doing what they need to be doing for that person and stuff."*
>
> *" I case co-ordinate for about six. Being a case co-ordinator wouldn't necessarily be an indication of how much involvement you had with that person. You might argue that I have more involvement with a person that I'm not case co-ordinator for than some that I am case co-ordinator for."*

The lack of clear operational policies seems to have had more impact on the relationship with external referrers than on the way that the team operated in terms of direct service provision. However, the lack of user focused risk assessment and management policies in a team which works with people who do present a high risk could have impacted significantly on the ability of the team to support people effectively. When asked about risk management, all team members answered this question in terms of how they ensured that the team was not at risk. The team manager referred to a home visiting policy which had been drafted by the team and was awaiting approval. One person thought that the home visiting policy had already been adopted and that a copy should be in everyone's file (it was not). The existing procedures were also felt by some team members to be inadequate.

> *"It's a problem if we visit people after hours and I think that's something we need to tighten up on. I was out on a visit with someone and I didn't finish until 10 past 5, and when I'd finished. I phoned the office... but nobody was here, everybody would have gone so what would have happened if there was a problem."*

Only one person mentioned risk assessment or management in relation to the service user and their position in the community, referring to a checklist that had been drawn up, but had yet to be implemented.

> *"The other stuff around what other risks the person might be open to or presenting to others isn't so formalised. We don't have a risk management framework.."*

This new team was working with a very complex group of people, but appears to be chaotic in terms of its operation and working in a fairly hostile environment.

5.2.8 Who did the team work with?

Outcomes of successful referrals	
Referred for assessment only (did not meet eligibility criteria)	1
Assessed but team could not provide a service because of family dynamics	2
Assessed but intervention not provided as team closed	2
Service user refused to engage	6
Service user said did not need service	1
Received intervention	25
Total	**36**

Table 5.17 : Outcome of successful referrals

The team accepted 36 referrals during the two years of its operation (see table 5.11). Interventions, i.e. therapeutic support based upon assessed needs, were provided to 25 people during that time. Of the 36 successful referrals, nearly 20% actively refused to engage with the service to the extent that the cases were closed. In addition another 3 service users refused to continue to engage with the service following a period of engagement – e.g. one person disengaged when his probation order expired and he was no longer required to attend the men's group. This means that the team was unable to meet the needs of 10 service users, one quarter of possible service users. There may well have been issues of cultural appropriateness but this is difficult to establish as the referral form did not request any information on ethnic origin. All 25 service users who received interventions were white.

	All service users who received an intervention	**Research group**
Gender		
Male	17	11 (65%)
Female	8	5 (62.5%)
Age		
18 – 30	12	7 (58%)
31 – 40	7	3 (43%)
41 – 50	5	5 (100%)
over 50	1	1 (100%)
Diagnosis		
Mild/ borderline Learning disability	18	13 (66.6%)
Asperger's/autism	10	6 (60%)
Personality disorder	4	2 (50%)
Schizophrenia	2	1 (50%)
Depression	2	3 (100%)
Total no. of Service Users	**25**	**16 (64%)**

Table 5.18 : Breakdown of service users by gender, age and diagnosis (N.B.service users had more than one diagnosis).

Number of diagnoses	**Service Users in Study Group**
1	9
2	5
3 or more	2
Total	16

Table 5.19 : No. of service users and no. of diagnoses.

Challenging behaviour	Total	Research group
Physical aggression	16	11 (69%)
Verbal aggression	15	12 (80%)
Vulnerable behaviour	7	5 (72%)
Inappropriate sexual behaviour/sexual offences	5	5 (100%)
Damage to property	5	4 (80%)
Obsessional behaviour (routines)	4	4 (100%)
Obsessional behaviour (people)	4	3 (75%)
Self harm	3	2 (66%)
Theft	3	1 (33%)
Arson	1	1 (100%)
Other	4	3 (75%)

Table 5.20 : Analysis of nature of challenging behaviour of the 25 service users who received interventions (service users had more than one documented challenging behaviour).

Tables 5.18 to 5.20 show the key characteristics of the service users who received interventions from the team, broken down by age, gender, diagnosis and challenging behaviour. All of the service users were unmarried, although one man has recently become engaged. The majority of people who formed the research group lived independently in the community. Six people lived alone and nine people lived with their families when they first began to receive a service. One person lived in an adult placement scheme.

The team worked with a very complex group of people who had significant levels of challenging behaviour. Fourteen of the 16 service users who formed the research group had previous contact with the police and five people had criminal records.

5.2.8 What did the team do?

In addition to the 25 individual interventions, the team also co-ran a sex offenders group for men with learning difficulties and set up and ran a women's group, a men's relationship group and a carers' group. The carers group continued to meet after the team closed.

	Number of contacts in first 6 months	Number of contacts in last 6 months
Mean	25.3	15.4
Std. Deviation	28.8	14.2
Minimum	2	1
Maximum	107	49

Table 5.21 : Frequency of contact between the team and individual service users

The service provided by this team was a more intense service than that previously received as both the table 5.21 and figure 5.6 show, and this fits in with the view that the team was operating on an assertive outreach model. Figure 5.6 also shows the difference in level of service received from the team to that provided by mainstream services. In all but one case, service users received a service which was based upon more frequent contact than that provided by previous services. In nine cases, the service user had had no contact with services in the six month period before receiving a service from the team.

Both the table and figure 5.6 are based upon the number of recorded contacts between the team and the service user during the first and the last six months of the operation of the team with an average number of contacts of 25 visits during the first 6 months of team involvement (roughly one a week), and 15 in the last six months of team involvement . The variation in number of contacts may be due to users' needs, the difficulty of engagement or lack of recording. The first 6 months would be expected to be a time of intensive contact as people were being assessed prior to receiving a service. In general, the team kept very poor records and based on observation by the researcher, probably under-recorded the number of contacts that they made. The variation between service users may be explained by the team providing a flexible responsive service based upon need and the difficulty of contact with some service users.

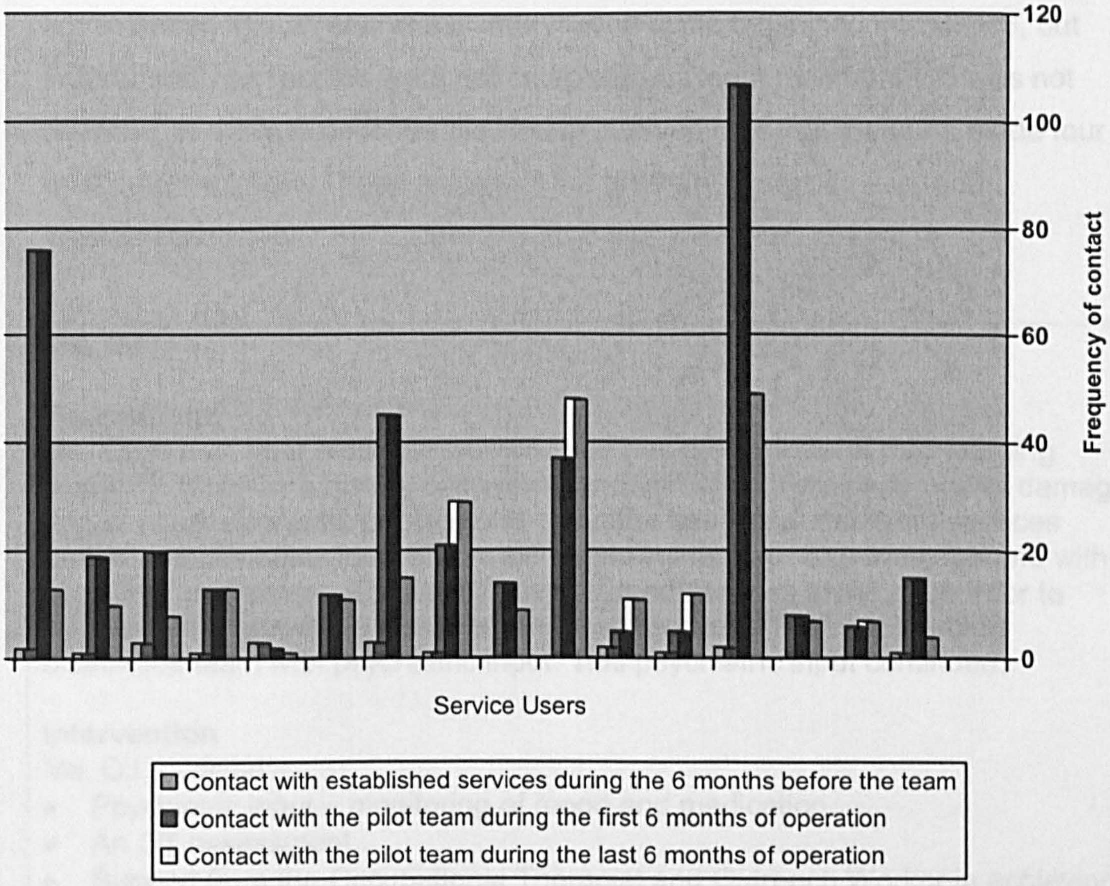


Figure 5.6 : No.of contacts between service users and mainstream services and service users and the team over 6 month periods.

The number of recorded contacts reflects to some degree the emphasis of the team on supporting people with challenging behaviour. However the number of contacts are not accurate – for example, the number of times someone attended a group was found not to be accurate when cross-checked with individual reports of peoples' attendances. It was not possible to obtain more accurate figures however. The number of contacts in the last 6 months is likely to be an under-representation, although some contact levels were affected by the occupational therapist and the social worker leaving before the formal end of the service. There were also problems maintaining psychiatric input with changes in personnel and the refusal of one of the post-holders to provide a service to some people because their IQ was too high. It is not clear why this situation arose as it would be expected that the psychiatric time bought in as part of the team would operate within the same eligibility criteria.

It was hoped that an analysis of intervention could be gained from PIMS, but unfortunately as records were not completed by team members this was not possible. In order to describe the kind of interventions that the team made four brief outlines follow. These represent the diversity of service user and intervention.

Ms. OJ

Background

Ms. OJ is a 21 year old white woman. She has a diagnosis of mild learning disability. She has a history of physical and verbal aggression, property damage and of obssession with people. She has often been excluded from services because of her behaviour. She is extremely vulnerable. She lives at home with her father and sisters. The family have refused services in the past. Prior to referral to the team, she was receiving a service from the local learning disabilities team with psychiatric input. This psychiatric input continued.

Intervention

Ms. OJ received:

- Psychiatric input – monitoring of mood and medication
- An OT assessment
- Support from the Occupational Therapist and Outreach Worker in achieving the goals initially on a fortnightly basis. She undertook various activities such as bowling, shopping, swimming, going to lunch etc.
- Support in attending a college cookery course
- Women's group run by OT and psychologist. She went to 19 out of 23 sessions.This enabled OJ to explore such issues as being a woman, relationships,contraception, parenthood and saying "no".
- Support when making an allegation of abuse against father
- A preliminary assessment of risk following the above allegation (not reviewed).

Ms. OJ's father received:

- Sessions with the Challenging Behaviour Specialist and the Psychologist
- Carers' Group. (He attended once).

Mr. NS

Background

Mr. NS is a young white man aged 21. He has a diagnosis of Asperger's syndrome and mild learning disabilities. He has a history of inappropriate behaviour, stealing and being verbally and physically aggressive. He has run up huge telephone bills which he was unable to pay and was unable to self-care without prompting. NS lives at home with his parents. Prior to receiving a service from the team he was allocated a social worker. However, the social worker did not feel that he had the expertise or access to resources to work with NS. NS received a service from June 1999 – May 2001.

Intervention

NS received the following assessments:
- Social work assessment
- Vineland ABS
- Challenging Behaviour assessment
- OT assessment
- Work skills assessment from Prospects

NS received
- Support from the OT in developing cooking skills when unemployed
- Support from the social worker and challenging behaviour specialist in coping with work, relationships, sex, communication. This was on a reactive basis.
- Access to and support with work placements
- Access to and support with college courses
- Support in gaining full-time employment and coping when he subsequently became unemployed
- Men's relationship group
- Assistance with benefits

NS's mother received
- Individual support from the social worker and challenging behaviour specialist in coping with N's behaviour on a reactive basis
- Carers' group

Mr. JQ

Background

Mr. JQ is a 31 year old white man with a mobility impairment. He has a diagnosis of mild learning disabilities. He has a history of inappropriate sexual behaviours, some of which have led to a criminal record. He has previously received a service from the local forensic secure service and psychiatry. At the time of referral he was not receiving a service, but was being assessed for a men's group aimed at men who have or are likely to offend sexually. JQ lives at home with his parents and is in full employment. He has had to leave previous jobs because of his behaviour.

Intervention

JQ received (from the team)
- A behavioural assessment
- An employment assessment

(from the psychologist running the sex offenders'group)
- Sexual knowledge assessment
- Victim empathy assessment

- Cognitive distortions assessment

- Support from the occupational therapist to develop coping strategies at work, including assertion techniques
- Support from the occupational therapist to access the DEA to manage conflict at work and to look for alternative employment.
- Support from the challenging behaviour specialist in exploring sexually inappropriate behaviours, considering ways to avoid and problem solve these triggers and reinforcing legal sexual activity.
- Access to a cognitive-behavioural treatment group for sex offenders run with local psychology and supported by the team. He regularly attended this group.

N's parents attended the carers' group on a regular basis.

Mr. LC

Background

Mr. LC is a 28 year old white man who was living independently in his own flat with support from his family at the time of referral. He had a diagnosis of mild learning disability which was later rescinded. He had a history of physical and verbal aggression, theft and property destruction. This had led to a criminal record. He also used alchohol and illegal drugs. His behaviour had led to him losing jobs. He was unemployed.

He had a social worker allocated from the generic social work team who felt unable to offer the specialist support that L needed. He was receiving psychiatric support.

Interventions

LC received:
- An initial social work assessment in October 1999
- A behavioural assessment in August 1999
- An occupational therapy assessment in October 1999.
- DISCO assessment September 2000
- A risk assessment in February 2001 by Psychiatry following threats to the team
- Forensic psychiatric assessment in February 2001

- Communication support and anger management training from the occupational therapist and the psychologist
- General support from the social worker and challenging behaviour specialist
- Five sessions of psychotherapeutic support from the psychiatrist and a team member (this person varied). LC attended 3 sessions.
- Referrals to local specialist support organisations for help gaining employment. LC did not follow these up.
- Support in attending local leisure activities and in carrying out domestic tasks – LC refused to particpate.
- Support in trying to find accomodation including attendance at the Homeless Unit, applications to panel for supported housing.
- Support in applying for benefits.

Chapter 6

Study 1 : Results

6.1 Background

All service users who had received an intervention from the team by October 2004 (n = 22) were asked if they would like to take part in the study (see pp 167 – 168). Sixteen service users agreed to take part. They were interviewed using the quality of life checklist at various points in the year depending upon when they began to receive a service from the team (see table 6.1). Semi-structured interviews and quality of life checklists were carried out a minimum of five months after the first checklist and 6 months after the service ended.

	First QOL (From Autumn 2000)	2nd. QOL and semi- structured interview (Spring 2001)	3rd. QOL and semi- structured interview (Winter 2001)
No. of service users	16	14	13

Table 6.1 : Interviews with service users

All service users were asked if their Mum, Dad or other carer could be interviewed. Permission to interview carers was obtained in twelve cases. It was hoped to interview carers once during the time that their relative received a service and once 6 months after the service terminated. However not all twelve carers were interviewed on both occasions.

Number of carers who were interviewed on both occasions	6
Number of carers who were interviewed on one occasion	5
Number of carers who withdrew	1
Total	12

Table 6.2 : Breakdown of number of carers who were interviewed

One carer withdrew from the study; he also withdrew his permission for any information he had been given to be included. One carer was only interviewed on the final occasion as she had been caring for her terminally ill husband at the time of the first interviews. Three carers chose not to be interviewed a second time, and one paid carer no longer supported one of the service users.

6.2 Getting a Service from the Team

One of the major difficulties reported in the carers' movement in general, is obtaining information about services which may be able to support their relatives. In this case, two carers did not know that referrals had been made on their behalf and one carer said that their son had found out about the service himself. Five carers thought that they had been referred to the serviced by a psychiatrist. This was only so in two of those cases.

6.3 Services from the Team – Service Users' Views

Service users views

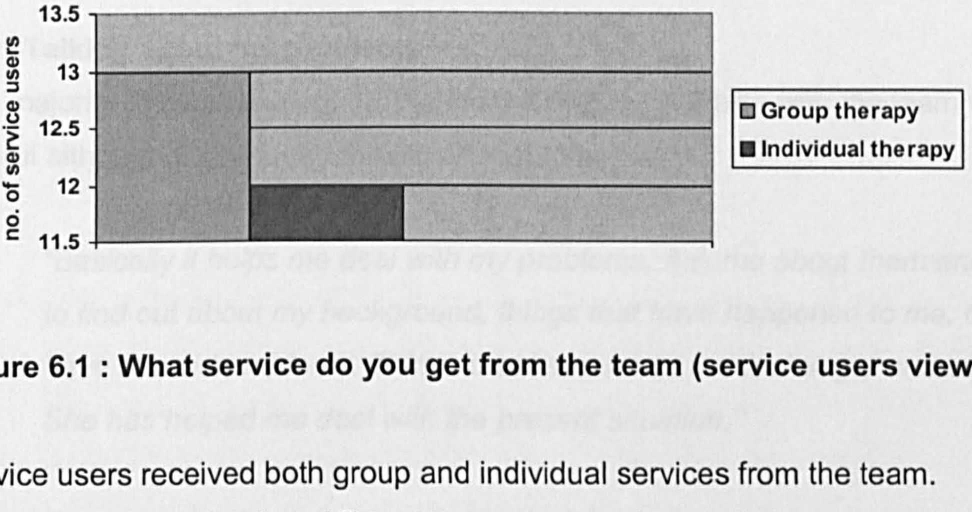


Figure 6.1 : What service do you get from the team (service users views)?

Service users received both group and individual services from the team. Thirteen service users (n = 16) had begun to attend groups run or co-run with the team. Twelve service users also received individually tailored support and two service users felt that they did not receive either group support or individually tailored support from the team.

Service users were asked what kind of things the team helped them with. Service users identified individual interventions rather than the groups they attended. It is possible that service users saw the groups as a separate activity from the individual interventions provided by the team, particularly as they were held in a different venue.

Kind of help	No. of service users
Talking (about problems) on a one-to-one basis	10
Cooking, cleaning etc.	4
Help with finding/staying in work	3
Help with benefits	2
Help with housing	2
Support with leisure activities	3
Help getting a place in college	1
Help with anger	1
Accompanying to hospital appointments	1

Table 6.3 : What kind of help do service users receive from the team (service users views)

Some service users identified more than one area that the team helped them with. Talking about problems was by far the most common area that service users felt they had help with.

6.3.1 Talking about my problems

The majority of service users (10) found the one-to-one talks with the team very helpful although some found it quite difficult to say why.

> *"Basically it helps me deal with my problems. Ask me about them and try to find out about my background, things that have happened to me, that have caused problems. Things that have made me feel angry and stuff. She has helped me deal with the present situation."*
>
> *"They just talk"*
> *Do you find that helpful?*
> *"Yes I do. Yes."*
> *Why do you find that helpful?*
> *"Because I just do. It helps me."*
>
> *Does it help you when you talk to C?*
> *"It does at times, yes."*
> *How does it help you?*
> *"She seems to solve a problem out at times."*

> *"Well, in the last few weeks, C has been doing with me what they call cognitive thought to help train your mind on situations, to approach things differently or cope with them differently in a frame of thought so to speak."*
>
> *"It helps you deal with different relationships and that when you talk to someone else about it. It helps you deal with any concerns you might have. He sort of suggests things, and helps you work things out yourself."*

Two people filled in diary sheets regarding different activities and discussed those with members of the team. One person was given some help with assertiveness.

> *"..she says try saying things this way. She gave me loads of sheets to read about being more positive about things and trying not to be passive and what do they call it, assertion skills."*
> *Did that help?*
> *"I don't know. Maybe. A little bit."*

Only one person did not find talking on an individual basis useful. This was one of the young men who had said that he received no help at all from the team.

> *"Its just a counselling session. They are doing nothing to address your social state, the way you interact with people, they don't for want of another word, clue you up and get you ready to go back into the community and do it all over again."*

6.3.2 Going to the group

Thirteen service users had been offered and attended a group on at least one occasion or had agreed to attend a group. There were three groups running during the two years: a men's group for men with sexually abusive behaviour; a women's group for women who were vulnerable and a relationships group for men.

One man's expectation was that the men's group would be very helpful for him.

"I think it'll understand me a bit more about relationships and things like that. You hear what other people have gone through and what they are going through, and some of it is quite interesting to hear really because you know you might go through it yourself, so its nice to have a bit of detailed information, not anything personal, but its nice to know, you know what I mean, you might experience the same thing later in life. Its nice to talk to people about what they've gone through, and I suppose its nice to talk to people too."

Members of established groups echoed the sentiment about sharing experiences and learning from each other.

".. you're all going through the same thing basically. One way or another anyway. And when you talk about it, other people can give a point of view as well."

Others felt that the group was helping them with particular issues:

"Its very good helping me out what we should do and what we don't do with our family."

Only one man and one woman did not find the groups useful.

Are you finding it helpful?

"No"

Why aren't you finding it helpful?

"Because they talk about football all the time."

"No –it's a bit far..One woman she had an epileptic fit when I was there, wasn't it awful? It was scary. She frightened all the others."

One women had somewhat mixed feelings about the women's group:

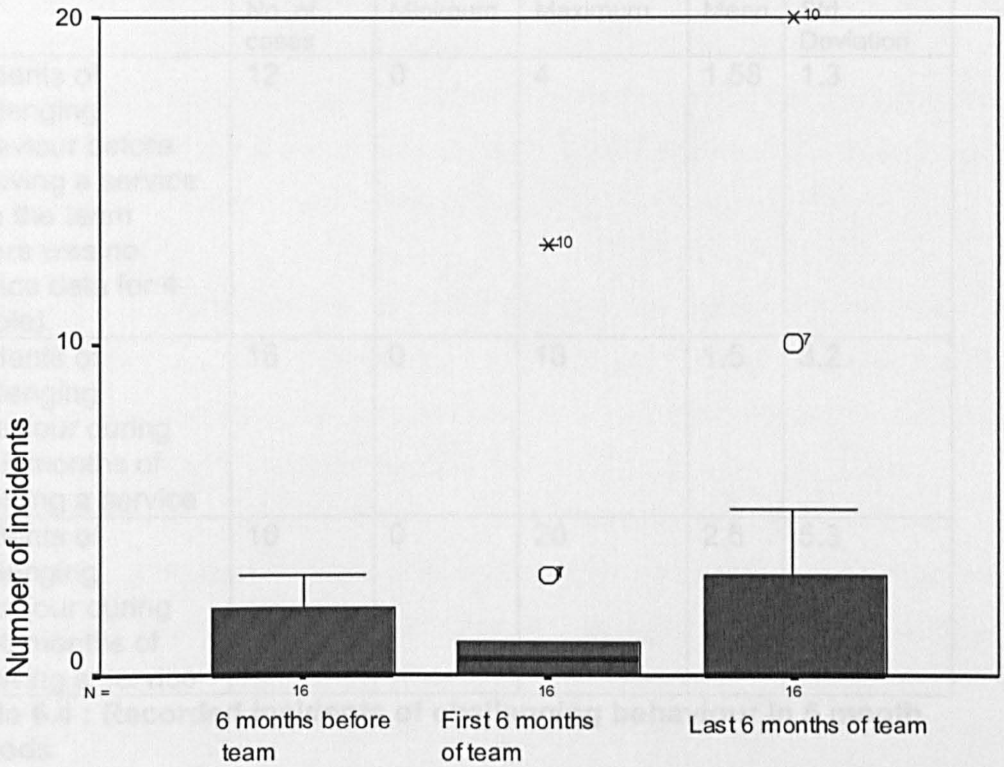
".when I first went to the women's group, I didn't want to say nothing to nobody when I first went in there. All of a sudden it just came out, and I talk to them now."

Does it feel better when it all just comes out ?

"Sometimes it does, yes. Sometimes I don't. Sometimes I feel worse and I think oh I'll leave it. They said to me if there's any problems, it doesn't matter how big or small, just give them a ring. Any day, maybe even

every day…I'll phone them back later and say I need your help, and they'll phone me back and say what's the problem and I'll tell them."

6.3.3 Staying out of trouble



Key : Shaded area represents interquartile range of incidents
Thick line represents median
T - represents outliers
* and 0 represent extreme cases

Figure 6.2 : Recorded incidents of challenging behaviour in 6 month periods.

Figure 6.2 illustrates the impact of the service on the recorded incidence of challenging behaviour when the 6 months prior to receiving the service is compared to times during the service. Given the limited service input from other services as evidenced by the low contact most service users had prior to contact with this team, the number of incidents before the team became involved are likely to be an under-recording. The average number of incidents drops throughout the period of receiving a service. The outliers may be explained by virtue of the fact that one person kept a diary of his behaviour to aid discussion with the team, resulting in a more accurate record of incidents that took place when he was alone (i.e. unsupervised) and that, although serious were not reported to the police.

	No. of cases	Minimum	Maximum	Mean	Std. Deviation
Incidents of challenging behaviour before receiving a service from the team (There was no service data for 4 people).	12	0	4	1.58	1.3
Incidents of challenging behaviour during first 6 months of receiving a service	16	0	13	1.5	3.2
Incidents of challenging behaviour during last 6 months of receiving a service	16	0	20	2.6	5.3

Table 6.4 : Recorded incidents of challenging behaviour in 6 month periods

It should also be noted that the range of number of incidents by service user increases during the last 6 months of receiving a service. This may be because of the level of anxiety that service users felt when they knew that the service was being closed down and were worried that there may not be alternative support for them. One service user admitted herself to hospital pretending to be deaf and without speech for a week. Another service user offended. He said:

> *"I think it was because I felt a bit annoyed about [the team] closing, nd I felt that I would probably be left with no-one and that they .. if I committed a crime when I was helped by no-one I probably ...they would think I was really bad and they wouldn't understand about [the team] closing."*

Four service users said that the team helped them stay out of trouble. All of these four had been in contact with the police. One person felt that if the team had been in existence then he night never have offended in the first place.

> *" ..if ..[the team] was there 10 years ago it would have helped. I didn't do anything too wrong. I spoke to some young girls which got me into trouble. I did some things that were wrong. I was rather silly and stupid.... And it just snowballed and carried on until I didn't know where I was."* (This service user was minimising his behaviour and describing his sexual offences in euphemistic terms).

Two service users thought that the team and the improvements it had made to their lives were central to their staying out of trouble. For both of these people, the fear of what further action the police might take if they repeated the offences also figured large in their calculations.

> *"...I had to go to court once...because I said to the police that I was raped but I wasn't, it was a false allegation, so they took me to court. But luckily enough, the judge said that he was going to get a psychiatrist to check me out, and he said that she's got psychiatric problems. So the court said that they couldn't put me away because she's got psychiatric problems, but if I do it again, they'll put me away. I'm on what they call a conditional bail....since then I haven't done it."*
>
> *"I haven't been in custody or in prison, but I have been cautioned by the police and the last time the police caught me, they told me they were arresting me and they took me to the custody area of [the local] police station, but they didn't know what to charge me with so they let me go. But J has told me that if the police were to catch me, and I were to be charged with something, I would have a good chance of being put into a care home, 24 hour supported accommodation."* (This service user masturbated in public places).

One person did not think that helping people stay out of trouble was the role of the team.

> *"Well you've got to really try and do it yourself rather than other people doing it."*

This man ceased contact with the team and stopped attending the men's group when his probation order finished, but then reoffended and subsequently ended up in prison with a life sentence for rape.

6.3.4 Other kinds of help

Other kinds of help include independent living skills, support with employment and money and for two users, the perception that they received no help at all.

Work on independent living skills such as cooking and cleaning were usually carried out in the service users' homes as the team did not have access to a training kitchen or flat.

> *"S comes occasionally. J and C come here. They might come together or they might come on their own. They ask me questions. What I have been doing and what I haven't been doing. S. asks me to polish things up, how to polish things, cookery, how to cook. And how to do lawnmowers. When she came here before she said do you want to do housework and cooking. When I cooked with her she did beans on toast and I did the upstairs and the downstairs using the Hoover."*

Help with finding employment usually meant supporting a service user following a referral to a supported employment agency.

> *"I'm getting on very well down there."*
> *What do you like about it?*
> *"Because we're all sorting things out, and its helping me out to get the job as well at the [supported employment agency]. They're doing it very well."*

It also meant supporting people when current employment became difficult.

> *"..mainly she talks to me about trying to communicate with other people at work, which is very difficult because they are very rude and nasty . .. Alright so I'm there to do my job, but there's no need to call me names and things like that. ...S has talked to me helping me work out things – to improve my skills at work, so I didn't get so stressed out... talking to me when I felt down about my job, but she said you know you seem to be coping quite well."*

> *"And he helps you, takes your mind off things. And different things like the [job] situation. I went and talked to him, its not fair, like someone to have a moan at really and that helped me not go into work and have a go at [my boss]."*

Help with benefits and housing consisted of filling in forms with people and advising them of the processes.

Help with leisure activities consisted of actually going to different mainstream activities such as bowling, Pizza Hut, often as frequently as twice a week, with service users who had previously never had the opportunity to undertake such activities.

The two young men who felt that they did not receive a service at all were currently being visited by the team in pairs because of perceived risks related to their previous threatening behaviour. Both men felt abandoned by the service and were becoming extremely frustrated with the team. Both men had been offered membership of the men's relationship group and refused this.

> *"..I've never physically threatened them. I've never went into a rage at them. ..Oh him, he's confused, or if he's anxious or if he's angry, then they won't bother coming round.. I think they should see me more often. I think they should take the initiative, go alone, put themselves in my shoes, think about how someone like me would feel, because I'm not a hundred per cent mentally secure. I'm very vulnerable about my state of mind. I can't speak for myself in very basic situations, like to deal with my housing, to deal with my rent, to deal with any benefits I'm due."*
> *"She's the one that told me she was going to see me today. I'm still waiting. She rang me up and cancelled. Quite a few times she's done this… I don't want to see her at all"*

6.3.5 Frequency of service

Of the 14 service users who said that they received a service from the team, only one person wanted to see them more frequently.

> *"More often. Help me out a bit more"*
>
> *The remaining service users felt that the team provided support when they needed it.*
>
> *"I think it started off every week, then every three weeks, then we would meet maybe once or twice a month. She only saw me when I felt like I needed to see her really, not all the time."*
>
> *"I think I see them often enough."*

Service users who worked often had a lower level of contact because of their work commitments.

> *"Its really difficult with working. I saw him every other week before I started working. Now I just give him a ring. I just give him a call."*
>
> *"I could see her once a week, but I can't fit it in with work...but I'm managing okay with once a fortnight at the moment and I have been since October."*

The fact that service users could ring the team if they had a problem was valued explicitly by twelve service users. They recognised that the team had other service users and that they might have to be contacted at a later time. However they all had confidence in the team's ability to return calls and maintain contact.

> *"There's only so much she can help me with. She keeps things ticking over. And I've got her number and I can ring her up occasionally after work."*

6.3.6 Quality of Life

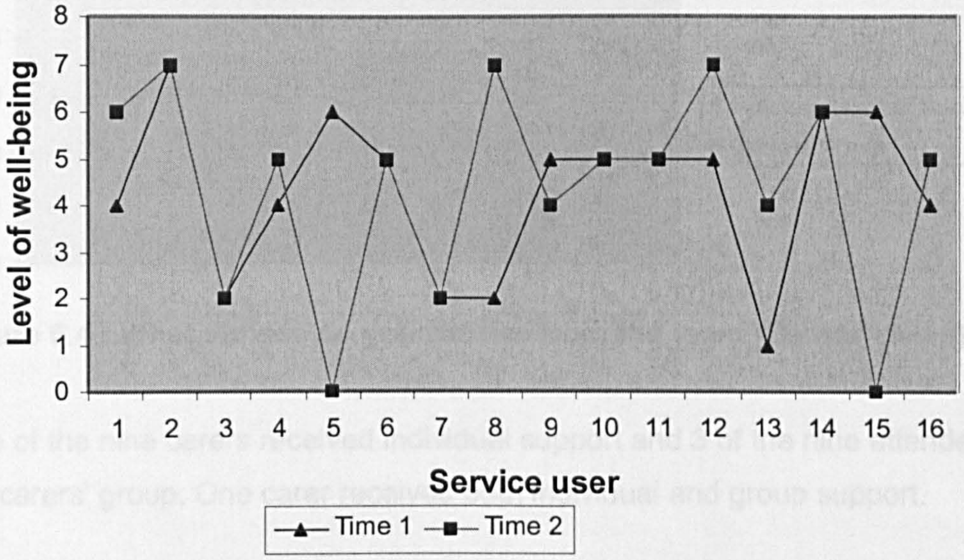


Figure 6.3 : Changes in general well-being for service users

	No. of cases	Mean	Std. Deviation
General well-being (time 1)	16	4.3	1.6
General well being (time 2)	14	5	1.7

Table 6.5: Changes in general well-being (1)

Changes in General Well Being	Number of service users
General well-being stayed same	7 (cases 2,3,6,7,10, 11and 14)
General well-being increased	6 (cases 1, 4, 8,12,13 and 16)
General well-being decreased	1 (case 9)
No information at time 2	2 (cases 5 and 15)

Table 6.6 : Changes in general well-being (2)

Quality of life interviews at two points – one in the early days of using the service, and the second a minimum of five months later show that six service users felt better about their life as a whole and seven felt the same. It is clearly difficult to establish whether the receipt of the service is the reason for this change as other life factors could well have impacted on this result. It is interesting to note however that the one person whose general well-being score decreased (Mr. JQ) was just about to have his case closed as the team felt that he no longer required a service.

6.4 Services from the Team : Carers Views

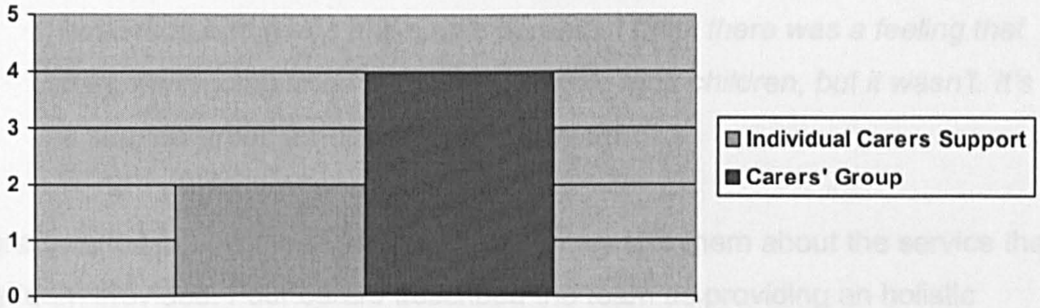


Figure 6.4 : What service do you receive from the team (Carers'Views)

Two of the nine carers received individual support and 3 of the nine attended the carers' group. One carer received both individual and group support.

> *" [A worker] also comes and gives me support and gives me advice. I can also phone up any given day. ..It means that I've got an outlet which I've never had before. Really for me they're just a lifeline to sanity, to maintaining my sanity."*

Use of Carers' Group	Number of carers
Not aware of carers' group	5
Aware of carers' group	5
Attend carers' group	3
Do not need support of carers' group	1
Work commitments clash with carers' group	1

Table 6.7: Carers' Group (n=10).

Only five carers said they were aware that there was a carers' group: Carers varied in their reasons for not wanting to attend the group – one carer felt that they did not need the support. One carer did not have time because of work commitments.

Three carers attended the carers' group.

> *"I go to the carers' group. I've been every time and I will go on Thursday. When they asked me about setting up a carers' group, I said that I thought it was a very good idea. It lets you know that you are not alone."*

> *"We do go to the carers' support group. I think when it first opened, there was much better support. I think there was about eight different families, husbands and wives and single parents. I think there was a feeling that they were going to be told how to handle their children, but it wasn't. It's a support group for us to talk about things.."*

Carers varied in how much their sons/daughters told them about the service that the team provided. Four carers described the team as providing an holistic flexible responsive service which was tailored to meet their son/daughter's needs. Thus support with employment, practical independent living skills and emotional support were all described as forming elements of the service.

> *" [They] see .. him once a week, and discuss.. his problems. Members of the team help him with washing up and shopping. It's a very good service. They make sure that he is capable of looking after himself and .... Makes sure that he's got his benefits, and eventually accommodation."*
>
> *"Well, its like an open house. They can always ring up and if there's not anyone to take his call, they do pick up his answerphone message and they do ring back. Its been absolutely wonderful. If he ever has a problem, and he does get very emotional about things. He's been very unhappy at work. He has been trying to change it for some time. Even on Friday, he got a rejection letter from an interview ...and he rang them up straight away. He just felt that he needed to talk to someone and it was like a relief for him, that he could pick up the phone, talk to someone who he knows will understand what he's been through."*
>
> *" N is able to contact at any given time, which is great for him, because he has someone to talk to. One of the things with Asperger's is that he doesn't have any friends, he doesn't have any social life and so he has got somebody to confide in and chat things over with. .....[A worker], at the drop of a hat, came down and saw N on Monday because there was a problem and he was going to see him later in the week.."*

The fact that the team varied their level of input according to the needs of the service user, and continued to provide a kind of "safety net" was particularly valued by two carers.

> *"I think they are really excellent. I can't praise them enough…always being there. Whenever J's rung, they've rung him back. ..They've rung back after 5, and I'm thinking, oh they must be finished. But they know that he doesn't get in late until after 5. ..As I say, they're winding him down. They haven't made any appointments to see him. They will ring once a month and he's welcome to ring them. So there is still a service for him. If anything happened ..if he gradually got worse or went into a depression or something ..I'm sure if they could physically do it , they would start to see him.."*

Of the nine unpaid carers interviewed, four carers felt that the team helped their son or daughter.

> *"I'm sure it does. 100%..they talk to him, they listen to him"*
>
> *"I think so. They were there that's the main thing. When he had a problem and he felt that he couldn't turn to us, he had them, didn't he? [The team] are always at the other end of the phone for him and I think that's marvellous. Just to have someone that he can talk to – I think that's marvellous. They can't always talk to you. M doesn't always make friends so they're the only people he has got."*

Of these four carers, three felt that the support offered to their son or daughter helped them too.

> *"I don't think we could have managed without the help that we got from the team. Definitely not."*
>
> *The fourth carer said the service did not help him directly, but "..[I]t helps me to relax and know that he is out of the house for a couple of days. And he is with people, and he is in company, so if anything did happen, that is, if he did have a fit, someone would be there."*

Three carers felt that the service could help their son or daughter if they co-operated with the service.

> *"They probably would if he let them or if he let them on a regular basis. But you know he doesn't. L is at fault a lot, but he won't admit it."*
>
> *"Its very difficult to know with T what helps her really. She says that they had a good talk, a good chat about lots of things...She enjoys going, so it brings her some enjoyment and a social activity even if it doesn't do anything else. "*

Two carers felt that the service had limited impact for different reasons. One felt that there had been a number of positive developments for her son, of which team was only one. The team had not been involved in finding K his job.

> *"I don't know if its ..[the team] or because K has changed his job. Because he was going to ..[the team] and then he started to go to [work] and he's really come out of his shell. He's an awful lot different this time this year, than he was this time last year. I think its more his job that has brought him out...With K what has helped him, is his job and the people he's been with. Its helped bring him out. This time last year, he couldn't take a joke."*

The other carer felt that the support she had expected for her son was not forthcoming. Her situation was exacerbated by the fact that her son had moved geographically closer to her which had put more pressure on her.

> *"I haven't seen any help yet. Actually, what I was hoping was that when [the team] took him in hand after [a low secure unit] and all that, that I wouldn't have this to do, but I still have. Since he's moved over here, I see him a lot more and I've ended up giving him dinners over here, which is coming out of my pocket. He already comes over for Sunday dinner, but I get him for Monday, Tuesday, Wednesday, Thursday as well. "*

Does the service help your son/daughter ?	**Number of carers**
Yes	4
It would help her/him if s/he co-operated	3
It has had little impact	2
Total	**9**

Table 6.8 : Does the service help your son or daughter?

6.5 Who helped you before the team was set up?

Service Users' Views

Eight service users had social workers or care managers that worked with them before the team was set up. One also had a Community Psychiatric Nurse. Three of these service users thought that their social worker had helped them. One care manager had helped a service user successfully leave an Adult Placement Scheme where he was unhappy and live with support in his own flat. Another had helped with a service user's domineering sister, and yet another had helped the service user find activities that he wanted to do. One service user felt that the social worker had helped her parents but not herself. Four people had not found their social workers helpful. This appeared to be because of a variety of reasons:

- The help that was offered was different - one service user felt that the support offered by team was of a much higher quality, possibly because a psychologist was offered a different service to that of a social worker, and
- The services social workers had referred service users to were unsuccessful, e.g. Crossroads or respite care.

The Community Psychiatric Nurse was felt to be very helpful, but unfortunately had been promoted.

Five service users said that they had no help before the team. One person had been in a low secure unit, following a conviction for arson, but said that this had not helped him. He described himself as running the group sessions etc. whilst in the unit. One person had been seeing a psychiatrist but saw him as a gatekeeper to help rather than help itself.

> *"I was an out-patient of Dr. B. from approximately 1990 – 1999. Outreach support services just weren't the thing for people like me to fit in. But he tried everything. He wrote letters to this, letters to that. Fought for this, fought for that, after he founded ..[the team], he left."*

Three service users identified a psychiatrist as being the only source of support offered to them. However they only saw the psychiatrist every 2 or 3 months or less. They did feel that the kind of support offered by the team was different and wished that they had received it sooner.

Who helped you before the team was set up?	**No. of service users**
Social workers/care managers	8
No-one	5
Psychiatrist	3
Total	**16**

Table 6.9 : Who helped you before the team was set up?

How helpful was your social worker?	**No. of service users**
Not helpful	4
Helpful	3
Helped my parents	1
Total	**8**

Table 6.10 : How helpful was the social worker?

Carers' Views

Who helped your relative before the team was set up?	**No. of carers**
Psychiatrist	5
Social workers/care managers	3
In a low secure unit	1
No-one	1
Total	**10**

Table 6.11 : Who helped your relative before the team was set up?

Five carers described their sons as receiving support from a psychiatrist.

> *"Just Dr. B. It was different from [the team]. He used to have a half hour chat with him every two or three months. And it was just talking. I suppose he was trying to get L talking and see what was going on in his mind."*
>
> *"We were going every 3 months. But then we were seeing different people and it was quite confusing. And they were all of foreign nationality and some of them were quite hard to understand. On the last visit, the waiting room was packed. They were running an hour to an hour and a half late. K had to go somewhere. We couldn't wait. "*
>
> *"He had help quite a few years ago. He was referred to the psychiatrist/psychologist...He was making phone calls and one of the neighbours, he put a rather naughty letter through her door about seeing her in a wet T-shirt...then the police were involved .. He had a couple of appearances at court. And then he had to see the forensic psychiatrist*

> *that works with people who are really involved with sexual things, but of a nasty nature. It was at the [local forensic secure service]. He did see a few doctors there for some time and he used to discuss his problems there, but its not the same kind of help that [the team] can give him. "*

Two carers described care packages which the team had enhanced.

> *"He goes to [local] Day Centre. He goes there Tuesday, alternate Thursday when he goes swimming with them. He goes there on Friday because he goes riding. ..They've got a bungalow, down there...When he does go down to the bungalow, a carer goes in twice a day. In the morning to make sure he's alright, he's showered and shaved and got something for breakfast, and evening to help him cook a meal...He does go to literacy classes.." (The referral to the team had led to two days work experience and attendance at a weekly evening men's group).*
>
> *"She goes to Adult Education, three days a week, and she goes to the [project]..., which is a group house, a community project. They all run the house together, so she does that for a day on Thursdays. She sees Sister Francesca on a Tuesday morning because she wants to be baptised."* (The referral to the team had led to attendance at a women's group on Tuesday afternoons).

One person had not received any services at all before the team was set up, and one person had been in a low secure unit. One person had had occasional contact with a social worker and was now in an adult placement scheme with on-going support from the team.

The carers felt positive about the support that their sons/daughters received from the team. They described the team as providing a different kind of service to that offered before. One carer described the difference between support from a psychiatrist and the team as being

> *"..sort off the cuff help, ordinary people, who seem to understand his ordinary everyday problems. They give him support in a different way. There they are and he can phone them up. The other people.. he wouldn't have been able to ring them up and chat to them. That wasn't a priority."*

Another carer described the difference between the service provided by the team and the day centre.

> *"The day centre is simply passing the day. Not to get him into work or get him into accommodation so that he can live independently. The day centre's like ..not a school, not a college, a friendship thing."*

6.6 What would you do if the service closed down?

Service users and carers were aware that the service was a pilot project which was funded for a short time.

Service Users' Views

What would you do if the service closed down?	**Number**
Don't know	10
I would manage	3
They are doing nothing anyway	2
I would ask my care manager for help	1
Total	**16**

Table 6.12 : What would you do if the service closed down?

> *"I wouldn't know what to do. I wouldn't know where to turn"*
>
> *"I don't know – it would be sad really. I know you shouldn't rely on other people, you know, but its nice to know someone is there if you need it."*
>
> *"I don't think that there would be no-one there to help me because [the team] has helped me since, I'd be too upset. I don't want to lose them, because if I did there would be no-one to talk to."*
>
> *"I don't know what would happen do you? Oh dear, wouldn't anyone else come do you think?"*

Of the 10 people who would not know what to do when the service closed down, four had a social worker and one a probation officer. All ten said that they would like to receive a similar kind of service to that provided by the team. Three people thought that their parents would have to help them even though they had a social worker or probation officer, and one person said he would rely on the Samaritans.

Three people thought that they could manage without support from the team.

> *"I suppose I would manage actually."*
>
> *"It's a bit of a difficult question to answer really. I think I would get on quite well. I think I could survive. ..."*
>
> *You know where to go if things go wrong?*
>
> *"I'd phone [team member] up and just say, like she said, if you want a chat just give me a ring and I'll make time to see you. I think I'd get by."*

Clearly the last respondent, although he described himself as being able to cope still felt that he would need the support of the team in the event of problems.

Of the people who felt that they could manage, one was already in receipt of a full support package and attended the women's group to address other issues; the second attended a men's group as a requirement of his probation order; whilst the third had received individual support until his case was closed. He now continued to attend the men's group.

The two young men who were unhappy about the service received from the team had slightly differing opinions. One stated that the team were not offering anything anyway. The other veered between his anger at not being helped sufficiently and the fear of being left without any help at all.

> *"If [the team] were to go, I would have to wait until a replacement was found or struggle on without and grit my teeth, and just try and get through the things I have to do. I thought [they] were going to help, going to make a difference...*
>
> *I thought here it is – people like me won't be left out in the wilderness anymore. We will actually be brought in from the badlands into the community, with the right coping strategies and the right coping mechanisms, the way to deal, to interact, but a year down the line, nothing has been achieved, nothing has been gained."*

Carers' views

What would you do if the service closed down?	**Number of carers**
Detrimental impact on myself and my relative	6
Limited impact on myself and my relative/person I support	3
Little difference	1
Total	**10**

Table 6.13 : What would you do if the service closed down?

Five carers felt that if the service was terminated through lack of funding then it would have a detrimental impact on their sons or daughters, and themselves, because of the lack of alternative appropriate services.

> *"N would just stay in the house and do nothing, so I think that would be soul destroying."*

> *"He would go off the rails. I'm sure he would. I don't know that we could carry on helping him. We would keep an eye on him, but we can't be there all the time....He definitely needs them. It would be a disaster for him. They have never failed us. If we have said anything to them, its always dealt with. I would like them to continue. I don't know what we would do if they weren't there."*

Another carer talking about circumstances before the team was set up said:

> *"L wasn't in [the social worker's] category. He looked after elderly people more. Because L didn't fit the criteria, L was dumped on [the social worker]".*

She felt that if the team closed and L returned to this situation

> *"..it would be going backwards, definitely, because [the social worker] has enough cases as it is. He used to say that before."*

> *"I will probably be in [local] mental hospital, on Social Services and so will N, so that's two of us the health service can support...There is nothing to help these people with Asperger's, absolutely nothing. There's nothing to help the carers and it just escalates. There's got to be a breaking point somewhere and it will start with the carers."*

Of the four carers who felt that the closure of the service would have limited impact on their sons or daughters, two people were receiving access to a women's group which was a time limited series of meetings, one person had yet to receive any substantial service and one person was receiving very low key support because of his reduced needs. When asked what would happen if the team was no longer funded, one carer replied,

> *".the bit about not being funded, well quite honestly , I don't think it would make a lot of difference to E or to me."*

Interestingly two of these carers were paid carers, and one in particular, felt that it would be her role to undertake some of the tasks that the team currently undertook. It is difficult to know whether paid carers felt challenged rather than supported by the team, because, by its very nature, the service was trying to fill in the gaps in the service provided by the paid carers. Some contradictions were expressed by one carer who saw the women's group as a social outing for the woman she supported, but on the other hand acknowledged that

> *"..she has got a lot of things in her life which are really quite painful and emotionally very difficult for her to deal with. I'm not sure that she'll ever come to terms with them really, but maybe talking about them will help her deal with them, and to people that you don't see every day, all the time, that aren't so close."*

6.7 Is there anything else that you would like help with?

Service Users' Views

Is there anything else that you would like help with?	**Number of service users**
No	11
Help with housing	2
More help	2
Keep me company at home	1
Total	**16**

Table 6.14 : Is there anything else you would like help with?

Most people were happy with the level of support and the kind of help they received from the team.

> *"I get all the help I need at the moment,"* (One woman who was in an adult placement scheme and also had mainstream social work support).

> *"I can't think of a time when I've thought oh, they should do this or do that. I can't really fault them."* (One man whose only source of support was the team.)

Two service users did want more help from the team, one because he wanted more of the same thing, and one because he felt he was receiving no help whatsoever.

> *"Talk to me a bit more about relationships, and what I like to do and what I don't like to do, and helping me out more getting this proper job."*
> *"I would like them to sort out my life more than I do myself. ..sort out the colleges before now. They said they were going to sort out the colleges before I moved here. Like I said I shouldn't be here. Why am I here now? When I could be in a place of my own."*

Two people also expressed some concern about the inability of the team to deal with their housing issues.

> *"They do help me in a way, but sometime I feel that they could get things done a little bit more quicker. I know they've got a lot of other people sort of on their books and all that, but a lot of times I go through a phase where I say I hate [them]."*
> *What would you like them to be quicker on?*
> *"Basically just my flat. Since January, when they started with me, I wanted to move out and I felt it wasn't until .. because I moved out of home for three days, with my now ex-boyfriend.. I felt it wasn't until then, which was the end of July, beginning of August, that they didn't really start doing nothing about it."*
> *"..I suppose with my current housing issue, I feel badly let down, I feel hard done by. I feel that they haven't grasped the bull by the horns, they haven't grasped the issue. I mean I had to wait until I was down here for 3 months before C even thought of moving the issue further on through medical grounds. That should be done from day one. That's why I'm on about dismissals and all that lot. In fact, what I would rather have, as you asked what would make me happy, would be for her dismissal."*

One person thought that she would like someone to keep her company at home when her family were out.

Carers' views

The main unmet current need identified by carers was accommodation for their son/daughter. This varied between accommodation and support in terms of moving to more independent living and 24 hour care of some description.

Is there anything else that you would like help with?	Number of carers
Accommodation	6
Information	4

Table 6.15 : Is there anything else you would like help with?

Four carers, all of young men, identified the need for low level supported accommodation, to enable the development of independent living skills.

> *"..If there are things that are around and about that are helpful for K you know, like leaving home. That might be his next step. I'm not pushing him out, but if he wants to leave home and get his own place, he might need help in that area. "*
>
> *"My hope is for N D is that he does get on independent living so that he can be supported. I mean he's never going to get away from me. I would still keep in touch with him. But I know that if something severe happened to me, as it did my wife, then he can live independently, he can be looked after. He will be able to do all the things he is doing now without much worry. And if he can do it while I'm alive, my life becomes much easier and I can, from my point of view, I can then get married which is what I want to do."*
>
> *"I would like N S to be rehoused with a flat of his own, with support, because when I went on holiday for two weeks, his Nan came down for a few days a week. His Nan is over 80. She's not in good health... So I would like him housed, and while I'm young enough so I can oversee him so that he's settled. I would just like my life back."*

Two carers identified a possible need for 24 hour accommodation. One carer suggested this as an option for her son who was refusing to co-operate on an on-going basis with the team and had not yet been given a diagnosis.

> *"He had a test recently for autism, and he doesn't fit in that category. It would be nice to know why he does it. If someone's physically handicapped, you know, you can make allowances for them...I have said to [a worker] about 24 hour care to let him be assessed because the doctors haven't seen him when he's really bad, really disturbed. He drinks and it makes it worse. They have never seen L when he's quite disturbed. They're adamant that there he hasn't a mental illness, but to me, there is definitely something wrong with the brain."*

A second carer had been very keen on 24 hour supported accommodation, because of the nature of the challenging behaviour of their son.

> *"The only thing that we were rather disappointed in, is the fact that he hasn't got 24 hour help as it were. We had vision of him going into protected accommodation, where there would be someone on duty all the time. I don't want to speak too soon, but I've seen a great improvement in him recently and he may not need that."*

Carers also identified their need, both on-going and retrospective, for information. This took two forms – an explanation as to why their son or daughter was behaving as they were, such as some kind of diagnosis (4) and some kind of information on which to try to predict what the future might hold for them and their adult children (2).

> *"I would like to say that I think that there ought to be more talk about this sort of thing. You hear about autism, but Asperger's, what is that, I've not heard of it. Then someone says its just a posh name for autism. I've seen autistic people and they're totally different to[my son]...... Will he go off and get married and have a family life like the rest of us, or some of us do. Things like that."*
>
> *"Right from a very early age, about 8 weeks, he caught whooping cough, and I don't know if that was the start of it. I don't know if its hereditary. No-one can tell me if its hereditary. There are no conclusive answers. Its just one of those things. I'm quite a realist in some ways and I think that if I know or I don't know its not going to make any difference. But not everybody can reason like that. In some ways I would possibly feel happier if I knew it was the whooping cough, rather than hereditary, because I think of my older son, and I think any children that they have,*

> *are they going to go down the same path as me? I would feel better knowing that it was the whooping cough for them. "*

6.8 Life after the service closed down

Interviews were carried out six months after the closure of the service. A total of thirteen of the original sixteen service users were interviewed – of the three who were not seen, one young woman had moved on to residential care and refused to answer her letters and staff refused to act as intermediaries; one young man had disengaged from services, did not have a phone and would not answer letters; and one young man was on remand in prison awaiting trial for allegations of rape. Two of the service users out of the 13 interviewed had moved out of the borough and one young man had been placed in 24 hour residential care in a specialist out of borough placement.

Seven carers were interviewed. Three carers from the previous group of the ten declined to be re-interviewed for the following reasons : - one was very angry with the team for failing to provide a service to her son, one paid carer was no longer involved with the service user as the placement had broken down and one carer agreed to be interviewed, did not arrive and refused any further appointments.

The majority of service users (11 of 13) had positive memories of the service provided by the team. Many service users were positive about the help they received from individual members of the team, usually stating that they felt that they had had good relationships with those individuals. The psychologist, challenging behavioural specialist and support workers were all mentioned as providing a particularly valuable service.

> *"Lots of help from .. [the behavioural specialist]. Someone to talk to. We had a good relationship with each other. Especially [the behavioural specialist], very good…twice a week..oh yes, and [the behavioural specialist] was always on the end of the phone."*

> *"[The psychologist] was very, very helpful and I do miss [the psychologist]. When I need that person to talk to, I do miss her…it was*

> *like seeing someone who was professional but having a nice chat to go along with it…and yet it was so much better, sitting down and having a chat instead of going to see someone like when I used to go and see Dr.X… going to a hospital and having to wait for it and all that…"*

This was validated by the carers' description of the service their sons or daughters received.

> *"He got quite a lot of support from [the challenging behaviour specialist]. Yes [he] was always on the phone. [He] supported him right to the end."*

> *"[The behavioural specialist] offered [my son] support and also support for me, because I could ring up and say [my son's] behaviour has altered and I think there might be something worrying me. Could you talk to [my son] and see if he is okay and [the behavioural specialist] would do that for me."*

For those who had attended a group, in particular the men's group, this was remembered as being very helpful and particularly missed.

> *"The men's group – very helpful. It helped me meeting other people, talking about problems and being open with other people and talking about other people's experiences, hearing about them, so they can talk to someone."*

> *"I was getting on okay with them at the men's group. ..Every single time I have been, but since it closed up I haven't been. They was talking about the sex type of thing in the men's group. It helped me a lot. How to keep your temper, how to work things out, what to do, what not to do."*

The men's group appeared to be particularly missed because of the social aspects that it offered as well as the therapeutic component. Many of the attendees referred to the other group members as their friends, and two of the men had linked up outside of the group, often going out for a drink together.

The two young men who had said that they were unhappy with the team continued to have extremely negative views of the service. When asked what kind of help was received these service users said:

> *"Zilch. Nothing at all. They ballsed up one of my forms, the DLA form."*

> *"Very low support. It was just chatting. There was no real help.. I needed practical help and counselling support, but they were determined, they would chat with you and chat with you, but we can't get down to or solve the problems that are worrying him, so we don't need to worry about what's bothering him."*

One carer who had negative views about the team believed that her son had committed offences as a result of comments that one of the team members had made about him to his landlord.

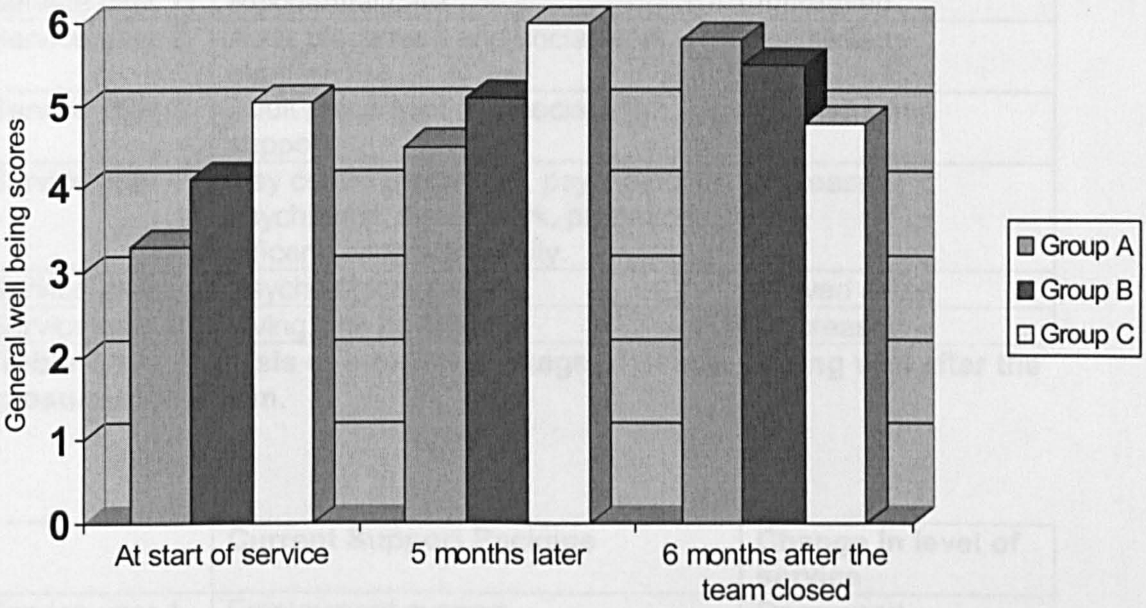
> *"And after [the team member] made that statement to the landlord, he did a lot of damage in that place, and he was charged and brought to court. And before that for quite a number of years, he hadn't been to court, he hadn't been in trouble with the police and things like that."*
> *In addition, she described her treatment by one of the team members:*
> *"[he] said that for personality disorders there was no treatment, and people with that diagnosis, the only future they had was to commit suicide or to be in prison...I'm sure that he will be struck off, because you cannot go round telling the mother of a child that she is ignorant on two occasions."*

6.9 In the wilderness

Following the team's closure, service users received different levels of services and had very different experiences. Some were indeed left to fend for themselves in the wilderness. This section explores the impact of the closure of the team and the services that replaced it.

	Mean	s.d.
Pilot team service users at time 1 (at start of receiving team's help)	4.31	1.7
Pilot team service users at time 2 (5 months later, with team)	5.00	1.6
Pilot team service users at time 3 (6 months after team closed)	5.46	1.7

Table 6.16 : General well-being scores



Group A : service users who received a comprehensive package of services after the team closed
Group B: service users who continued to receive a service from a team member through a different access point
Group C : service users who received no service following the closure of the team

Scores indicate levels of satisfaction with life –1 = things couldn't be worse
7 – things couldn't be better

Figure 6.5 : Comparison of general well-being scores

The mean quality of life scores, measured as general well-being, shown in table 6.16, disguise the variation in individual experiences, particularly after the service closed. This is reflected in figure and shows that although some service users appear to have experienced an increasingly improved quality of life, other service users who were trying to manage with little or no support did not. Those service users who experienced a reduction in services and quality of life also had an increase in challenging and offending behaviours.

How are you coping?	No. of Service Users
Coping well	6
Coping with great difficulty	6
Not coping at all	1
Total	**13**

Table 6.17 : How are you coping 6 months after the team closed down.

	Current Support Package	Change in level of service
Service user 1	Residential care	Increased
Service user 2	Adult placement and social work support	Increased
Service user 3	Adult placement and social work support	Stayed same
Service user 4	Day centre placement, psychologist, psychiatrist, social work, probation officer. Living with family.	Increased
Service user 5	Psychological support	Stayed same
Service user 6	Living with boyfriend	Decreased

Table 6.18 : Analysis of support package of people coping well after the closure of the team.

	Current Support Package	Change in level of service
Service user 1	Employment support	Decreased
Service user 2	Employment support	Decreased
Service user 3	Employment support	Decreased
Service user 4	Probation officer	Decreased
Service user 5	Day centre placement, Prospects, care manager	Decreased
Service user 6	Support worker, care manager	Decreased
Service user 7	Care manager, mother	Decreased

Table 6.19 : Analysis of support package of people finding it difficult to cope after the closure of the team.

From this breakdown of support packages, it is evident that peoples' ability to cope seems to be directly related to the level of support that they were being offered. In two cases where people were not coping well, parents argued successfully for continuation of some of the specialist services that they were previously receiving. Although it had been agreed at senior management level that no-one would be left without a service, this message did not appear to be passed on to the teams and it proved to be quite difficult to successfully allocate people to teams. Evidence collated by the researcher was fed back to key stakeholders in the decision making process which determined the future of the pilot service. However, the researcher had no control over this process. The future of the service was determined mainly on the basis of funding availability and local priorities – this group of people was not one of those. The lack of a safety net in the event of the service closure, or indeed a protocol relating to the transfer of service users to existing services was negligent to say the least. A protocol should have been drafted by the team leader and endorsed across agencies to ensure that the statutory duty of care was met. Service users and carers were given contact letters with details of who to contact when the team closed down. Unfortunately when contact was made with mainstream services following the closure of the team, they appeared to be unaware of any arrangement. There were frequent delays in being allocated to a different service or even being picked up by the same service that had been previously working with the service user. People from both boroughs were left without any services from the care sector. It appears that people who did not meet eligibility criteria but were in need of a service before the pilot team was established, not surprisingly still did not meet eligibility criteria and still needed a service. This had a detrimental effect on their ability to cope and the quality of their lives.

Frequency of challenging/offending behaviour 6 months after service closed	Self-report	Carers' view	Total
No. of people with increase of challenging behaviour	5	5	**7**
No. of people with same levels	4	2	**4**
No. of people with decrease in challenging behaviour	2	1	**2**
Grand total			**13**

Table 6.20 : Frequency of challenging/offending behaviour 6 months after service closed.

Even as early as 6 months after the end of the service, seven out of thirteen services users had experienced an increase in offending or challenging behaviours, including violent behaviours. Of these seven, only one had increased in challenging behaviour during the time that she was receiving a service from the team, and this was when she learnt that the team was closing down. One person who had the same level of challenging behaviour during and after receiving a service from the team, subsequently restarted his offending behaviours shortly after the 6 month period and it is likely that he was actually offending at the time of those interviews but chose not to disclose this. One person, who claimed that his levels of challenging behaviour had decreased, had actually increased his offending behaviour during the time that he received a service when he learnt that the team was going to close. He subsequently received a more substantial care package from mainstream services following his offence and subsequent family move out of London.

Kind of employment	**Whilst receiving a service**	**After the team closed**
Supported employment	1	1
Mainstream paid employment	3	1
Casual labour		1
Work placement (therapeutic earnings)	1	1
Sheltered employment	5	1
Total	**7**	**5**

Table 6.21: Number of people in study group in employment.

Only five out of the sixteen people in the study group were in some form of employment, and these were all men. People with learning disabilities have the lowest employment rate of all disabled people, so this is not unusual. Three men (Mr. BS, Mr. JQ and Mr. NS) had ordinary jobs. Mr. KS changed employment himself during the course of receiving the service with minimal support from the team.

After the service ended, there were some changes in the work pattern of the study group. There were still five people in some kind of employment, and they were all male. Only Mr. BS continued to hold down an ordinary job. He was still receiving the same level of support as he was when the team was running. Mr. JQ and Mr. NS had resigned. Mr. JQ decided to resign from his ordinary job because he could no longer cope with the hostile environment at work without the support of the team: he was currently looking for further employment. It was unclear whether Mr. NS had resigned or had been sacked because he was no longer meeting the requirements at work: he was currently attending college. Both of these men were experiencing difficulties and were finding it hard to cope. Neither had received any input from statutory services since the team had closed. Mr. NS reported increasing difficulties at college and his carer reported increasing levels of challenging behaviour at home. Mr. JQ subsequently went on to commit another offence on gaining another job.

Mr. KS was in supported employment and had changed his job since the team closed down. He had been made redundant from his previous job and was now being supported in employment by a job coach. He was not coping well at all with the stress of the new job and his challenging behaviour was increasing.

Mr. MN was offered an extremely comprehensive care package after committing an offence when he heard that the team was closing – this included a full-time placement at a day centre/sheltered workshop where he did woodwork. Another young man (Mr. TS) was currently doing some casual work for an uncle.

Employment was extremely important to some of the young men, who desperately wanted to work in full-time ordinary jobs. It was also important to one of the women, Ms. TG, who was actively trying to set up her own dog-walking service. She had previously had a temporary ordinary job which she had had to leave because she could not cope with the stress. She had no input from services after the team closed down but was in an extremely close and supportive relationship.

Although peoples' employment circumstances changed during the time that they received the service and afterwards, there were no substantial changes overall to peoples' satisfaction with employment (see Appendix 20). This is likely to be because of the differing employment aspirations and opportunities available to people, the small numbers in the study and the length of time that the service operated.

For this group of people, employment was not a stabilising influence, but rather presented another set of circumstances which they found extremely hard to deal with. When work went well, it did enable people to feel more positive about themselves and their lives. However, for most of the people, most of the time, employment presented an environment full of challenges and difficulties that they needed support with. When that support was not available, they began to fail with disastrous consequences.

Many people did not have close relationships. Mr. BS was in a relationship and said he was planning to get married, throughout the time he received a service and after the team closed down. Mr. US was in a relationship with another disabled woman who he serially abused – the pilot team also offered her a service. She finally left him. Ms. TG was absolutely desperate for a relationship and finally met someone who was extremely supportive shortly after the service closed down. This certainly impacted positively on Ms. TG's life and she no longer engaged in behaviours which put her at risk.

The women in the study group were an extremely vulnerable group of women, and the younger women certainly wanted to engage in relationships. For one of these women, this had led to her being sexually exploited on a number of occasions.

Many of the men also wanted to engage in relationships, but the majority had difficulty in developing relationships of this kind and four of the men had a history of sexually offending against women.

Mr. ND attempted to enter into a sexual relationship with a woman from his day centre some time after the pilot team had closed. This had disastrous consequences with the police being called by the woman's family and the subsequent separation of the couple. Mr. ND did not understand why any of the consequences happened and was very confused by the turn that events had taken. He wanted to talk about it, but he felt that there was nowhere for him to do this despite him having a full package of support. He had previously discussed these issues in the men's relationship group which had closed down along with the team.

Most people lived at home with their parents throughout the course of the study. Most of the parents defined themselves as carers for their sons or daughters, although in three cases, the families were the recipients of the challenging behaviour. In one case, this led to Mr. LC becoming homeless as his father refused to have him back in the house. He subsequently ended up in an out of borough specialist residential placement. In most cases, families struggled to try to positively change the behaviour of their sons or daughters and needed a great deal of support in doing this. In one case there was some concern that the challenging behaviour of one young woman was the result of abuse that she suffered at home.

	Living situation at start of study		**Living situation after team closed**	
	Men	**Women**	**Men**	**Women**
At home with parents	8	2	6	
At home with siblings		1		
Residential care			1	2
Adult placement scheme		1		1
Prison			1	
Living independently	3	1	3	2

Table 6.22 : Living situations of service users

Changes in living situation	**No. of people**
Living situation became more independent	1
Living situation became less independent	5
Living situation stayed same	10

Table 6.23: Living situations at beginning of study and after team closed

Accommodation was a major issue for both service users and carers. Service users were consistently unhappy with their accommodation throughout the study and most wished to move (see Appendix 21). The above table shows a slight move towards more restrictive environments for some people without the support of the pilot team. For this study group, accommodation changed as a result of peoples' behaviour – i.e. it became more restrictive or less independent as a result of perceived increase in challenging or offending behaviours. Unfortunately, because of the lack of suitable accommodation with support, people who had decreasing levels of challenging behaviour or those who simply wished to move away from the parental home, were unable to do so. This was partly due to the lack in available supported living services for this group of people at the time and partly due to the way in which the team was set up. The team was unable to buy in suitable accommodation of this nature because of the budgetary restrictions on the team, nor were they able to link into existing mechanisms for either strategically highlighting this issues or for accessing individual placements. This role fell to already existing services.

Of those who had the same living situation at the end of the study as they had had at the beginning of the study, three people living with parents were already experiencing problems which could jeopardise them continuing to live at home. One woman was also experiencing problems living alone and had applied for a larger flat so that she could move back in with her mother.

Only Ms. TG, was living in a more independent situation at the end of the study, 6 months after the service ended. She had formed a positive and supportive relationship and had moved out of London with her boyfriend. Mr. KN had lived in his own flat with support from the team, his family and importantly, a support worker paid for by the team for some time. Following the disclosure of the plans to close the team and the loss of his support worker, this man deliberately reoffended. He was placed on the Sex Offenders register and as a condition of his probation order, moved back in with his parents. As stated earlier he was currently in receipt of a comprehensive day care package.

The following stories tell what happened to the four people whose interventions were described earlier.

Ms. OJ

Ms. OJ had received a service from the team up until its closure, including the women's group, help with leisure activities from the support worker, individual sessions with the psychologist and occupational therapist and support for her father, who was her main carer, from the challenging behaviour specialist and the team manager.

"They just come round and helped me, that's all. And if Dad's got a problem they would sort that out for him."

She now had support from a care manager who worked part-time and some hours from a support worker.

Life had been very difficult for her since the team closed. She described things as:
"Its gone pear shaped. It all started when things got worse and I walked in there and punched him [her Dad] right in the face, punched him, because he hurt me too many times and I wasn't standing for it. I was quite pleased when I done that. Got a knife and put it to my throat. Threatened to harm myself..and gave her [the social worker] the knife and I was pouring out with tears ..ran into my Dad, and I just punched him one."

Following the incident she described, Ms. OJ left home and her care manager had been helping her find accommodation.

"Basically I have had 5 addresses since September [one month]. They moved me to one address then another address. I'm just confused."

She had also been in trouble with the police.
"Smashing windows. Don't care and don't want to know. I'm on my last warning – criminal record. They needed a statement from me. So I did wrong, didn't I?"

Some months later, Ms. OJ was arrested for possession of a knife and was remanded to Holloway. She was convicted and placed in a medium secure unit.
"I've had a few run ins with the police. I don't give them the time of day no more ...just about silly things. I've been given a couple of cautions."

Mr. NS

For Mr. S, when the team closed down all support ended. However as a result of his mother campaigning, he had been reallocated the challenging behaviour specialist for a temporary period. Mr. S. had previously received a service from the challenging behaviour specialist and had attended the men's group. His mother said:
"When [the team manager] actually came and told us that it had closed and we would not be receiving a service, it was horrendous for the next few weeks, because [my son] had deteriorated and his behaviour pattern had deteriorated, and I flew around between my GP and Social Services, trying to get some sort of service for him. .What did the GP do? Referred him to the CAT team. Didn't hear anything for 3 weeks and [my son's] behaviour was unacceptable, disturbing me of a night, being abusive, and I met one of my friends. She took one look at me, and said you need to get down to Social Services while you are like you are now. ..I plonked myself down at [the Social Services office]..she also did a profile of him..and I plonked that on Social Services desk, and said that's what I'm living with. I need help. I need support. So does my son....and they turned round and told me I can't have a social worker, because they don't deal with young autistic, they only deal with the elderly. I had a phonecall from [the challenging behaviour specialist] to say that a letter had got round to the adult learning difficulties team regarding [my son] and that was from the GP. But we're talking another 3 or 4 weeks down the line. Then I was told that they were willing to take him on although they are not geared up for mild learning difficulty..in view of the fact that [my son]was in receipt of a service and there was nothing available to him now..but the input [from the challenging behaviour specialist], which is all I require will finish in December [4 months], and then we will be back to square one."

Mr. S. described the service he had received as "general advice really." Since the team closed down his life had been:
"Okay actually. Some good and some bad. I think I definitely need help. I just get things wrong. There have been a few incidents since [the team closed]. Misunderstandings and things like that. I've said something that means different things and you get a written warning [from college]and you don't know why."

Mr. LC

Life had improved for Mr LC who had also offended whilst receiving a service from [the team] and was now on a probation order. He was currently in an out of borough specialist residential placement for people with challenging behaviour and had moved there two months after the closure of the team. Overall, neither L nor his mother found the team helpful, referring to times when they had requested assistance which had not been forthcoming.
"From late last year when [my son] went to G...., he wasn't getting any service from them. You know, they washed their hands of him. I used to ring them up and tell them how low he was. On several occasions I told his social worker that he needed 24 hour care..nothing..In January, [my son] was very low, I asked the team manager for respite. And he said no, they didn't have any money for that."
Subsequently her son had received respite care on a first request from the assertive outreach team.

"It was difficult, I was expecting them to help, as it was this pilot thing, with specialists from different departments. I thought yes, hurrah, I'm going to move on with my life, but they were there for nearly two years...."

As stated earlier, both Mr. LC and his mother claimed that he had committed an offence as a direct result of unprofessional comments about him by a team member to his landlord.

Following the team's closure, *"Well for most of June to the end of July, I found myself unsupported, I found myself homeless for a month and a half, I found myself in bed and breakfast. I found myself getting money by dodgy means for bed and breakfast charges and food and other things I needed. One day I basically had enough. I just went to Social Services and I said could I speak to someone who is in charge .. and I was met by the boss, the top man ..for mental health services. I wasn't clean shaven. I had just over a week's growth of beard. I stank and smelt absolutely rotten. I explained that I was sleeping on the streets, How they had done nothing for me, only exacerbated my problems, made my problems worse, they didn't address any of the needs that I had, and I found myself very frustrated. At the end of the 10 minute chat that we had, he said I'm going to do something about this.."*

During this period, he had also been arrested for breaking into a football ground to sleep.

Mr. LC was eventually accepted by the assertive outreach team who assessed him, provided him with respite and placed him in residential care where he was receiving help with anger management, budgeting and building up his self confidence. His mother had had to fight to obtain a service for him. *"When [the team] were folding up they referred him back to [his social worker], and he was very honest and said there was no point taking [my son] on ...they had no funds available and there was no help they could give him. .I spoke to his boss... I rang him up ... and said please could there be respite for L...and he said no, there was absolutely nothing available."*

LC said : *"I was just someone who was like ..help me, help me, help me, I need a place where people can do the worrying and I can, not take it easy, but I can* *get on with sorting out my life. I can back out there into society, living the life, not that I want, but how I'm able to."*

Both mother and son were happy with the services that they were receiving now, his mother describing his new placement as "heaven." Her son said *"..I find myself saying that there is a life, whereas earlier this year, I just wanted to end my life."*

Mr. JQ

Mr. JQ had received support with interpersonal difficulties in his employment, support with dealing with his inappropriate sexual behaviour and had attended a men's group. His case had been closed but on the understanding that they could return to the team if they needed to. When the team closed down he was not referred elsewhere. He had encountered significant work related problems which he was struggling to deal with. He had support from a specialist employment project and the DEA.

Mr. JQ had handed his notice in to his job of 8 years.
"At the end of September, I just couldn't handle it any more and I said enough is enough I'm not working for them anymore for anything."
His parents added
"We used to try and encourage him to keep the job going for as long as possible, and then in the end when he was saying about he was going to throw himself under a bus, we took these threats quite seriously. So we said we'll support you, give this job up, and I think that's the time he would liked someone to speak to from [the team]."

Mr. JQ had continued to ring the team although he knew that it was closed and had tried to overcome his isolation and obtain support by ringing the Samaritans 53 times over the period of 3 months leading up to him handing his notice in.
"I've no one to contact and I'm not in contact with anyone."
His parents said..
"53 calls and even [my son] couldn't believe he'd made that many calls. So come back [the team]. I mean I'm sure he wouldn't have made 53 calls to them. I mean every 5 minute call or ten minute call would last him a fortnight if he was down."

Mr. JQ managed to obtain another job, and continued to phone the Samaritans. A year after the team closed Mr. JQ made an obscene telephone call to his workplace resulting in the loss of his job. His offending behaviour escalated.

There appear to be four main kinds of unmet need which people were often still experiencing following the closure of the team even where they had access to other services:

1. individually tailored expertise, in particular access to a psychologist or challenging behaviour specialist

2. individually tailored practical support packages which enabled both an increase in independent living skills and access to mainstream facilities, including employment
3. therapeutic input of the kind provided by the groups on relationships, particularly sexual relationships and anger management
4. a whole team approach to providing a service for people with highly complex needs who were extremely vulnerable so that an immediate response to someone does not depend on the service user's case worker being available.

For many people then, the team appears to have provided a unique and apparently irreplacable combination of support which enabled people to develop skills in order to cope with everyday life.

> *" ...when the team opened, it took them a while like with any clients, but in a very short time, those clients, the difference in anyone of them..well, it was like a miracle. Peoples' lives and ....parents ..were a misery. Then all of a sudden the team comes along and it was nothing short of a miracle."*

Chapter 7

Study 1 : Discussion

7.1 Reliability and validity

Much of the data is based upon self-report by service users, and at times the self-report was somewhat inaccurate. Many of the service users interviewed were extremely skilled at presenting a picture which they thought was the one that the researcher wanted to hear. Thus negative experiences, such as crimes, were underrepresented and positive experiences, such as numbers of friends were overrepresented. This is not to suggest that the group of service users interviewed were lying but rather, that given the level of contact with services and the general disempowering experiences that people had endured, for better or worse, the service users had developed a set of survival skills. These included making their lives seem as ordinary as possible, and telling stories which were enough to keep professionals interested, but not so accurate as to threaten themselves. It was felt that service users were more likely to provide a more accurate description of their lives as a relationship was developed with the researcher, although this was not always the case. In some circumstances, because of the nature of the some of the service users' impairments, e.g. Asperger's syndrome, there was a different understanding of the impact, if any , of their actions .

Although users' views are reported faithfully here, the positive slant that people put on their lives needs to be borne in mind, together with the positive regard that personal services attract regardless of the quality of the service (Mansell and Ericsson, 1996). This is not to say that the information given was invalid.

It is also fair to say that for many participants there may also have been other agendas when taking part in the study. A small minority of carers had mental health issues and cognitive impairments of their own and were skilled in dealing with services – some of these sought to mask the chaotic nature of their own lifestyles and to blame their son or daughter for the difficulties they encountered.

Professionals, too, may have had agendas in that some external professionals may have felt that they were devalued by the creation of a team to deal with a group of people that they felt they were already working with and may have been overly negative in their portrayal of the team's work, in particular eligibility criteria and referral processes. Team members also may have wanted to reflect the team more positively in order to gain additional funding and be part of a success.

Whilst all these themes run through the description of the service, the views reported show considerable overlap in the views of service users, carers and the information reported by various professionals on files in terms of the positive impact of the service on peoples' lives, and its strengths and weaknesses.

7.2 Methodological Issues

Evaluating the team proved to be extremely difficult. When the team was set up, no consideration was given to establishing a baseline assessment of peoples' social functioning, risk levels or challenging behaviour which would have been expected in a pilot team. The research began approximately a year after the service started, so this made it difficult to measure the impact of the service on peoples' lives from a "before" and "after" perspective. This was further complicated by the often complex negotiation needed for the team to establish when it was appropriate to introduce the researcher to the service users due to the sensitivity of on-going therapeutic work. Thus the first set of QOL questionnaires took place at widely varying points in the time during which service users received a service and the first measures therefore represent the quality of life of that service user at that particular time rather than a true baseline.

It was anticipated that these difficulties may have been overcome by requesting staff to complete HONOS and Life Skills Profile checklists to measure improvements in behaviour and skills during the time when people were receiving a service. These checklists were used in other assertive outreach teams as they

> *"..were considered easy to complete and did not present a great burden for the team.."* (Tasker, 1999, p.11).

Nevertheless, staff failed to complete these checklists despite many reminders.

A retrospective file analysis was undertaken to try to evidence the work of the team. File entries were validated by cross checking with all other involved agencies during the time that every service user received a service from the team, but team records were poor. There was a lack of quality and consistency in much of the information recorded by some team members. Many decisions regarding assessment and intervention were made at the team meetings – these decisions were rarely recorded on the service users file or even minuted. Contacts were under-recorded: telephone messages remained in a note-book and were not always recorded on files. Reviews and case-coordination meetings were also often not recorded.

Record keeping was so poor that it was even difficult to establish how many referrals the team had received and how many people the team had worked with. The researcher was often handed lists with names on, with the team at one point claiming that it was working with 40 people. However when a file analysis was undertaken this could not be evidenced. There were also claims that 97 referrals were received. There were no files to back this up. Given that these larger numbers were circulated at the time when the refunding of the service was being discussed it is likely that the definition of "referral" and "working with" was defined extremely widely in order to justify the team's continued existence.

As the team was a new team piloting a different way of working, there should have been a clear operational policy, drafted from the very start, specifying how the aims and objectives were going to be achieved, measured and monitored. This would have enabled more robust evidence to be given to commissioners at a stage where the funding of the team could have been guaranteed. Unfortunately, although there was substantial evidence in the form of users' and carers' views, there was not enough hard evidence because of the factors outlined here of the development of skills and reduction in challenging behaviours to convince key stakeholders to refund the service.

7.3 Aims and objectives

The aims and objectives did not refer to learning difficulties or mental health needs. This together with the lack of definition of low social functioning, which appears to have been interpreted by some people as social isolation, seems to have led to an interpretation of the aims, objectives and target group of service users which varied from professional to professional. It is of no surprise then, that when the first round of referrals were rejected with a standard letter stating that the referrals did not meet the eligibility criteria, but not explaining how the eligibility criteria were not met, that a certain degree of frustration and confusion about the work of the team was caused. The cause of rejection for most of these referrals was that people were in 24 hour staffed residential placements either in or out of borough – a criterion that is certainly not explicit in the aims and objectives. This lack of focus about the target group also led to expectations in some cases that the service would bridge every gap or that the team did not work with the kind of people identified as most in need (when in fact it did) and subsequent criticism arose when the team failed to accept referrals that other professionals thought were appropriate. Because of the misconception about the exact nature of the target group, some professionals did not make referrals and therefore continued to feel that the team was wrongly focused.

It is also rather strange that although the aims and objectives of the team refer to offending behaviour that this was not mentioned in the leaflet for referrers and in fact, the team would only accept referrals from the probation service, and not from other parts of the criminal justice system.

There is evidence that eligibility criteria need to be clearly defined in order for new services, such as assertive outreach teams, to receive appropriate referrals (Morgan, 1999). Assertive outreach teams should work with the most complex and hard to engage people, and in order to achieve this

> *" clear referral information, of inclusion and exclusion criteria, needs to be established and communicated throughout the area service to all potential referring agents."* (Morgan et al 1999 p. 5).

Slade et al (1997) found the lack of a consistent definition of severe and mental illness across 20 government departments, professional bodies and user groups in England and King (2001) also found two differing definitions of eligibility criteria in operation in a study of a mental health team – one based upon clinical diagnosis which allowed the team to gatekeep and manage the flow of referrals, and one based on a more holistic definition which enabled the team to offer services to those who they felt would benefit.

From the experience of this pilot team studied here, it would seem that the original definition of the target group was too broadly defined and needed to be made more specific. This was recognised by the team and the steering group and some refinement happened through a stakeholders' workshop in 1999 and discussion at the steering group in 2000 to which the team reported. Specifically the exclusion criteria around mental health and the definition of challenging behaviour were made explicit. Unfortunately little of the information agreed was cascaded down from key stakeholders and members of the steering group to operational staff so further resentment was caused when a leaflet and a promotional "tour" seemed to further limit opportunity to refer to the team in 2000.

This lack of clarity around the role and purpose of the team, together with the suspicion which setting up a new team, particularly one of experts, may engender as "any new provision implies some deficiencies in current practice" (Burns and Guest, 1999), led to the team working in a fairly hostile environment. This was certainly not helped by the lack of clarity and information from the team. It also appears that some people did not support the creation of the team, possibly thinking that the resources should have come to their service. This seemed to influence their perceptions of the team, resulting in extremely negative views.

How could it have been different? The history of the team shows that there were problems recruiting a team leader. This person is clearly key in leading on the setting up a service. A lead person was temporarily seconded into the team and began establishing the framework for the team, but this did not appear to be carried on once the team leader was appointed. The experience of the Birmingham assertive outreach team is helpful in looking at how a team may be set up more successfully (Tasker, 1999). The team leader was recruited five months before the team began to provide a service. This team leader worked closely with local stakeholders to:

- Establish the framework for the operational policy

- Hold planning meetings with statutory sector services, voluntary organisations and user/carer organisations to agree staffing levels and composition, day-to-day management issues and operational procedures
- Liase with other mental health teams to identify potential referrals
- Familiarise staff from other teams with referral procedures and how the assertive outreach team would integrate with other services .

• **Aims and objectives of the team**	• **Principles of a team approach**
• Target population	• Relationship to other functional teams
• Referral criteria	• Specific measurement of change/outcomes
• Staffing composition of the team	• Training/induction programme
• Core tasks/focus of the team	• Health and safety policy

Table 7.1 :The framework of the operational policy in the Birmingham ACT
(Tasker, 1999, p.4)

Because of this development work, there was clarity about the nature of the target group of the Birmingham service and all 60 referrals were accepted. There was also clarity and a shared understanding about the focus of the team and how it fitted into the service structure. What is also noticeable about the setting up period is that in Birmingham, unlike the pilot team in London, attention was given to ensuring that the team had shared philosophies and ways of working, established through staff training and clear policies and procedures.

Team	**No.of referrals**	**% unsuccessful referrals**	**Time period**
Pilot team	88	60%	2 years
Tulip assertive outreach team*	122	41%	2 years
Support and Management Team (SAM)**	13	23%	3 months

Table 7.2: Comparative analysis of referrals to teams
(Sources: *Gauntlett et al , 1996, p.54; **Bridgen, 2000,p.2)

A comparison of referrals to what could be broadly called assertive outreach teams shows that the Birmingham experience of 100% success in referrals is not a common experience. The above table compares the rate of unsuccessful referrals between the pilot team, Tulip (see Appendix 22)– a newly set up assertive outreach team, and SAM (see Appendix 23) – a new specialist health team for people with challenging behaviour and learning disabilities working across two boroughs. Only SAM does not have an open referral policy. Referrals to SAM had to be agreed by the community teams for people with learning disabilities and supported by three professionals. This should have enabled the rate of unsuccessful referrals to be minimised. Of the unsuccessful referrals to Tulip, just over 24% were rejected because they did not meet the eligibility criteria. The remainder were withdrawn for other unspecified reasons (Gauntlett et al, 1996, p. 53). Interestingly 23% of referrals to SAM also did not meet the eligibility criteria. The pilot team studied here rejected 60% of referrals because they did not meet the eligibility criteria and this does support the view that there was a lack of shared understanding around the aims, objectives and interpretation of the eligibility criteria amongst key stakeholders, potential referrers and the service providers themselves. From the experience of the pilot team, it would appear that the essential components to a shared understanding would include consistent and clear (i.e. non-changing) eligibility criteria; consistency in the interpretation of those criteria and to a lesser extent stability in staff composition of both referrers and the team given that referrals tend to be based upon professionals' shared knowledge (Marriott et al 1996, Clemence, 1998).

7.4 Inputs and Processes: Was the pilot team an assertive outreach team?

The team appeared to operate on a loose assertive outreach model in that the team had small caseloads, worked with the service users on their own territory, offered a range of interventions and had one point of access to the team. However there was a degree of deviation from a pure assertiveness outreach model which may have impacted on the effectiveness of the team. In addition, the team encountered, and were unable to overcome, many of the obstacles to multi-disciplinary team working identified by Cutler (1998) e.g. lack of shared philosophy, formation of internal cliques, ill defined operational policy and lack of leadership.

(i) Difficulties in establishing a team approach.

The main differences between a "pure" assertive outreach team and that of the pilot team arose from the skill composition of the team and the part-time nature of many key people which had a direct impact on developing a team approach.

Generally speaking assertive outreach teams are composed of professionals from multi-disciplinary backgrounds, but often those specialisms are secondary to being a team member and offering a similar service across the team. This was clearly not the case with the pilot team where professional expertise was valued and clear roles maintained for some team members. For others there was a high degree of confusion about their role within the team and this led to lower scores overall in terms of role clarity compared to the Tulip assertive outreach team (Gauntlett et al, 1996).

	Personal Role Clarity	
	Mean	Std. Deviation
Tulip team	29	3.7
Pilot team	19.2	2.9

Table 7.3 : Comparison of personal role clarity scales

The composition of the team was revised after about a year of operation following the departure of some key team members, with an expansion of the challenging behaviour specialist role and the recognition that there was unmet need for psychiatric and particularly psychology input. In many ways the composition of skills that the pilot team were striving for pre-empted government guidance about the kind of skills an assertive outreach team should have. There were also real dilemmas about the role of the social worker and the nature of the relationship of the team social worker with the borough's social workers and case managers. These issues led to friction between the team and the mainstream services within which it operated. Referrals were made to the team often on the understanding that the team offered specialist clinical expertise and when this appeared to be lacking because of capacity issues there certainly was a feeling that the team was either limiting the work it offered or failing to provide the service that was anticipated. The confusion around the role of the social worker in particular encapsulates the lack of "fit" between the new pilot team and already existing services. The argument about where responsibility for key social work tasks lay adversely affected both the service provided by the team and the perception of the team. These difficulties actually created the opportunity to develop protocol for the future and enhance shared ways of working but these were ignored, and resentment between the team and main services developed instead. Morgan et al (1999) recommend the maintenance of a whole system approach to meeting the needs of people who receive a service from assertive outreach teams. Based upon the actual experience of setting up and delivering services, they identified three main ways of doing this :

- Developing clearly established criteria and operational policies for assertive outreach teams *in relation to other parts of the service,* including how service users may move across services according to changing needs
- Involving representatives from other parts of the service in the development of the team and it impact on other parts of the service, e.g. changes to referral criteria
- Developing mechanisms such as networks to promote partnerships across sectors and agencies.

The focus on professional roles and the use of experts had two main effects – the development of a professional hierarchy within the team and limiting the amount of service which could be provided. The development of an assertive outreach team with only one outreach worker clearly limited the amount of support that the team could provide in terms of basic support. During the life of the team various allegiances based around professional expertise developed and different team members felt that they were left out or that their role was not valued. Professionals very much worked alone in terms of their intervention although it would be inaccurate to say that there was no team working at all – indeed a small group of people providing an extremely competent professional service formed a tight knit team within a team, and it was this "team within a team" which delivered most of the interventions and struggled to bring some order into the chaos of the larger team. The whole team appeared to have been stuck at the pre-forming phase throughout its life as the team manager did not have the skills to deal with team development (Tuckman 1965, Major 2002).

Major (2002) suggests that teams which have not gone through Tuckman's steps have no sense of alliance or identity with the team resulting in such consequences as ill health as a result of anxiety and stress, a sense of disagreement and hostility and extreme dissatisfaction. The pilot team scored extremely low scores in team identity when compared to the Tulip assertive outreach team. Some of this may be reflected in the record keeping which significantly deteriorated towards the end of the team's existence. Team members left in the early days because of changes in improved personal circumstances. Team members were leaving or wished to leave, towards the end of the team's life because of difficulties within the team, such as frustration with the lack of leadership, rather than knowledge of the closure of the team. The lack of a coherent team identity limited the development of a whole team approach – one of the core concepts of an assertive outreach team.

	Team identity	
	Mean	Std. Deviation
Tulip team	37	3.5
Pilot team	27.2	2.9

Table 7.4 : Comparison of team identity scores.

Interventions were initially quite uncoordinated even at a diary level, so that on one occasion different team members visited the same person on 4 occasions during one day and then had no contact for weeks. Team members from the "team within the team" subsequently decided to develop case co-ordination meetings which would help plan interventions with service users. These meetings could be called by anyone working with a particular service user. In assertive outreach teams this function would be facilitated by a combination of daily handover meetings and keyworker led meetings (e.g. Burns and Guest (1999), Tasker (1999), Gauntlett et al (1996)). This would have been impossible in a team composed of part-time workers where the staff team were only present for one day a week.

(ii) Case co-ordinator

Following on from the case co-ordination meetings, the team leader decided to develop the role of case co-ordinator. This role was not the same as that of keyworker within an assertive team. In assertive outreach teams, keyworkers co-ordinate and participate in interventions and organised reviews. All service users know who their keyworker is. In the case of the pilot team the co-ordinator may have not been involved in providing a service and because of this did not have any influence in the development of interventions. As there was no policy guiding the frequency of reviews, reviews were held at different frequencies based upon professional opinion. It would have been difficult for the case co-ordinator to determine when the review should be held if he/she was not directly involved in providing support. The role of case co-ordinator was never really fully developed and team members often did not know who was supposed to be co-ordinating who. It is likely that this was because some people did not have a case co-ordinator. This led to confusion within the team as to who should lead on reviews and subsequent criticism that reviews were not held appropriately by both team members and external professionals.

Despite the number and length of team meetings, the small number of cases and the small size of the team, team members clearly identified the need to develop focused communication and planning tools to ensure that a good service was delivered. Interestingly, it was not the team manager who led on this development but team members who took it on as an additional duty in order to fulfil their professional responsibilities. It was also a team member who led on identifying service users' case co-ordinators and planning review dates.

(iii) Leadership, management and supervision

The main focus of the literature on assertive outreach teams has not been the team leader but rather the team members. However, Navarro (undated) states that

> *"..[t]he ultimate responsibility for practice decisions, allocation of tasks, management and direction in any team is the manager's. The manager will track the work and coordinate the service by using the potential of the Team Approach to its fullest. This will include highlighting workers' strengths and weaknesses both in individual supervision and in a group setting – ensuring that training and development for individuals and the team is ongoing and appropriate to the service needs. Part of the manager's responsibility is to enable the team to have a space to think creatively about the care of the client and the direction of the service. This will be facilitated by group clinical supervision and the planning and development of aims and objectives."* (Navarro (undated) p. 3).

In addition Hemmings (1999) identifies staffing issues as being crucial to the success of the team:

> *"Assertive outreach requires quality leadership, clearly defined duties and expectations of staff.."* (Hemmings (1999) p.145).

One of the most striking factors about the way in which the team operated in this study was the consistent failure of the team leader to fulfil any of these functions.

The team leader was not consistently managed by one professional for the early life of the service but received consistent supervision from the Trust service manager for over 15 months. This would have been an excellent opportunity:

- to ensure that the pilot team linked into the range of services currently being provided and
- to ensure representation on commissioning and service planning groups.

Unfortunately this did not happen and the team was never properly integrated into the service structure, something identified by Lowe(1996) and Hemming (1999) as being vital to the development of effective teams. This made the service extremely easy to close down as it was never really seen as part of an integrated range of provision.

The team leader also had limited managerial responsibility for the team. Moss (1994) identifies management supervision as an essential feature of professional work and necessary for all members,

> *"..so that the work of the team members may be aggregated and directed."* (Moss, 1994, p.172).

This lack of supervision makes it hard to identify what model of team, if any, that the team might fit into (e.g. Ovretveit 1993) and suggests that in many ways, the team was a team in name only.

Management supervision would have been an opportunity to ensure that there was consistent practice across the team in terms of roles, processes, timescales and philosophy and that there was a coherence in understanding and meeting the aims and objectives of the service. Given that there were no policies or procedures for much of the team's life and that the team manager did not even have job descriptions for team members there was a huge need for supervision to ensure consistency. This was not provided within team meetings which appeared to be the main vehicle for doing this, and contributed to the low levels of team role clarity experienced within the team (see table 7.4) and the low levels of identification with the team.

	Team role clarity	
	Mean	Std. Deviation
Tulip team	28.4	4.2
Pilot team	18.1	4.9

Table 7.5 : Comparison of role clarity scores.

Ovretveit (1993) states that multi-disciplinary teams need leaders to achieve their collective purpose and that team leaders derive much of their authority and direction from policy. In the pilot team, the team leader was responsible for writing the policy and ensuring that the team worked in a consistent way. It took the team leader well over a year to draft some of the operational policy and the team closed down before the policy was completed. The lack of a clear risk assessment policy and consequent management plans for a group of people with complex needs, high levels of challenging behaviour and forensic histories was negligent to say the least.

The team leader also appears to have created much of the confusion and chaos which existed within the team by abrogating his managerial responsibility and pushing operational and managerial decisions back to the team through team meetings in an unstructured way – this meant that everything was up for discussion and that there was no clear point when a decision was made, if ever. Onyett and Ford (1996) and Lowe (1996) distinguish between a “democratic” team where team members participate in decision making and decision making based upon consensus which is time-consuming and ineffective. The model operating in the team was the latter. The team manager also failed to represent the team adequately with external services by both not attending the appropriate fora or by misrepresenting or giving confused messages about the work and value of the team.

(iv) Interventions

The team did operate a fairly intensive service, but at the average of 3.3 visits per month (average of total number of visits for first and last 6 months of the service) fell short of the level of interventions usually provided by assertive outreach teams. Burns and Guest (1999) suggest that in Britain this is an average of 2 contacts a week. Tasker (1999) suggests that it could be up to 2 contacts a day. This level is also less than the frequency of contact of intensive case management in the UK700 trial which was 4.4 visits per month (Hassiotis et al, 2001).

It is difficult to say why there was a comparatively low level of contact, as the team had a minimum of 3 full time workers plus 6 part-time workers throughout its life. One full-time worker (team manager) and one part-time worker (administrative assistant) did not provide interventions. The remainder (approximately 4.5 fte) held a caseload of 25 between them – i.e. a caseload of approximately 5.5 each. This is a much lower ratio than that of 1:10 in most assertive outreach teams and 10 –15 in the UK700 trial. Even taking into account the group work that the team supported, one can only surmise that the nature of the contacts and the kind of need that service users had led to a lower frequency – there is a difference between the basic level of support provided by assertive outreach teams such as assistance with daily living or budgeting, and the more intense service which was often provided by the pilot team, such as cognitive therapy. In some cases, joint visits were made in order to ensure the safety of the workers, and this too would have impacted upon the number and frequency of contacts. However, it is likely that assertive outreach teams would also provide joint visits for this reason. The extremely long team meetings and the need to co-ordinate case work through informal and formal smaller meetings may also have contributed to the number and frequency of contacts. It is also possible that more contacts were made than were evident from the files as the recording within the team was extremely poor. The pilot team were flexible and did on occasions provide daily support to service users, when the need arose. For example, a young woman remained at home when her parents went on holiday – the team provided support in activities of daily living, employment and continued the cognitive therapy that she was receiving.

The team did not operate a crisis intervention service nor did it have close links with existing crisis intervention services as recommended by Hemming (1999). Service users were merely advised to contact their GP out of hours (i.e after 5 p.m.) At no time were there plans to extend the service either in terms of days or hours per day. Most assertive outreach teams do provide support over a longer day and at weekends. However, the level of support provided by the team within the week in terms of its responsiveness to peoples' needs and the ability of the team to adjust the intensity of the service appeared to meet peoples' needs fully and reduce the occurrence of weekend crises.

(v) No Closure policy

It was extremely unclear as to whether the team operated a no closure policy or not. Cases were closed on two occasions with the offer of coming back to the team if they needed support. It was not clear what the process would be if someone needed support and approached the team as a self referral and how the problem of identifying a keyworker in a mainstream service would have been resolved. It was also not clear on what basis other cases were closed as there was no system for writing handover/closure reports. Some reports for more complex people were written extremely retrospectively following the pilot team's closure as a result of pressure from outside agencies.

7.5 Outcomes: the impact of the service on service users' and carers' lives

The aims and objectives of the service were met and indeed in some cases surpassed, despite the shortcomings of the team. Multi-disciplinary interventions were provided for up to 25 users (including the 8 service users identified by previous reviews) who fell within this general description. Prevention of out of borough placements and diversion from secure provision were achieved for all service users when receiving the service. In addition reductions in the levels of challenging behaviour and improvements in the quality of life were identified through file analysis and quality of life checklists for the majority of the 16 service users who formed part of the study group.

The team also worked with service users who had significant levels of challenging behaviour as stated in the aims and objectives. All of these people had a primary diagnosis of learning difficulty or high functioning autism/ Asperger's. However, because of the exclusion criteria of having a primary mental health diagnosis and the views of mental health professionals it would be fair to surmise that the team did not work with people with the most enduring, complex and challenging behaviour known to mental health services.

One of the aims of the team was also to work with people who fell between gaps of existing services. It was expected that these people would also not be known to services but this was not the case. The only person who had not been previously known to services was one woman who was outside of the study group who was referred to the service by her GP. In general, the fact that referrals would only be accepted if a keyworker was nominated prevented the acceptance of people who were not known to services. However, just because someone was known to services, did not mean that they either met the eligibility criteria there or received an adequate service. In some cases, people had received a service as a result of committed professionals "bending" the eligibility criteria. This was particularly the case where people had been batted between services – a substantial number of these people had high functioning autistic spectrum disorders and did not meet either learning disability or mental health eligibility criteria. The team also worked with people who had received a poor service from existing services or people who needed an additional element to their care package.

There were also some people who were referred to the team who were not offered a service because of their refusal to engage with the service. Some of these people had extremely complex challenging behaviour and would only have received a limited service, if any, elsewhere. The concept of refusing to engage seems to have been interpreted differently in some cases. Thus a man with a history of sexual offending against children received less than a quarter of the visits that a woman with a history of sexual vulnerability received before their cases were closed. This could be because of the team's views of its expertise and ability to manage risk. However, it does raise issues about whether the team felt that there were some people who met the eligibility criteria that they could not provide a service to.

There is a recognised lack of information on people with learning disabilities, mental health needs and offending behaviour (Baron et al, 2002). Only one other study has looked at the impact of a similar model of service provision – that is, intensive case management for people with mental health needs and learning disability (Hassiotis et al, 2001). The focus of the UK700 study was on very different outcomes – number of days spent in hospital for psychiatric reasons, costs of care and clinical outcomes. An intensive literature search failed to identify any evaluations of forensic community teams. McFayden (1999) suggests that what evidence there is

> *".. linked to programmes of assertive community treatment, where good psychiatric through-care (care which follows the person through the penal system) is linked to court diversion services and application of normal "disposals" to mentally disordered offenders, was associated with reductions in both symptoms and law-breaking behaviour*" (McFayden, 1999, p. 1439).

Buchanan further comments that

> *"given the high profile of mentally disordered offenders and the costs associated with their inpatient management, which is often in secure settings, the lack of research into models of community care for the offender patient is both striking and surprising"* (Buchanan, 2002, p.235-6).

Quality of life scores identified in this study were slightly higher than those identified in the UK700 study. It is extremely difficult to ascertain why this was. The UK 700 study was a randomised controlled trial which compared the efficacy of intensive care management (a model comparable to the pilot team) with standard case management for people with severe psychosis, including a sub-group of people identified as having a borderline IQ through the use of the NART test (Hassiotis et al 2001, Walsh et al, 2001). For the majority of participants in the UK700 study, the intensive case management model had no impact on the outcomes measured (Burns et al, 2002). However, Hassiotis concluded that intensive case management was cost effective for people with severe psychosis and borderline learning difficulties, and that service users showed higher levels of satisfaction with services.

	Mean	s.d.
Pilot team service users at time 1	4.31	1.7
Pilot team service users at time 2	5.00	1.6
Pilot team service users at time 3	5.46	1.7
UK 700 sub group of people with learning difficulties	4.55	0.71

Table 7.6: Perceived quality of life scores.

Walsh et al (2001) report that intensive care management in the UK 700 group had a lack of impact on people with severe mental illness in reducing violence. In addition, Walsh et al identified an association between learning difficulties and violence (in their study, learning difficulties was defined as receiving special education). However, study 1, although a very small exploratory study suggested that for people with a diagnosis of mild/borderline learning disability and a diagnosis of mental illness, the converse may actually be true. People who had a history of violence against property or people did not reoffend during the time of receiving a service, with one exception. This exception was a young man who felt that the service was not meeting his needs, particularly with respect to accommodation, and caused substantial damage to his flat.

Baron and others (e.g. Atkisson et al, 1992; Cohen and Eastman, 1997, 2000 quoted in Baron et al, 2002) have noted that

> *"...measurement of efficacy should not be restricted to recidivism, but should cover clinical, rehabilitation and humanitarian and public safety domains, or in more general terms, "the ability to benefit"."* (Baron et al, p. 460-461).

Klimecki at al (1994) in one of the few studies to examine reoffending in people with learning difficulties identified three factors which may have impacted on recidivism. These were employment, relationships and accommodation. In their study employment was positively associated with a reduction in recidivism, having a domestic relationship had a positive effect on recidivism and accommodation had no impact. This study of the impact of the pilot team suggests that adequate and appropriate support was central to not only preventing reoffending or offending, but also to service users maintaining jobs and relationships. When this support was withdrawn, people failed in employment and in relationships and reoffended.

Accommodation was an area which the pilot team were unable to influence in any way despite it being an issue identified by both service users and carers alike as essential to an improved quality of life for both parties. It would appear then that either a budget or the ability to access budgets for supported living placements together with robust links with independent and statutory sector housing agencies would be a key component in any future teams.

From this small study, then it appears that the receipt of a package of services which were appropriately skilled, flexible and responsive to that individual's need, was the best way of enabling people to remain or develop independent living in the community, reduce challenging behaviour and increase the quality of life. Care packages did not have to be extensive, and in fact most people needed minimal levels of support. There were some flaws in the way that the pilot team was set up both external and internal flaws – externally, the team would have benefited from having closer links with existing services, including access to budgets for accommodation and internally, the team would have benefited from good policies and procedures and more outreach workers to support the professional expertise. A competent team manager would have helped overcome some of these issues.

The experience of the pilot team identified those components which should be present in any service which aims to effectively support this group of people in the community. The flaws in the way the team was set up and in its operation made the positive outcomes difficult to evidence during the life of the team, nevertheless most service users and carers were extremely positive about the team's work. The closure of the team, and the subsequent difficulties which people faced, were perhaps the strongest evidence of the success of the team in providing a service to people which enabled them to improve their quality of life and reduce their challenging behaviour.

Chapter 8

Study Two : Methodology

8.1 Background

Previous research has established that people with mild/borderline learning difficulties, mental health needs and challenging behaviour are often poorly served by community services. This group of people, who do not meet eligibility criteria for access to mainstream services, have extremely complex needs. Yet they only come to the attention of services when there is a crisis. Frequently, the local services feel they have a lack of local expertise and appropriate placements, so the response is usually to send the person to an out-of-borough specialist placement (e.g. Murphy and Fernando, (1998), Vaughan (2000); Joyce et al (2001)). Anecdotal evidence suggests, however, that once someone is placed in an out-of-borough placement, it is extremely hard to bring them back to borough, and so they may remain "stuck" there.

There have been some recent studies published on the quality and costs of residential care for people with learning difficulties and people with mental health needs (Cambridge, P. et al (2001), Emerson et al (1999). However, these mainly look at the needs of more disabled people with learning difficulties who often do not have challenging behaviour or are not at risk of offending. Only one small study has been completed on a residential setting which provided a service for this complex group of people e.g. Murphy and Clare, 1990. In addition, most studies focus on the vulnerability of people with learning difficulties and if they consider risk management at all, it is in relation to protecting vulnerable residents, rather than the need to prevent residents committing offences. There is a gap in research which looks the resident as a possible perpetrator of abuse rather than a victim of abuse.

8.2 Aims of Study Two

Study Two is a small scale project which aims to examine the quality of care and treatment provided in a range of residential out-of borough settings for people with mild/borderline learning difficulties, challenging behaviour and mental health needs who may also be at risk of offending or reoffending. Study

Two focuses on those out-of-borough providers used by the same two London boroughs in which the pilot team from study one was based.

8.3 Methods

Residential settings were identified using purchasing information from the NHS Trust and the local social services from both boroughs. Information about the service user was used to identify those homes which would take people with mild/borderline learning difficulties, mental health needs and challenging behaviour. Further information was obtained from Registration and Inspection Units in order to ascertain whether the homes were meeting the required standards. As a result of this, one setting was taken off the proposed list of settings. This left a list of eight settings situated in South London and across Kent.

Permission was sought, and granted, from the Tizard Centre Ethics Committee, the Lewisham Ethics Committee and the West Kent Ethics Committee. The West Kent Ethics Committee gave permission for the research to be carried out in settings across Kent. The submissions to the ethics committees included a description of background, aims and objectives together with copies of all consent forms, information sheets and schedules (see Appendices 4,6 and 19 - 32). The West Kent Ethics Committee requested revisions to be made to the patient information sheet, an additional consent form for staff members and a standard letter for relatives to be sent out with the questionnaire - the final versions are contained in the appendices.

8.3.1 Participants

Participants in this study were residents from the homes, family carers, keyworkers and managers of the homes.

(i) Residential Settings

Setting Type	Location	No. of residents	Kind of residents
Medium Secure Unit (Organisation D)	Kent	40	Learning disability, mental health needs, challenging behaviour, risk of offending
Independent Hospital – one unit*	Kent	8 – 10	Learning disability, mental health needs and forensic problems
Residential home 1 (Organisation A)	South London borough	15	Mental health/learning difficulties
Residential home 2*	South London borough	18	Mental health
Residential home 3*	Kent	6	Learning disability
Residential home 4 (Organisation B)	Kent	11	Learning disability
Residential home 5 (Organisation E)	Kent	16	Learning disability
Residential home 6*	Kent	17	Learning disability, mental health
Residential home 7 (Organisation C)	Kent	3	Learning disability, challenging behaviour
Residential home 8 (Organisation D)	Kent	3	Learning disability, challenging behaviour

Table 8.1: Study 2 : Residential Settings (NB: * setting withdrew from study)

The first eight settings in the table were contacted to see if they would be willing to take part in the study. No refusals were received. However, when further contact was made with managers of the settings, two settings declined to take part in the study. The independent hospital withdrew on the grounds that they believed that the residents did not fall into the category of people being studied, although this was incorrect. Residential home 6 withdrew on the grounds that the residents all had a form of autism and therefore according to the manager would not be able to cope with answering questions. This was also probably incorrect. Subsequently, residential homes 2 and 3 withdrew from the study part way through. The manager from residential home 2 felt that the residents should decide if they wished to take part in the study. Following visits and 6 months of phone-calls which were unable to ascertain whether or not residents wished to take part in the study, it was concluded that the manager did not wish either to take part in the study or be seen to refuse to do so. Residential home 3 identified two residents as being possible participants in the study. Despite numerous visits over a 6 month period, the home also withdrew as it was felt that the two residents were both undergoing difficulties at the time and so it was not appropriate to interview them.

As a result of managers' withdrawing during the course of the study, an additional two smaller homes were added to the list of settings. These were identified through the move on of residents from existing homes in the study. All residential settings were independent sector providers.

(ii) Residents

Not all residents from all of the settings fell into the target group of study two. Initial meetings were held with managers to identify who would be suitable for the study (i.e. people with mild/borderline learning difficulties, challenging behaviour who were at risk of offending). Managers also identified people who they thought might be suitable but who might be going through some kind of crisis, and therefore should not participate. However, once residents had been identified as possible participants in this way, it was left up to the individual resident to choose whether or not to participate in the study. A similar process to that described in study one was undertaken to gain informed consent. There were few refusals, although two men decided not to complete the schedules. One man also became ill and was sectioned before completing the interviews. Often, residents would request that they were interviewed, particularly after they found out about the payment (see below). Some also requested to be interviewed more than once!

The method of introduction worked differently in different places. In most settings, the researcher was introduced to the resident. If the resident was happy to talk to the researcher, then the study would be described and the consent form would be completed. It was emphasised that it was okay to say no to answering some or all of the questions and that people could change their minds at any time and withdraw from the study. One setting was concerned that residents may not be able to say no to the researcher. In this setting, the researcher visited and explained the nature of the research. Consent was then obtained by a staff member in some cases and by the researcher with a member of staff supervising in others. In the latter situations, consent was often double-checked by a member of staff from the setting to ensure that informed consent had in fact been given. In this setting, people who had initially said no, then changed their minds following discussion with other participants and requested to be part of the study at a later date.

Because there were four different schedules to complete, interviews were carried out at the resident's own pace, with as many breaks as the resident wanted. Some schedules were completed over 6 visits, but most were completed in under 3 visits. On completion, residents were paid £10.

In total, 30 residents were interviewed from across the 6 residential settings. The disparity in numbers may be explained by:

- Not all residents were suitable for the study
- There were some vacancies in some settings
- Only two 8 bedded units were selected in the large medium secure unit
- There were some refusals (4).

(iii) Family Members

Residents were asked if a questionnaire could be sent to their family to find out what their family thought about where they were living. Twenty people agreed that their family could be contacted in this way, with some people specifying particular family members. Large print copies were sent to some parents as residents reported that parents had some visual impairment. Contact telephone numbers were on the literature to enable parents to contact the researcher for more information if required.

(iv) Managers and Keyworkers

All managers from each home were asked to become involved. Where the home was part of a larger organisation, someone from head office became involved with the operation of the study on 4 occasions.

Meetings were held with staff in some settings to explain the purpose of the research. In other settings managers cascaded the information down to their staff. In general, it worked better where there was direct contact between staff and the researcher. Keyworkers were identified by the manager and asked to complete information about the person they keyworked, and their views on the home. There was usually one keyworker for each person in the residential homes. Due to staff changes, keyworkers took on additional responsibilities for residents during the course of the study. In the medium secure unit, lead nurses were asked to facilitate the study as they were felt to be better informed. Unfortunately this meant that some had responsibility for as many as 3 residents.

8.3.2 Measures

A range of measures were chosen which have all been used in previous projects (see Appendices 4, 6 and 19 -32). The majority of those chosen were those used by Emerson et al (1995) in a large Department of Health funded project which looked at the quality of residential support for 547 people with learning disabilities. Some schedules also overlap with the large Cambridge et al study (2001). This study was also funded by the DoH and followed up people with mental health needs (128 people) or learning difficulties (275 people) who had been discharged from long-stay institutions. The ABS was also used in the MIETS study of people with mild learning disabilities at risk of offending (Murphy and Clare (1990); Clare and Murphy (1993)). The CSSRI has been used in the Cambridge et al study (2001)) and many mental health studies. The Lancashire Quality of Life Profile has been used in many studies of people with mental health problems and more recently in studies of people with mild/borderline learning disabilities. These measures comprise self-completion schedules for staff and interviewer administered questionnaires. However it was intended that the researcher would be on hand to help complete some of the schedules with managers and staff members, including administering any of the schedules and providing guidance where necessary. The measures examine a spectrum of issues including how the home was run, staff and resident's and family members' perceptions, together with measures of social functioning, challenging behaviour and quality of life. All of the schedules for residents had been used with people with learning difficulties before, although the quality of life profile has only recently come into use as a measure for people with dual diagnosis.

Some adaptations were made to the standard Emerson schedules. In particular questions about costs apart from general prices were omitted. The ABC checklist was omitted and additional information requesting specifically about offending/challenging behaviour substituted instead as it was felt that this was better suited to the group of participants. Additional questions were also added in order to explore how challenging behaviour is addressed and the extent to which, if any, residents presented a risk to others. Qualitative data was analysed using the framework analysis approach described on p. 142.

Retrospective case file analyses were carried out, with the intention of using base-line assessments to ascertain whether the individual needs of residents as assessed by that setting or the placing authority had been met. Particular attention was paid to the management of risk and challenging behaviour and the development of independent living skills and activities. Timeliness of reviews and length of residence were also noted where this was on file.

This range of measures were chosen in order to gather information so that the experience of individual participants and the quality of care in settings may be compared with other larger studies.

Area	**Measure**	**Author**	**Completed by**
Organisational aims and philosophy, staffing, policies and procedures, other services	Provider Organisation Questionnaire (adapted)	Emerson et al	Manager
Information on residents, building design, practice.	Living Environment Schedule	Emerson et al	Researcher with manager
Background information on residents	Individual Schedule (adapted)	Emerson et al	Keyworker
Resident's views	Individual resident's interview (adapted)	Emerson et al	Researcher with residents
Staff's views on individual residents	Interview schedule (adapted)	Emerson et al	Keyworker
Staff and residents' view on the setting and its practices	Sheltered Care Environment Scale	Emerson et al	Staff self-complete Researcher to assist residents
Challenging behaviour	ABS-2	Nihira et al	Keyworker

	Plus additional schedule on management of challenging behaviour		
Daily living skills	ABS-2	Nihira et al	Keyworker
Social Network	Social Network Guide	Forrester-Jones et al	Researcher with residents
Services received	CSSRI (adapted)	Cambridge et al	Keyworker
Quality of life	Lancashire Quality of Life Profile	Oliver et al	Researcher with residents
Validation of information and retrospective analysis	File analysis		Researcher

Table 8.2: List of measures

8.3.3 Procedures

(i) Residents

Residents were interviewed by the researcher in a confidential setting – usually an office or quiet room within the setting. In two settings: residential home 7 (Organisation C) and the medium secure unit, the researcher was escorted during the interviews. In residential home 7, two members of staff assisted with much of the interview, and in the medium secure unit, a member of staff observed in order to ensure the researcher's safety.

Before each interview began, participants were reminded that they could answer all or none of the questions and that they should say when they wanted to take a break. Participants varied in how they responded to the interview – some took short cigarette or tea breaks and completed the schedules in one day; some preferred short 10 – 15 minute interviews over a period of weeks.

Most schedules were completed in written format and participants were asked if they would like a copy. Two participants requested a copy.

Most people had a good understanding of the questions. They had greatest difficulty in answering the semi-structured interview schedules when they were asked what kind of changes they would like to make (see Appendix 34).

All residents were informed that a file analysis would take place as part of the study. The medium secure unit requested that a separate consent form be devised to obtain specific written permission for this. Two of the 11 residents from the medium secure unit did not agree to have their files looked at.

(ii) Family carers

Eighteen family carers were sent a questionnaire and covering letter. Reminders were sent after 3 weeks and a further copy of the questionnaire at about 3 weeks later. Three parents contacted the researcher by phone for clarification.

(iii) Managers and Keyworkers

Managers were asked to complete a consent form and two schedules about the homes, the settings and the operation of the home. Managers were offered the opportunity of completing the schedules as either an interview or by themselves. Most chose the latter. One manager was interviewed, and another manager completed the schedules whilst the researcher was present.

Keyworkers were also asked to complete a consent form, one schedule on their views on the home and four schedules on the person they keyworked. They were offered the chance to do all or some of these as an interview with the researcher but all preferred to self-complete. It was estimated that if the keyworker knew the person well, the schedules would take about one and a half hours in total. To assist the self completion, the researcher offered sessions in case people were experiencing difficulties, together with brief guidance on completing the schedules and a telephone number for help. One manager completed two sets of schedules with the researcher present for advice – this took two hours.

Chapter 9

Study 2 : Results

None of the organisations returned a full set of schedules. Organisation E did not return any of the organisational schedules despite 3 copies being sent to two different locations, and the organisation claiming that at least one set had been posted back.

The greatest difficulty, however, was experienced in obtaining those schedules which keyworkers were required to complete. It is difficult to know why this was. In some organisations, the information was difficult to obtain because of poor record keeping. This particularly applied to historical data. Some managers reported that despite instruction, staff consistently refused to complete the schedules! This would suggest that either staff (including managers) were not committed to the research or that staff refused to follow management instructions. In some organisations, keyworkers may not have felt confident in completing the schedules and in one organisation, workloads were blamed for non-completion.

9.1 Characteristics of The Homes

(i) Size and remit

Type of setting	**Organisation**	**Number of homes**
Large residential home	A, B,E	3
Small residential home	Organisation C	2
Medium secure unit	Organisation D	1

Table 9.1 Settings

Five organisations took part in the study. Organisation C had two homes which took part, making a total of six different settings. The large residential homes were larger than the current recommendations standards – ranging from 11 to 22 beds. The small group homes had 3 beds each. The medium secure unit had 40 beds in units of 8. All organisations were from the independent sector – four of the organisations specialised in people with learning disabilities. Organisation A provided one home for people with mental health needs (which was included in the study) and one home for older people (which was not included in the study). Organisations C and D described their residents as short-term and had policies stating this. Organisations A, B and E provided long-term accommodation for residents.

(ii) Services provided

Managers were asked to completed a tick box schedule showing which services residents received. Managers were also asked to state whether those services were provided by their organisation or not (Appendix 38). The four organisations that completed this schedule showed that, based upon managers' reports, there was access to the range of support services and community based facilities that one would expect to find in good quality residential provision. Not all managers responded to all the questions and there clearly was some misinterpretation or misrepresentation of services supplied directly by the organisations – e.g. two organisations claimed to have their own community learning disability teams and GPs. As would be expected, because of legal restrictions, residents from the medium secure unit were more likely to be unable to access community facilities. However, the unit provided more services on site, e.g. education. In general, all organisations found it difficult to access social clubs, holidays and employment. Organisations also found find it difficult to provide holidays for residents, despite this being a requirement of the new care standards, for financial reasons. Difficulties in accessing social activities and employment are not confined to residential homes. There are very limited opportunities for people with mild or borderline learning disabilities as they often do not meet eligibility criteria for specialist services and may not be able to cope with mainstream services. This had led to some of the organisations (B, D and E) developing their own day activities on site, e.g. leisure activities, aromatherapy.

(iii) Planning for the future

All of the organisations had been established for over 5 years. Only one of the settings had been in operation for less than 5 years. This setting had experienced local hostility and

> *"One local protester entered the administration building a few weeks after the building opened."*

One other setting had also experienced local hostility.

There were some plans for change. The National Care Standards had impacted on all organisations, but two had to make particular changes. Organisation A needed to undertake extensive refurbishment in one home in order to have en-suite facilities and adequate room sizes resulting in a reduced number of beds. Organisation C was undertaking feasibility studies into the continued financial viability of the two small residential homes, now that every home was required to have a qualified manager. This organisation was considering de-registration of some properties and was also expanding.

Organisations B and D were planning to undertake some changes in order to meet the needs of their residents. Organisation B was planning an extension to provide more communal space and a staff room. Organisation D was building a half-way house to enable residents to develop or regain independent living skills before they returned to the community.

(iv) Aims and Philosophy

Three organisations had a written statement of philosophy (A,B and D). They defined the aims of their organisations quite differently.

Organisation	Aims of organisation
A	"1. To provide a professional service 2. to ensure clients are receiving best treatment, aware of their rights and happy within a house environment 3. to ensure that the house operates according to guidelines laid down by R and I and to work in partnership with other agencies."
B	"To create friendly, safe and relaxing therapeutic environment for adults with a range of learning difficulties and behaviour problems To encourage residents to achieve their potential, retain their individuality and unique approach to life To consistently offer a kind, caring and flexible approach to each resident."
D	"To provide a high quality, safe and secure environment which encourages the development of skills and competencies in adults with learning disabilities To provide assessment and treatment programmes aimed at improving mental health, eliminating inappropriate behaviour and establishing appropriate patterns of coping and problem solving Work closely with referring clinical teams in order to facilitate patient's return to their home area at the appropriate time"

Table 9.2: Aims of Three Organisations

It is actually quite difficult to pull common themes from these aims although treatment or therapy is mentioned in all three and partnership working is mentioned in two. What is apparent is that the aims reflect the different nature of the homes – one provides long-term accommodation for people, one provides medium to long-term accommodation and treatment for people and the other provides focused interventions. They also differ in level of security, with one (D) providing a secure service.

(v) Staff

Staffing ratios were 1:1 for the residential homes and 2.2:1 in the medium secure unit. None of the organisations used any volunteers.

Staff turnover was very low – less than 0.6% for two organisations and zero for others within the last year. Staff sickness was reported to be non-existent in the last 6 months for 3 organisations and was low in the fourth (one organisation reported 4 days sick per whole time equivalent staff member in the last 6 months).

42.9% of staff were male. 80% of the staff working in these services were white. The mental health home had twice as many people from Black and minority communities as white people on its staff team. One home had a 100% white staff team. One of the factors that would influence the ethnic makeup of the staff team is the makeup of the local population. Organisation A (the mental health home) was located in inner London. The other organisations were located in south east England.

The majority of staff were unqualified. Organisation D had a team of specialist qualified staff including clinicians - the medium secure unit. This reflects the nature of the specialist service provided rather than other factors, for example, bed numbers. It appears that most of the support in the settings was provided by unqualified professionals. Of the non-secure organisations, only Organisation A – the mental health home, had more than one qualified member of staff.

Organisation	A	B	C	D
Qualification				
Nursing	7	1	0	17
Social Work	0	0	0	2
Teaching	0	0	0	5
Doctor	0	0	0	3
Other medical	0	0	0	0
Other professional	0	0	0	3
Total qualified professionals	7	1	0	30
Percentage qualified professionals	35%	2.8%	0	16.9%

Table 9.3 : Number of qualified staff by organisation

These results are also somewhat at odds with results in Appendix 38 where organisations claimed to be providing a range of services in the home. For example 3 organisations claimed to be providing social work support but only one organisation (D) had any qualified social workers.

Given the lack of professional qualifications, induction and training would be essential to ensuring that there was an adequately skilled staff team. All organisations provided induction and training for staff but this varied considerably in length and depth. Organisation A merely provided a 6 month probationary period with no training whilst Organisation D provided 3 weeks intensive classroom based training. Organisation A also did not provide support for external training. It appears that for Organisation A, the presence of nursing staff in the staff team was seen to be sufficient in terms of providing adequately and appropriately skilled interventions. On-going training for all organisations commonly covered health and safety, first aid and NVQs.

Two organisations described the role of staff as carers. One organisation described the role as

> *"healthcare workers who support clients to maintain a good standard of hygiene and to be as independent in lifeskills as individually able."*

One organisation did not describe the role of staff.

9.2 Characteristics of Service Users

(i) Age

None of the organisations focused on a particular age group, with residents being aged between 18 and 65. One of the small group homes stated that they only accepted people aged 18 – 25 – however only one of the residents who participated in this study was within this age range. The age range of 18 to 65 is reflected in the residents who took part in the study.

Number of residents	Minimum age	Maximum age	Mean	Std. Deviation
30	18	65	35.7	11.6

Table 9.4 : age range of all residents who participated in the study.

Organisation	Minimum age	Maximum age	Mean	Std. Deviation
A	23	37	29.6	7
B	26	52	38.4	7.6
C	18	38	28	8.2
D	19	65	36.6	15.2
E	26	40	32.6	7

Table 9.5: age range of residents by organisation

From the tables it can be seen that the greatest age range is to be found in Organisation D, reflecting the both the size and the specialist nature of this provision. It is interesting to note that the mean average age was highest in Organisation B – a setting which offered long term placements.

(ii) Gender

Setting Type	**Men**	**Women**	**Total**
Medium Secure Unit	7	4	11
Residential home	17	2	20
	24	**6**	**30**

Table 9.6: Participants in Study Two.

Three settings only had male residents at the time of the study. One subsequently became male only, when the female resident moved out just as the study began. Two settings had in the region of 20% female residents, with the medium secure unit dedicating two units as mixed units. This study focused on the mixed units, leading to slightly more women in the sample group.

(iii) Ethnic origin

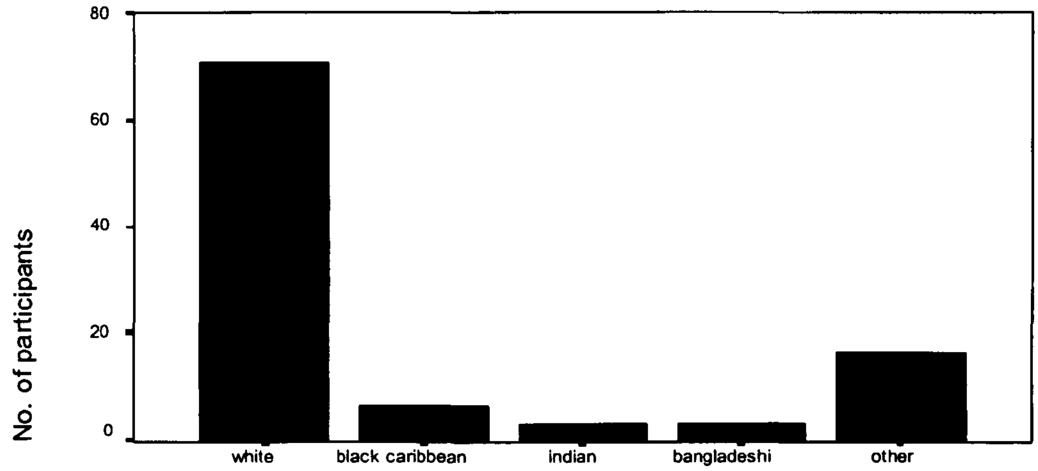


Figure 9.1: Analysis of ethnic group of residents who participated in the study.

Ethnic origin	**Men**	**Women**
White UK	17	4
African Caribbean	0	2
Bangladeshi	2	
Indian	1	
Turkish	1	
Turkish Cypriot	1	
Greek	1	
Romanichal gypsy	1	

Table 9.7 : Ethnic composition of participants

The majority of participants were white. However a significant minority were from non-white ethnic groups. These people tended to be concentrated in two settings.

Organisation	Men	Women	Total	% of residents interviewed
A	3	0	3	100%
B	1	0	1	12%
C	1	0	1	25%
D	2	2	4	35%
E	0	0	0	N/A

Table 9.8: Breakdown of residents interviewed from Black and minority ethnic groups

This analysis shows that residents in this study, who came from Black and ethnic minority groups and were seen to have learning difficulties, mental health needs and challenging behaviour, were more likely to be found in services that catered for people with mental health needs (rather than a primary diagnosis of learning disability) or in medium secure provision. Given the small numbers in this study, it is hard to draw any conclusions from this. It may well be endemic of institutional racism which leads to people from Black and ethnic minority communities as being more likely to be labelled as "mad" and/or dangerous. It may also be reflective of the catchment areas – Organisation A takes local people from London and Organisation D takes people from London and south-east England.

(iv) Residential History

It was difficult to obtain validated information on residential history in one of the homes. This organisation catered for long-term residents and in five cases no information could be found on file. Information in this section comes from a combination of completed schedules from residents, staff and file analysis. There was very little information on care pathways into any placement, with the exception of Organisation D. In other organisations, record keeping was historically extremely poor.

Previous placement	**Organisation A**	**Organisation B**	**Organisation C**	**Organisation D**	**Organisation E**	**Total**
Special school			1			**1**
Family home	1	1				**2**
Group home	1	6	2		1	**10**
Hostel	1				1	**2**
Learning disability hospital		1				**1**
Psychiatric hospital		1	1	6		**8**
Secure unit				3	1	**4**
Prison				2		**2**

Table 9.9 : Previous placements of residents participating in this study.

Most residents who participated in this study had come directly from some other form of placement – usually from another group home following a placement breakdown. Only two people had come from directly from home – both of these were young men from an Indian or Bangladeshi background whose family could no longer cope. Organisation D was more likely to take people from secure provision than any other organisation.

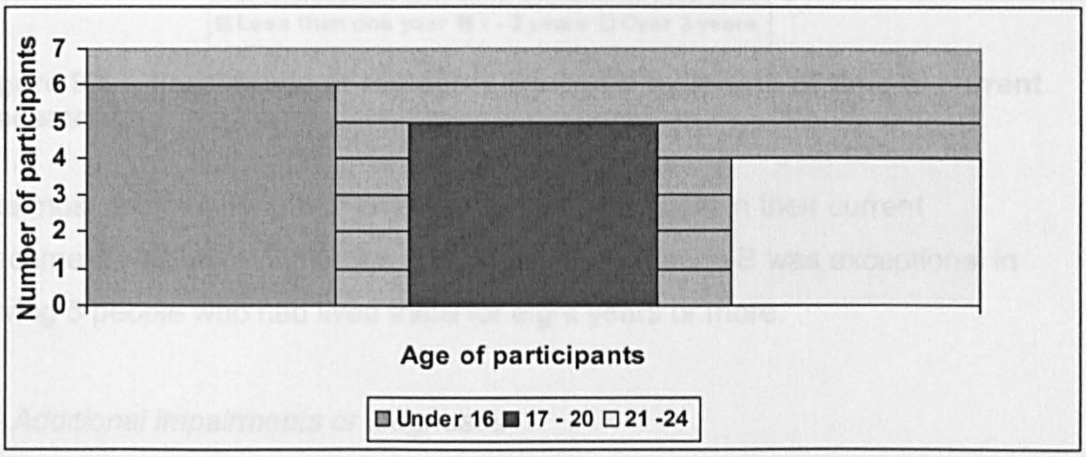


Figure 9.2 : How old were you when you were first admitted to psychiatric hospital

Just over half of residents (16) had been admitted to psychiatric hospital in the past (see figure 9.2). Of those that could remember (15) how old they were when they were admitted to psychiatric hospital, 6 (37%) had been admitted to psychiatric hospital when they were 16 or younger. Nine residents were unhappy at the thought of returning to live in a psychiatric hospital. Seven people who felt okay or happy at the thought of returning to psychiatric hospital- of these, five were living in the secure unit.

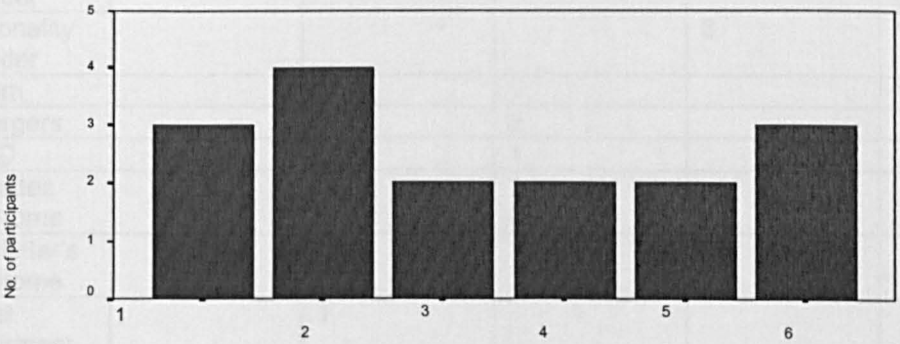


Figure 9.3 : How happy are you at the thought of returning to psychiatric hospital? (1 = couldn't be worse, 6 = very good)

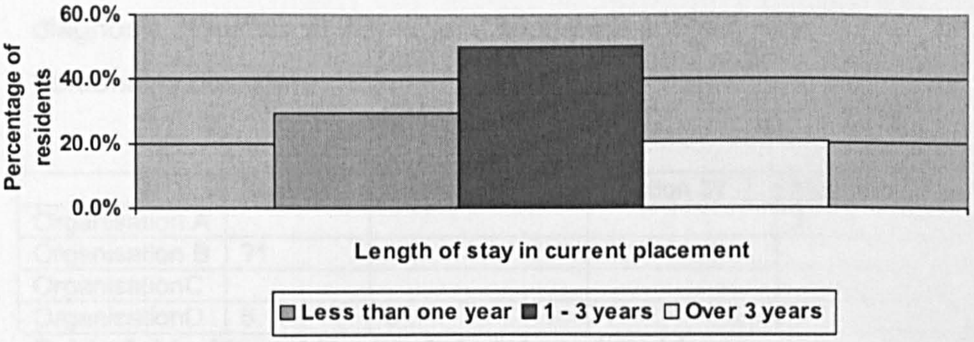


Figure 9.4 : Percentage of residents analysed by length of time in current placement

The most common length of time that people had spent in their current placement was either 6 months or 2 years. Organisation B was exceptional in having 5 people who had lived there for eight years or more.

(v) Additional impairments or diagnoses

All participants had a diagnosis of learning difficulty. The following information on additional diagnoses was gained from a combination of schedules completed by staff and information on files. The information on residents in Organisation B is likely to under-represent the impairments or diagnoses of this group of residents due to a combination of poor completion of staff schedules and record keeping.

Other diagnosis	**Organisation A**	**Organisation B**	**Organisation C**	**Organisation D**	**Organisation E**	**Total**
Schizo-Phrenia	3			1		**4**
Bipolar affective disorder				1	1	**2**
Personality disorder				3	1	**4**
Autism		2			1	**3**
Aspergers			2			**2**
ADHD			1			**1**
Tourettes Syndrome			1			**1**
Klinefelter's Syndrome				1		**1**
Visual impairment		1				**1**
Deafness			1			**1**
Epilepsy		4			3	**7**
Paedophilia				2		**2**

Table 9.10: Additional impairments or diagnoses of residents.

A total of 6 residents had a formal diagnosis of mental illness. 5 residents had a diagnosis of autism or Asperger's syndrome and 4 residents had a diagnosis of personality disorder.

	Section 3	Section 37/41	Section 37	Section 117	Guardianship
Organisation A				2	
Organisation B	?1				1
OrganisationC					1
OrganisationD	5	5	1		

Table 9.11 : Mental Health Act status of residents

Half of the residents interviewed were receiving treatment under the Mental Health Act. Organisation B stated that one resident was on a section, but did not know which section of the Mental Health Act they were on. Most of the residents on section were located in the secure unit which was also registered as an independent hospital.

(vi) Abilities and Behaviour

All keyworkers were asked to complete the ABS behaviour scales for residents who agreed to be part of the study. Unfortunately , as stated earlier, it proved extremely difficult to gain keyworkers co-operation in this matter and only 15 (i.e. 50% of the total number interviewed) scales were returned. Summary results are shown below. Descriptive ratings relate to performance by members of the group used to establish norms – in this case the group was a group of people with learning difficulties living in residential provision or in the community.

Domains	Average standardised score	Std. dev	Descriptive rating
Independent functioning	13.2	3.11	Above average
Physical development	12.4	2.19	Average
Economic activity	11.6	1.95	Average
Language development	13.6	1.34	Above average
Numbers and time	13.6	2.07	Above average
Domestic activity	14.4	3.58	Above average
Vocational activity	8.4	4.39	Average
Self-direction	10.6	3.36	Average
Responsibility	10	2.24	Average
Socialisation	11.2	2.49	Average

Table 9.12: Standard scores for ABS part one for secure unit residents

Domains	Average standardised score	Std. dev	Descriptive rating
Independent functioning	14.1	2.03	Above average
Physical development	14.6	1.06	Above average
Economic activity	14.4	3.11	Above average
Language development	15.0	2.33	Superior
Numbers and time	14.0	2.73	Above average
Domestic activity	14.8	2.31	Above average
Vocational activity	10.5	2.56	Average
Self-direction	13.8	2.38	Above average
Responsibility	12.8	1.58	Average
Socialisation	13.4	1.30	Above average

Table 9.13 : Standard scores for ABS part one for residential homes

Domain	Average standardised score	Std. dev	Descriptive rating
Social behaviour	8.8	3.15	Average
Conformity	9.8	1.75	Average
Trustworthiness	9.8	1.75	Average
Stereotyped behaviour	10.3	2.25	Average
Sexual behaviour	10.6	2.00	Average
Self-abusive behaviour	11.5	2.00	Average
Social engagement	11.0	1.51	Average
Disturbing Interpersonal behaviour	8.6	4.21	Average

Table 9.14: Average scores for ABS part two for residential homes

Domain	Average standardised score	Std. dev	Descriptive rating
Social behaviour	6.2	3.70	Below average
Conformity	6.4	1.52	Below average
Trustworthiness	8.2	2.59	Average
Stereotyped behaviour	8.2	2.95	Average
Sexual behaviour	7.4	1.14	Below average
Self-abusive behaviour	10	3.94	Average
Social engagement	9.8	3.70	Average
Disturbing Interpersonal behaviour	4	2.12	Poor

Table 9.15: Average scores for ABS part two for secure unit residents

The results from the ABS scales show that when compared to other people with learning difficulties living in residential or community settings, this group of people were extremely able in independent living skills with the significant exception of vocational ability and socially acceptable behaviour. With regard to the ABS part II, residents from Organisation D scored less than residents in residential homes in all areas, but particularly in the disturbing interpersonal behaviour domain. Although the mean scores for social behaviour and disturbing interpersonal behaviour scores fall into the average range of abilities, the standard deviation shows that for some of these residents these domains highlighted significant difficulties in functioning.

(vii) Offending behaviour

Of the 30 residents interviewed, 20 residents had a history of offending -type behaviour. The remaining ten were felt to be at risk of offending. Eleven residents had had convictions – 8 of these people lived in the secure unit. Some residents had convictions for more than one offence.

Nature of offence	**No. of people with convictions**	**No. of people who had engaged in behaviour but had no conviction**
Shop lifting		2
Theft	2	3
Burglary	4	
Fraud and deception	1	
Criminal damage	4	1
Violent assault	5	5
Indecent assaults against children	5	2
Abduction of child	1	
Manslaughter	1	
Arson	2	
Breach of peace	1	
Not known	1	

Table 9.16 : Offending behaviour of all residents

With the exception of manslaughter, kidnapping and arson, people with similar kinds of offences were found in both residential homes and secure units. People who persistently sexually offended against children and those who had an on-going history of violence were more likely to be living in the secure unit.

Some people also had significant challenging behaviour which was not offending behaviour. Some people self-harmed (8) or were at risk of committing suicide (5). Most of these people were in the secure unit (5) and four of these five residents were women. Some people consistently neglected their own care (6) –this included attention to personal hygiene in Organisation A (2). Vulnerability was also identified as another form of difficult behaviour – sexual (3), physical (3) and financial (4) vulnerability were identified as issues. With the exception of financial vulnerability, most people with high levels of need were living in the secure unit.

9.3 The Physical Environment

Managers were asked to score the homeliness of the home that they managed on a score of 1 to 5, with 1 being very homelike and 5 being non-home like.

Area of home	**A**	**B**	**C**	**D**	**Total no. of homes scoring "very homelike"**
Living room	X	X	X		3
Dining room	X	X	X	X	4
Bathroom	X	X	X		3
Bedrooms	X	X	X		3
Garden	x	X	X	X	4

Table 9.17 : Number of homes scoring "very homelike" (n = 4)

Managers, in general, rated their homes as being very homelike or homelike. The secure unit was rated slightly lower than the residential homes in most areas with the exception of the garden and the dining room. Within these ratings there was considerable variation in the homeliness of the rooms, particularly in the size and in what the Living Environment Scale calls "personal touches". Communal rooms were pretty bare.

When asked about the physical environment, residents supported the managers' description of the homes as "homely" environments. There were no significant differences between the views of residents in the homes and those in the secure unit.

Question	**Yes**	**No**
Is the furniture here comfortable and homely?	90%	10%
Is the lighting very good here?	90%	10%
Do the colour and decorations make this a warm and cheerful place?	86.7%	13.3%

Table 9.18 : Residents' views on aspects of the physical environment.

Managers were also asked to describe any restrictions on residents' movements, e.g. were any areas out of bounds and were there any special adaptations to the home that might detract from a homely environment.

	No. of homes answering yes
Are any areas out of bounds?	3
Does the building have any specially strengthened fabric?	4
Is there any specially strengthened furntiture?	1
Is there specially adapted equipment?	1
Is there a seclusion or safe room?	1
Are there any internal locks etc. ?	3
Is there a secure perimeter fence?	2

Table 9.19 : Restrictions and special adaptations to the home (n = 5)

As can be seen, in the majority of cases, based upon managers' reports, there were few physical restrictions imposed on residents' movements and limited use of specially strengthened equipment or furniture. The main exception to this was of course, the secure unit. Although two homes said that there were no areas that were out of bounds to residents, in all of the six homes the researcher observed access to the kitchen and office areas being restricted, although not always by physical means.

9.4 Management Practices

(i) Individual Planning

Using the Living Environment Schedule designed by Emerson et al (1995), managers were asked to rate the systems that were in place in order to support such activities as individual planning, assessment and teaching, planning daily and weekly activities, arranging staff support for residential activities and the training and support of staff. Internal procedures were rated on a scale of 1 to 4, with 1 representing no operational system for those activities and 4 representing well-established clear operating systems and good communication systems. They were also asked to rate the frequency of user involvement in these activities.

Managers' ratings indicate that there are robust systems in place with substantial user involvement in the short and long-term planning of activities and goals. With the exception of the secure unit, where there were well kept files, records and reports in keeping with the Care Programme Approach, it was difficult to evidence that these systems were in place.

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
person centred planning - general rating	5	4	4	4.00	.00
person centred planning user rating	5	2	4	3.40	.89
assessment and teaching general rating	5	3	4	3.80	.45
assessment and teaching user rating	5	2	4	3.60	.89
planning activities general rating	5	3	4	3.60	.55
planning activities user rating	5	3	4	3.80	.45
staff support general rating	5	2	4	3.40	.89
training and supervision	5	3	4	3.80	.45
Valid N (listwise)	5				

Table 9.20: Managers' rating of working practices and user involvement.

When asked if residents waited for staff to set up activities, 77.8% of residents said that they did. It appears that managers may have reported systems in a slightly more positive way than that experienced by staff and residents. It is also difficult to evidence the quality of some of the systems in place – for example, supervision and training, without access to personnel records and that was not part of this study. It is clear that different organisations had widely varying commitments to training and induction as reported earlier. Equally, given the lack of qualified staff within organisations, the quality of supervision would be likely to vary substantially.

Managers' ratings suggest that most residents are involved in all aspects of individual planning – a score of 3 represents some residents and 4, all residents. Residents were also asked about their level of involvement in planning meetings.

Do you go to meetings about what you do?	Yes	No	Total
Organisation A	1	2	3
Organisation B	7	2	9
Organisation C	4	0	4
Organisation D	9	2	11
Organisation E	3	0	3

Table 9.21: Residents' attendance at individual planning meetings

Six residents did not go to individual planning meetings. 4 residents said that they did not have meetings about what they did or where they lived. Two residents said that they did have meetings but did not go to them. All of the residents who lived in residential homes and went to meetings were helped by someone in those meetings, usually a keyworker. 8 out of 11 residents in organisation D were supported – 7 of these by a keyworker. Only one person was helped by an independent person – a solicitor. One person wanted some help in their meetings.

Are you able to say what you want?	Yes	No	Total
Organisation A	1	0	1
Organisation B	7	0	7
Organisation C	4	0	4
Organisation D	7	2	9
Organisation E	3	0	3

Table 9.22 : Are you able to say what you want in those meetings?

Only 2 people felt they were unable to say what they wanted to in meetings. One person said:

> *"Don't trust them enough."*

The other person said:

> *"There's a crowd of people and I get nervous."*

All of the residents who were able to say what they wanted, felt that they were listened to.

One man said that he wanted more meetings. One man said that he would like to change what happened in the meetings.

"Before my last review, I had an incident with another resident who used to live here. We lost our tempers and at my last review they discussed the incident. I would prefer it if they didn't discuss things like that with my parents present."

5 (45%) residents from the secure unit wanted a different outcome from the meeting – they all wanted to leave.

> *"I just want to get out of here – see where they can put me."*
>
> *"Hope my social worker comes up with something."*

Individual Planning	**% of residents with a keyworker**	**% of residents with a case manager**	**% of residents with an individual programme plan**
Organisation A	100%	33%	66%
Organisation B	100%	100%	88%
Organisation C	100%	100%	100%
Organisation D	100%	100%	100%
Organisation E	100%	66%	66%

Table 9.23 : Individual Planning and Case Management status of residents in study

All managers reported that nearly all of the residents in the study had a keyworker, care manager and/or Individual Programme Plan. However there was considerable variation as to the frequency of all kinds of meetings with both keyworkers and care managers.

Frequency of meetings with keywoker	**Weekly**	**Monthly**	**Less often than monthly**	**No information on frequency**
Organisation A	33.3%			66.7%
Organisation B			44.4%	55.6%
Organisation C	100%			
Organisation D	9%	27.3%	9%	54.7%
Organisation E	66.7%		33.3%	

Table 9.24 : Frequency of meetings with keyworker

Frequency of meetings with case manager	**Every 6 months**	**Less often than 6 monthly**	**No information on frequency**
Organisation A			100%
Organisation B	77.7%	11.15%	11.15%
Organisation C	50%	50%	
Organisation D	27.3%	18%	54.7%
Organisation E			100%

Table 9.25 : Frequency of meetings with care manager

(ii) Social climate

Feature of institutionalisation	**Score**
Social distance	23.3%
Depersonalisation	28.3%
Block treatment	37.5%
Rigidity of routines	30%

Table 9.26 : Summary scores for social climate

The Group Home Management Interview in the Living Environment Schedule was used to rate the extent to which the home embodied what Emerson et al (1999) describe as the "cardinal features of total institutions." The results (the percentage of the maximum possible score on each scale) are shown here as summary scores. There was very little difference between any of the homes in scores with most managers reporting a mixed (i.e. group and individual) pattern of activity. These scores still show considerable levels of instititutionalisation, with rules governing most aspects of life from waking times to using the kitchen to when people watched tv. Where organisations scored differently on specific issues, these are reported below.

	A	**B**	**C**	**D**
Have own keys	No	No	Yes	No
Has set times for residents to visit	Yes	No	Yes	No
Allow dating under specified conditions	No	No	Yes	Yes
Kitchen staff plan menu and do shopping	No	No	No	Yes
Staff handle bank accounts	No	No	No	Yes
Residents handle bank accounts	Yes	No	No	No
Staff supervise meal times and do not eat with residents	Yes	No	No	No
Staff supervise TV and do not watch TV with residents	Yes	No	No	No
Pets are allowed	No	Yes	No	No

Table 9.27 : Specific features of social climate

(iii) Contact with other services

Although managers from Organisations A,B,C and D stated that all residents had access to advocacy services, this statement was not borne out by keyworkers' reports. In Organisation B, keyworkers claimed that they provided independent advocacy.

Organisation	Percentage	Nature of organisation
A	None	
B	None	
C	75%	Local vicar, someone from local hospital
D	80%	Local advocacy organisation
E	None	

Table 9.28 : Percentage of residents interviewed who managers stated had access to an independent advocate.

Organisation B had the widest range of contact with other services and the largest proportion of residents who had contact with other services. Organisations D and E did not submit any data. However, the file analysis carried out in Organisation D showed that there was contact with an equally wide range of services as Organisation B.

Service contact	A	B	C	D	E
Nursing services		11%			
Chiropodist		44.4%			
Education classes		22%			
Social worker	33.4%	55.5%			
GP	33.4%	33.3%			
Dentist		22%			
Optician	33.4%	11%			
Psychiatrist		11%			
Psychologist		33.3%			
Physiotherapy					
Music therapy		11%			
Adult education classes		22%	50%		
Day centre		11%			
Gateway/social club			50%		
CPN	33.4%	11%			
Eye hospital		11%			
Speech therapy			25%		
Voluntary work			25%		
Other homes in organisation			50%		
No contact with other services	66.6%	11%	50%		
No information		22%		100%	100%

Table 9.29 : Percentage of residents that had contact with other services in the last 3 months by organisation

(iv) Health Needs

Residents were asked to rate their satisfaction with their physical and emotional health on a scale of 1 to 7, where 1 represented "couldn't be worse" and 7 "couldn't be better." Most residents were satisfied or very satisfied with their physical health. Residents were less satisfied with their mental health.

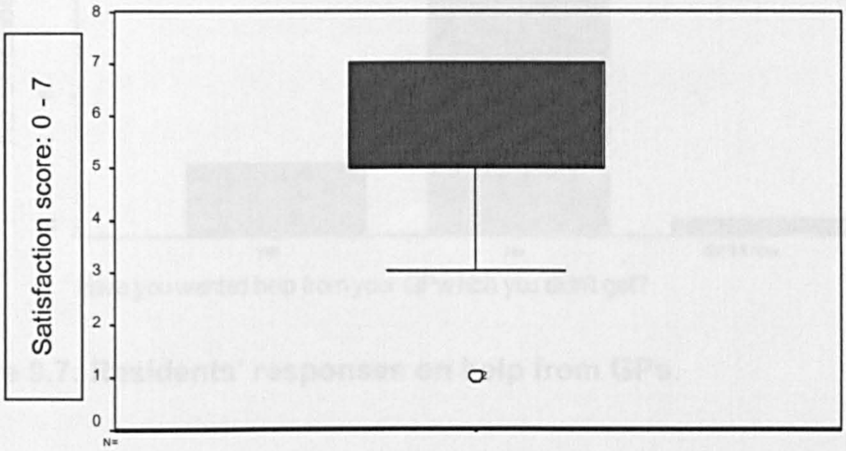


Figure 9.5 : Resident's satisfaction with their physical health

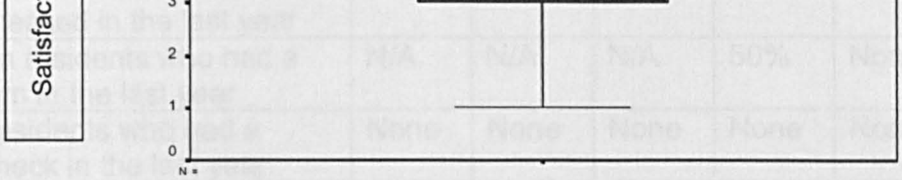


Figure 9.6 : Residents' satisfaction with their mental health

All of the residents were registered with a GP. Only 5 out of 30 residents (16.6%) received annual health checks. Organisation C reported regular health checks at least yearly for 3 out of 4 residents. Organisation B reported annual health checks for 2 out of 9 residents.

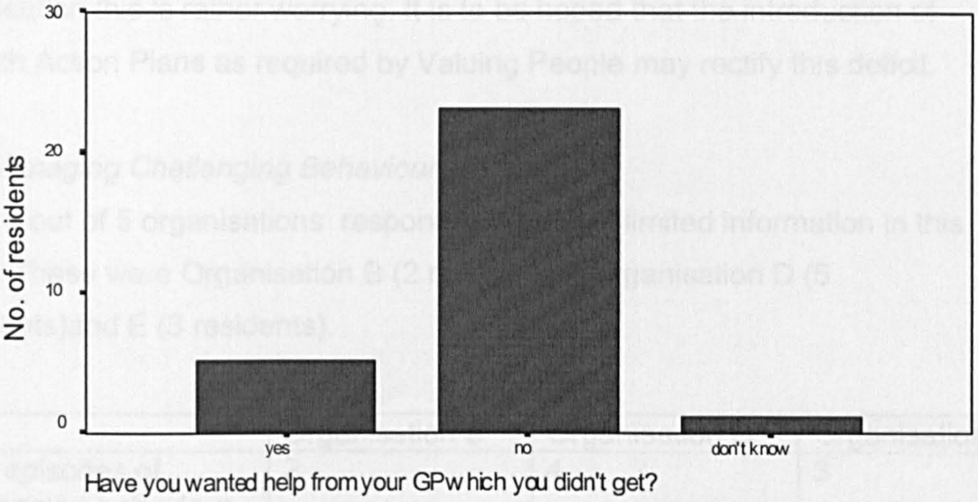


Figure 9.7: Residents' responses on help from GPs.

Despite the very low frequency of regular health checks received by residents, the majority of residents did not feel that they needed any additional help from their doctor.

Visits to the dentist were not routinely reported in all organisations. In 7 cases (23.3%) dates of visits to dentists could not be ascertained. In 73% of cases, however, keyworkers said that residents had visited the dentist within the last year.

Organisation	**A**	**B**	**C**	**D**	**E**
% of residents who had their blood pressure checked in the last year	None	55.5%	75%	100%	None
% of women residents who had a mammogram in the last year	N/A	N/A	N/A	50%	None
% of men residents who had a testicular check in the last year	None	None	None	None	None
% of residents who had an eye test in the last two years	33.3%	55.5%	100%	80%	None
% of residents who had an ear test in the last year	None	88.8%	75%	60%	None
% of women residents who had a cervical smear in the last 5 years	N/A	N/A	N/A	50%	None

Table 9.30 : Percentage of residents who had routine health checks

Either organisations were not recording health checks, or residents were not always receiving the full range of health checks, particularly breast and testicular checks and cervical smears. Given that most residents were receiving medication this is rather worrying. It is to be hoped that the introduction of Health Action Plans as required by Valuing People may rectify this deficit.

(v) *Managing Challenging Behaviour*

Only 3 out of 5 organisations responded with very limited information in this area. These were Organisation B (2 residents), Organisation D (5 residents)and E (3 residents).

	Organisation B	Organisation D	Organisation E
Brief episodes of challenging behaviour	2	4	3
Sustained episodes of challenging behaviour		1	
Happens once or more a week		2	1
Less often than once a week	2	3	
Less often than once a month			2

Table 9.31: Length and frequency of episodes of challenging behaviour of 10 residents.

All organisations reported that the recipient of challenging behaviour was usually a staff member. This view was not supported by residents who either described incidents in which they were hurt or felt that that they were at risk from other residents. The usual level of response in all organisations was verbal (as evidenced by incident reports). However a variety of methods were sometimes be used to control the person's behaviour (see tables below).

	Usually	Sometimes	Rarely	Never
Physical restraint			X	
Seclusion				X
Sedation	X			

Table 9.32 : Methods of restraint used in Organisation B

	Usually	Sometimes	Rarely	Never
Physical restraint	X			
Seclusion			X	
Sedation	X			

Table 9.33: Methods of restraint used in Organisation D

	Usually	Sometimes	Rarely	Never
Physical restraint			X	
Seclusion		X		
Sedation		X		

Table 9.34 : Methods of restraint used in Organisation E

Only one person in this small group for whom reports were available (n = 10) was able to come and go as they pleased. The remaining 9 required escorting.

Formulated behaviour plans were only in operation in Organisation D, the secure unit, in line with the cognitive behavioural support programme. Organisation E used a combination of 1:1 sessions and encouraging a resident to use anger management coping strategies to manage the behaviours. They did not have access to any outside help.

An analysis of files shows that all organisations used risk assessments of various levels of sophistication to help manage behaviour. However, not all residents within the organisation had risk assessments. In Organisation C, for example, one man did not have a risk assessment on file despite six recorded incidents of verbal abuse and one of property damage in two months. This may have been because these incidents were alcohol related and alcohol management issues were in his care plan. Risk assessments in the residential homes usually identified risks and a strategy for dealing with those risks. Sometimes guidelines were also on file.

Area of risk	A	B	C	D	E	Total
Danger to others	1	5		9	1	16
Verbal threats				1		1
Danger to self		2		5	1	8
Suicide				5		5
Self neglect	2	1		3		6
Absconding		2		4		6
Going out alone		1				1
Road Safety *	1	2			1	4
Inappropriate Sexual Behaviour		6	1	4		11
Obsessive behaviour				1		1
Risk taking behaviour		3				3
Sexual vulnerability		1		2		3
Physical vulnerability		1		2		3
Financial Vulnerability		3		1		4
Non-awareness of danger *				1		1
Damage to property		2		2		4
Theft				1		1
Social Isolation *		1				1
Fire setting	1	2		2		5
Epilepsy		1		2		3
Book buying		1				1
Substance abuse		1		3		4
Access to the community *			2			2
Fishing*			1			1
Attending college unaccompanied *			1			1
Travelling by car			1			1
Swimming *			1			1
Cycling *			1			1
Auditory hallucinations	1					1
Threatening/abusive phone calls	1			1		2
Smoking	1				1	2

Table 9.35 : Analysis of risk assessments on residents' files (* indicates risks related to community presence rather than challenging behaviour. Residential homes n = 13, secure unit n = 9)

As might be expected, Organisation D, the secure unit operated an extremely sophisticated risk assessment and management process. The assessment scored risk on a scale of 1 to 5 according to severity, probability and frequency and listed the action needed. Within each area of risk, the possible victim, the likely situations and the consequences of any behaviour were identified. Existing controls, staff training and any actions required to minimise risk where also identified. Safeguards and weaknesses were also examined from a resident, victim and environmental perspective. Risk assessments were reviewed frequently – usually on at least a monthly basis during the residents' first few months.

The risk assessment process was an integral part of an overall approach in the secure unit – the cognitive behavioural support programme. The programme provided

> *"..a structured framework that seeks to provide meaningful engagement and the maintenance and development of both practical skills and coping strategies. Residents are able to earn points that can be spent in the unit shop on small daily purchases or saved to purchase larger items."* (Extract from policy document).

Coping strategies were developed through coping goals which were ways of enabling residents to deal constructively with difficult situations. In this way, residents were able to develop their own skills rather than relying on physical methods or staff controlling their behaviour. An example of a coping goal is – "When I am angry or upset, I will go to my bedroom or to the calming room until I feel calmer." Residents' behaviour and use of coping goals were closely monitored and analysed, and comprehensive guidelines distributed to staff. Residents were also offered other tools to help them understand and manage their behaviour such as mood diaries and anger management groups.

One man, who had committed manslaughter, had learnt a way of managing his anxieties and his behaviour when he saw small boys that he was attracted to when out in the community.

> *"I've been in hospital for 22 years. I did a very bad thing. I killed a 12 year old boy. I regret it very much. It was because I was jealous, he went off with a boy of his own age and I didn't expect it to happen. I was 20 then and I'm 49 now. I don't want to leave hospital, I want to stay here for the rest of my life. I want to stay here because I'm scared that I might do it again. I don't want to hurt anyone."*

> *"If I get upset about children, I do my prompt – [tap member of staff] twice on the back and then we move elsewhere."*

Risk assessments in Organisation B were the most sophisticated of all the residential homes. They usually clearly specified the nature of the risk e.g.

danger to others, rather than an activity, e.g. cycling; classified the risk as high, medium or low; and had a range of mechanisms to deal with the behaviour. Organisation B also addressed the management of recorded incidents through the risk assessment process. Some organisations included behaviours which are not normally seen as risky, e.g. excessive book buying behaviour. In all of the organisations, most recorded incidents were of verbal or physical aggression to residents or staff or damage to property. In Organisations A, C and E, the areas in the risk assessment did not reflect the nature of the incidents recorded. In Organisations A and C the main response to areas of risk identified were supervision and medication. Clearly enabling residents to develop ways of managing their own behaviour requires some degree of sophistication in terms of analysis and strategy, and therefore it is worrying that some organisations did not offer this at the time of the study.

Review dates varied - there appeared to be little consistent approach. In Organisation C, one home reviewed their risk assessments every 2 months. In Organisations A and E, it was usually every 3 months. In Organisation B, frequency varied considerably and residents who had been there for longer periods of time had their risk assessments reviewed annually.

(vi) Increasing Independent Living Skills

The majority of residents thought that some new skills were being taught and an analysis of file records confirmed that staff were supporting the development of skills in a focused way. It is possible that some residents may not have considered the development of self-care skills etc. which was one of the key areas identified, as the teaching of new skills as in most cases most people knew how to carry out these tasks but needed prompting.

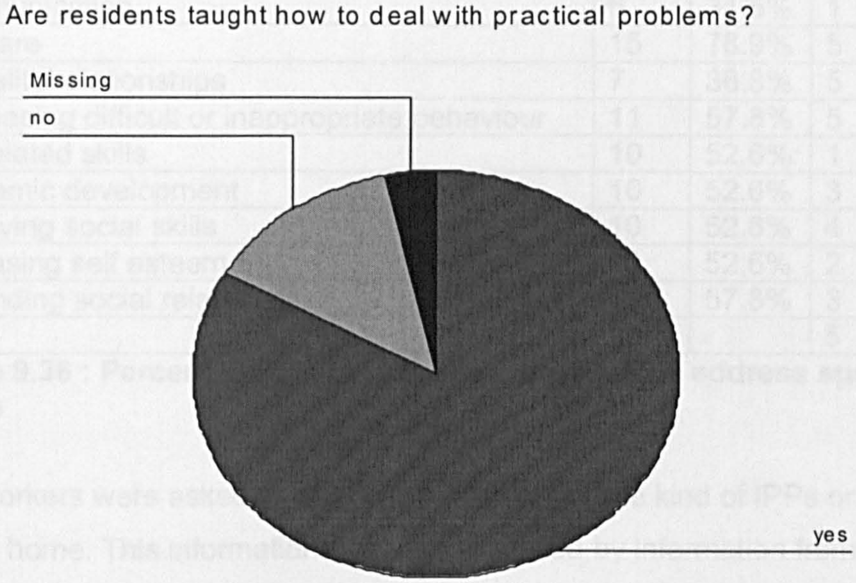


Figure 9.8 : Residents' views on teaching how to deal with practical problems.

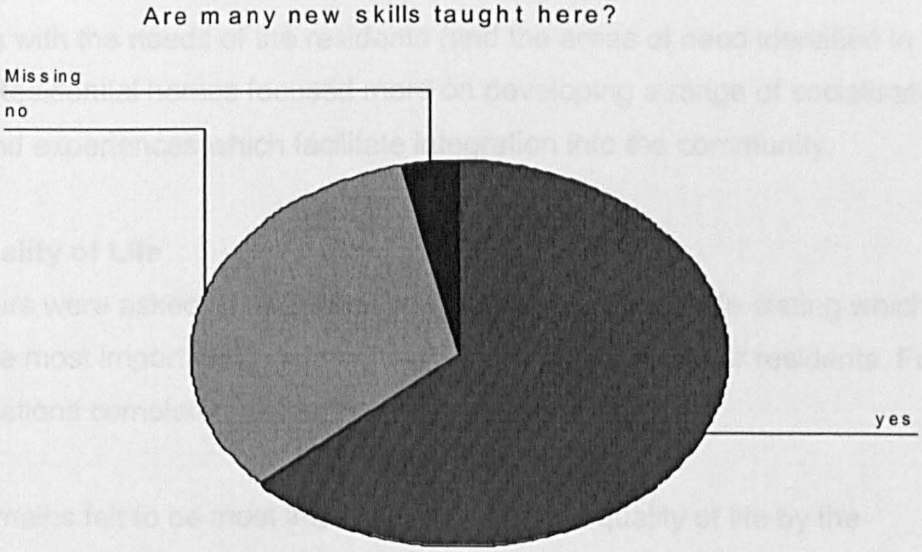


Figure 9.9 : Residents' views on whether new skills are taught.

	Organisation A, B,C and E		Organisation D	
Area of Individual Programme Plan	No.	%	No.	%
Communication	6	31.5%	1	20%
Self care	15	78.9%	5	100%
Sexuality/relationships	7	36.8%	5	100%
Decreasing difficult or inappropriate behaviour	11	57.8%	5	100%
Job related skills	10	52.6%	1	20%
Academic development	10	52.6%	3	60%
Improving social skills	10	52.6%	4	80%
Increasing self esteem	10	52.6%	2	40%
Expanding social relationships	11	57.8%	3	60%
Total	19		5	

Table 9.36 : Percentage of plans for residents which address specific areas

Keyworkers were asked to give information about the kind of IPPs or care plans in the home. This information was supplemented by information from files where this was possible. The areas of focus in the IPPs differ somewhat between the residents of residential homes and those residents in the secure unit for whom information was received. All the IPPs support the development of self care skills. The secure unit focused more on decreasing difficult or inappropriate behaviour and on the areas of sexuality and relationships in keeping with the needs of the residents (and the areas of need identified in the ABS). Residential homes focused more on developing a range of socialisation skills and experiences which facilitate integration into the community.

9.5 Quality of Life

Managers were asked to rate various domains of quality of life stating which were the most important in determining a high quality of life for residents. Four organisations completed this section (see Appendix 39).

The domains felt to be most important to residents' quality of life by the managers were :

- Choice over day to day matters
- Emotional support from others
- A range of regular scheduled activities
- Respect from others
- Being happy and contented

- Protection from exploitation and abuse
- Privacy
- A clean and safe home environment
- Choice over where to live and who to live with
- Involvement in decisions about house standards and rules
- Having religious needs met.

This section will examine the outcomes for residents and in particular ascertain whether or not the most important aspects of quality of life as identified by managers (with the exception of a clean and safe home environment) are actually delivered in the homes that they are responsible for managing.

(i) Choices

Managers identified choice over day to day matters and choice over where to live and who to live with as important aspects of quality of life for residents. Residents were asked if they could choose what time they got up and went to bed; when and what they ate; what they did; who they lived with; members of staff and who their keyworker was. Residents were also asked about their current placements. There was often no agreement amongst residents about what they could choose from the same house.

The majority of residents said that they could not choose what time they got up or went to bed during the week. Sometimes this was because they had to be up by a certain time to attend day-time activities or to have breakfast.

> *"Well, you can choose, but you have to be up. The staff knock on your door and say come on you have to come down for your medication. If I'm having a bath, they have to wait until I'm dry and dressed. Usually I miss breakfast because I get down too late. I'm in the bathroom washing my face and cleaning my teeth and by the time I get down the breakfast is cleared away."*

Residents could often stay in bed later at the weekend.

> *"Monday to Friday, they prefer me to be up by half past nine, ten o'clock so I'm up and about. Saturdays and Sundays I can stay in bed a bit longer. "*

Residents were able to go to bed early, but not usually stay up late.

> *"If you're tired and you've taken your pills, you could go to bed early."*
>
> *"I go to bed early – they say you go to bed too early. I don't care, I just go to bed."*
>
> *"No you can't choose what time you go to bed and get up. There was this film on tv the other night. I watched a bit of it and then had to go to bed."*

Residents from all organisations were unable to choose what time they ate. Most residents (22) said they had no choice or limited choice of what they ate.

> . *"[I] eat non-halal meat. Not pork. I'm a Muslim – I need to eat halal."*
>
> *"There is a menu and you can choose what you eat on it. If you don't like it – you eat nothing."*
>
> *"If you don't like it, just ask for salad or eat some, leave it and go on to pudding. You're not allowed to eat pudding unless you eat half your food. There isn't enough food and I'm hungry a lot."*
>
> *"No you can't choose. The food is not always edible. The staff fill up their plates and we only have 3 potatoes. They should fill up all our plates. They sling it in the bin. They won't allow us to have seconds at all. They should give us big meals here."*

Of the residents (8) who said that they could choose, six lived in organisation B.

Food was a particular issue in the secure unit. Most of the residents complained about both the quality and quantity of the food.

Residents had some choice of activities. Clearly residents in the secure unit had more restrictions on community based activities. Activities will be discussed in more detail in the next section.

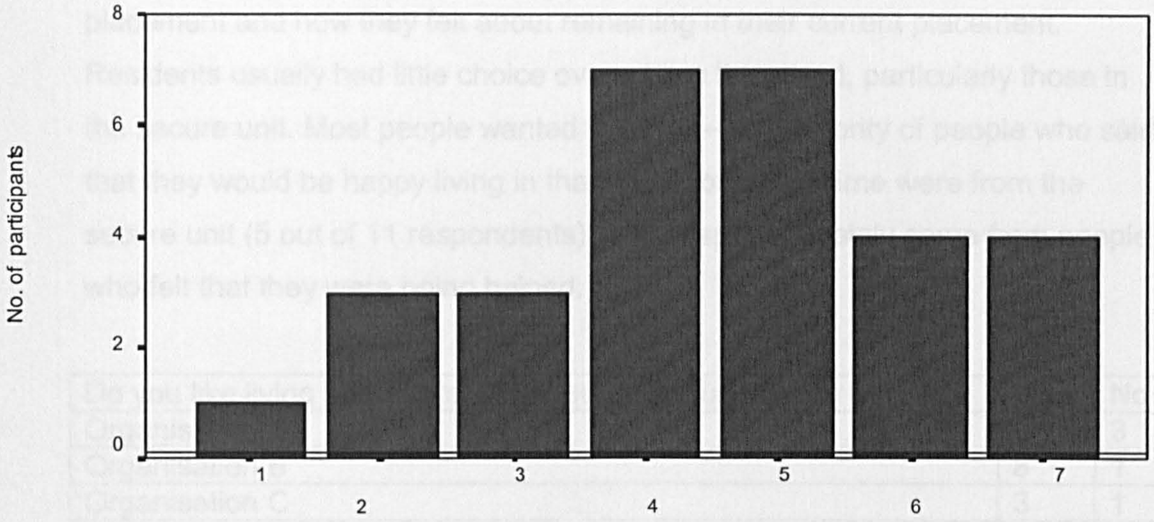


Figure 9.10 : Residents' level of satisfaction about living with the people that they did.

Residents were asked to say how happy they were living with the people that they did, on a scale of 1 –7 with 1 representing "couldn't be worse", and 7 "couldn't be better." Nearly 25% of residents (n=7) said that they were not happy or very unhappy about living with the people that they did. Four of these lived in the secure unit. Only residents in Organisation B reported being okay or happy living with the other residents.

Residents could not choose who they lived with or who worked with them. Although managers stated that in some organisations, residents had a say in who was appointed, none of the residents were aware of this. The majority of residents could not choose their keyworker. Four residents in Organisation B said that they had chosen their keyworker.

> *"[they said to me..] how about a mad keyworker who supports Arsenal? I said yes alright."*

Residents in Organisation D were divided as to whether you could choose your keyworker or not.

> *."You can't pick and choose."*
>
> *"I think they're allocated to you. You could ask for them to be changed, they would consider it."*

Residents were asked if they preferred their current placement to their previous placement and how they felt about remaining in their current placement. Residents usually had little choice over where they lived, particularly those in the secure unit. Most people wanted to move – the majority of people who said that they would be happy living in that home for a long time were from the secure unit (5 out of 11 respondents). This response mainly came from people who felt that they were being helped.

Do you like living here better than your previous home?	Yes	No
Organisation A	0	3
Organisation B	8	1
Organisation C	3	1
Organisation D	4	7
Organisation E	2	1
Total	17	13

Table 9.37 : Residents' views on current placement.

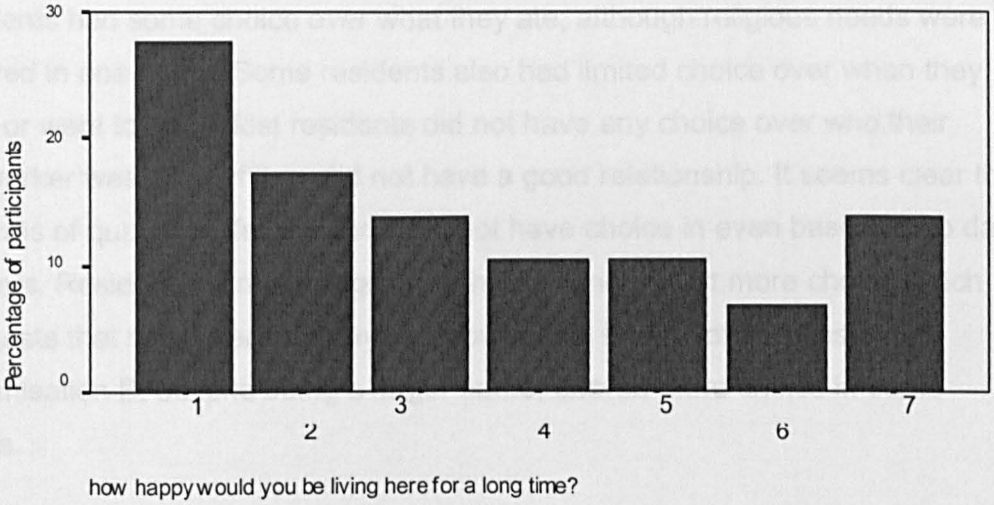


Figure 9.11 : Residents' views on staying in current placement (1 = "couldn't be worse", 7 = "couldn't be better").

Residents who liked their current placement usually liked the staff, the location and other residents. In some cases, residents had come from a more restrictive environment or from an unpleasant situation – e.g. being bullied or living on the streets.

> *"I like it here. Some of the patients are against the place. I like it. Its better than nothing: otherwise its cardboard boxes."*

Residents who did not like their current placement tended not to like the staff, residents or location. Some residents had preferences for a mixed home rather than male only.

> *"too far from bigger towns, no cinema, nowhere to go."*
>
> *"change some of the clients. Have some quiet ones."*

For residents from all the homes, but particularly the secure unit, moving from a less restrictive environment was a key factor in their preference for a previous placement.

> *"I could have home leave and go to my nan and grandad's for a whole night."*

In summary, as regards choice, residents were unable to choose where they lived, who they lived with, when they ate and who worked with them. Some residents had some choice over what they ate, although religious needs were ignored in one home. Some residents also had limited choice over when they rose or went to bed. Most residents did not have any choice over who their keyworker was, even if they did not have a good relationship. It seems clear that in terms of quality of life, residents did not have choice in even basic day to day matters. Residents from small group homes did not report more choice which suggests that there were equally rigid routines in homes of all sizes. Organisation B, despite being a larger home, offered more choice in some areas.

(ii) A range of regular scheduled activities

Organisations differed widely in the range of scheduled activities that they provided. There were also differences within homes as to the level of activities each resident had access to. This appeared to be related to the local facilities and resources available, the length of time the resident had been living in the home and the commitment of the keyworker. Many residents were often bored – particularly in the evening and weekends. Residents were asked what they did during the day, in the evening and at the weekends. They were asked if they enjoyed those activities and whether they would like anything to be different.

The experiences of residents from residential homes was different from that of those living in the secure unit, as the secure unit had a Learning Support Unit on site which provided a wide range of activities for residents on weekdays.

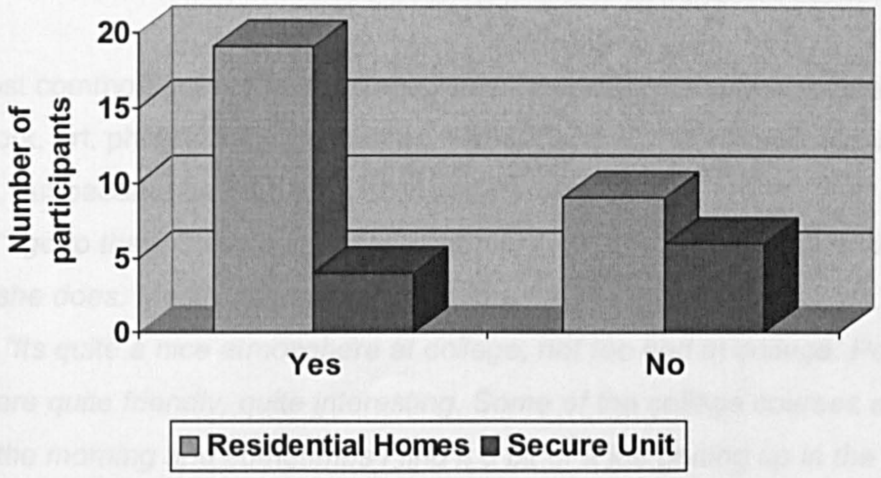


Figure 9.12 : Have you been bored during the last month ?

Organisation	Number of residents attending regular scheduled activities
A	0 (out of 3)
B	6 (out of 9)
C	4 (out of 4)
D	11 (out of 11)
E	2 (out of 3)
Total	12

Table 9.38 : Number of residents attending regular scheduled activities

Type of activity	Organisation B	Organisation C	Organisation D	Organisation E
College	4	3		1
Day centre	1			2
Voluntary work	2	1		1
Swimming	1		2	
Reading and writing*			4	
Arts and crafts*			5	
Computers*			4	
Sports			4	
Life Skills			3	
Woodwork*			3	
Gardening			2	
Music*			2	
Bowling			2	
Horseriding			2	

* Activity carried out in Learning Support Unit on site of Organisation D.

Table 9.39 : Type of activity attended by residents living in residential homes

12 out of 19 residents from the residential homes attended some form of regular scheduled activities. Most of these activities were very part-time. Three residents attended activities for between 21 and 25 hours a week. The remainder attended activities for less than 10 hours a week.

The most common activity was college – residents attended cooking, literacy, woodwork, art, photography, gardening, French and IT. Residents enjoyed college, but became bored during holidays.

> *"I go to the PC day centre for computers. K takes me and S down there, she does. Mostly its just us."*
>
> *"Its quite a nice atmosphere at college, not too bad at college. People are quite friendly, quite interesting. Some of the college courses are in the morning and sometimes I find it a bit of a job getting up in the morning."*

Residents also enjoyed the day centre. 2 residents attended a day centre run by the organisation.

> *"Never can tell what we do next – cooking, soap making, bath crystals. D [keyworker] says I'm too able – but I like it."*

3 residents also had part-time voluntary work. One woman went for 2 days a week, and one man for 2 mornings a week. One man worked in the house garden.

> *"Its excellent. It keeps me occupied. I love the summer flowers."*
>
> *"I like going for something to do. I like helping people – doing something for someone. Like paying my money back to society. Bit scared sometimes – you can meet some strange people."*

Residents who did not attend any day time activities – all 3 people from Organisation A, 3 people from Organisation B and 1 person from Organisation E found different ways of filling their days. They played pool, watched tv and listened to music. One resident used to go home and take his child to and from school. Another man spent his time walking and sleeping or visiting Turkish cafes. Staff from Organisations B, D and E also organised ad hoc activities such as bowling, shopping and pub lunches.

11 residents (out of 19) said that they got bored during the day. 9 residents wanted to change their day-time activities. Some people were not sure what they would prefer to do, and some people wanted to do more than one thing. 4 residents wanted to go to work, 4 residents wanted to go out more, 2 wanted to go to college and 1 resident wanted to visit friends.

> *" I would like more things to do. I would like to go out a lot more- day trips, do more things and go to London more often. I'd like there to be more activities, more fun things – cinema trips, museums. Another course, possibly woodwork. Get a job and more friends. When I get bored, I drink to pass the time."*

The 11 residents in the secure unit all attended the Learning Support Unit. This provided similar activities to those received by residents from residential homes who attended college. Residents from the secure unit mostly liked all their activities. One resident did not like the people he did the activities with. One resident did not like doing sports.

> *"I go out on Thursdays – we go different places, bowling. I don't go swimming. We wash the vehicles down in the summer with a hosepipe. Its not too bad here you know."*

> *"I do art in my room, English and sums in my room. I couldn't read when I first came here, but I can read a lot better now. I like going on the computer. I'm doing a table cloth for my Mum and Xmas decorations. I do English and sums with a proper teacher. I do a Library project about space. I do woodwork – I made a lovely table for my Mum. I do gardening and I do life skills. I go out. "*

> *"I like the activities. Its like a rehab to get off drugs and really I'm really pleased with that. Helps you get back into the community. Makes you think of what you need on the out."*

Residents were also expected to do their house activity goals during any free time which included anytime during the day – this often included cleaning activities. Residents had very mixed feelings about this.

> *"I'd like to go to the pictures and to the seaside instead of cleaning every 5 minutes."*

7 people from the secure unit did not get bored during the day. 3 residents wanted changes to their day-time activities – 2 people wanted to go out more. One person wanted "a discussion group to talk about society and everyday life."

Evening and weekend activities tended to be very similar for residents in all of the organisations.

Evening and weekend activities	Watching tv	Watching videos	Listening to music	Reading	Going to the pub	Cinema	Other
Organisation A	3		1				3
Organisation B	7	3	4	2	3		6
Organisation C	4					2	
Organisation D	6	6	2	1			5
Organisation E	2	2			2		2

Table 9.40: Number of residents undertaking evening activities in the last month

Evening activities were generally carried out with staff, other residents or alone. Other activities included having a bath (5); doing goals (2) ; going to social clubs (1) and ,in the case of Organisation A, sleeping and walking (3). 16 people liked what they did in the evenings – 9 of these lived in the secure unit. 17 residents were bored in the evening – 6 of these were from Organisation B and 3 from Organisation A. 18 people would like different things to do in the evening – going out more, especially to the pub.

> *"..more activities, places to go, things to do, places to see."*

Weekend activities were undertaken with staff, other residents or by themselves. Other activities including goals (4), playing football (2), playing on the computer (1), going to car boot sales (1) and going shopping (5). For

Organisation A, this was sleeping and walking. 17 people liked what they did at the weekends. 9 of these residents lived in the secure unit. Some people found it hard to cope with the level of activity offered there.

> *"I've got so much to do but because I feel less motivated, isolated, the weekends are pretty hard. And because of my illness and that it stops me doing regular things in my bedroom. Sometimes the voices get busy in my head and it stops me doing things."*

18 people got bored at the weekends. 7 of these lived in Organisation B. Again most people wanted to go out more.

> *"Sometimes it would be nice to go out more. We don't go out much because we are short of staff. We don't do much here – so either more activities in the home or go out somewhere."*

> . *"I don't like staying in every Saturday and Sunday. I do have a go at them sometimes. I went out – car ride to Asda, Argos. I like to go out. These staff are really boring."*

> *A "day seems a long time trying to find what to do: It's a bit like catching a plane."*

In summary, only Organisation D offered a range of scheduled activities that appeared to occupy residents during the week. Residents seemed to be able to manage their unstructured time without getting too bored because of this. Organisation A offered no external activities at all for residents, although file records did show that attempts had been made to find activities for one resident. Organisations B, C and E offered some structured activities, but there were high levels of inactivity and boredom in all of these organisations, particularly Organisation B.

(iii) Emotional support, respect from others and social networks

Positive relationships have long been recognised as being an essential part of a high quality of life. Friendships, relationships with staff and other family members are explored in this section.

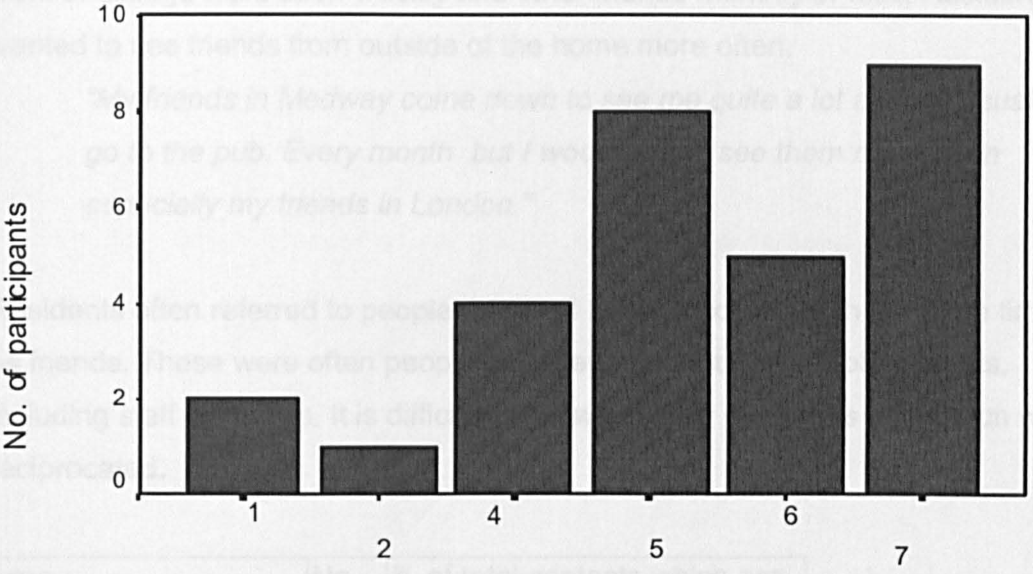


Figure 9.13: How satisfied are you with the number of friends that you have? (1 = couldn't be worse, 7 = couldn't be better)

The majority of residents said that they were fairly satisfied with the number of friends that they had (a score of 4 (okay) or above). However, 21 (n=30) people also said that they would like more friends. Of these two people said that they did not have any friends.

> *" I want to have more friends but they've got to be not violent."*
>
> *Some people did not want more friends.*
>
> *"I don't like too much friends – too many makes you go crazy. Too many and I have to use a lot of brains with them because they all different."*

Most people described co-residents and, in the residential homes, members of staff, as friends. One person did not.

> *"Friends in here are not proper friends."*

Sometimes people felt that they saw the same people too often.

> *"I get bored seeing them day in, day out. I'd rather go out and see different faces."*

In general, friends who were co-residents were seen every day, friends from work or college were seen weekly and other friends monthly or less. Residents wanted to see friends from outside of the home more often.

> *"My friends in Medway come down to see me quite a lot and we usually go to the pub. Every month but I would like to see them more often especially my friends in London."*

Residents often referred to people they had not had contact with for some time as friends. These were often people that they had met in other placements, including staff members. It is difficult to know whether or not this perception was reciprocated.

Area	No.	% of total contacts which are of this kind
Household	108	26.67
Residential staff	124	30.62
Visiting staff	30	7.41
Work/day	34	8.40
Clubs etc	7	1.73
Service contacts	1	0.25
Neighbours	0	0.00
Family	67	16.54
Other friends	32	7.90
Social acquaintances	2	0.49

Table 9.41: Social Networks : Area of life where contact occurs for residents in the residential homes.

Area of Life	No.	%
Household	79	25.57
Residential staff	94	30.42
Visiting staff	15	4.85
Work/day	60	19.42
Clubs etc	0	0.00
Service contacts	2	0.65
Neighbours	0	0.00
Family	40	12.94
Other friends	19	6.15
Social acquaintance	0	0.00

Table 9.42 : Social Networks : Area of Life where Contact Occurs for residents in the secure unit.

	No.	%
User	123	30.37
Staff	176	43.46
Advocate	0	0.00
Retail	1	0.25
Family	67	16.54
Social acquaintance/ other friends	38	9.38

Table 9.43 : Breakdown of social network of people in residential homes (n = 19)

	No.	%
User	113	36.57
Staff	128	41.42
Advocate	7	2.27
Retail	2	0.65
Family	40	12.94
Social acquaintance/ other friends	19	6.15

Table 9.44 : Breakdown of social network of people in secure unit (n =11)

An analysis of information gained from the social network grid highlights the limited nature of peoples' social networks and the opportunity to make friends outside of their home.

> *"Its sad when you leave, I always cry I do. I always cry I do. I'm leaving my friends behind."*

It was remarkable that not one resident had contact with neighbours and although a number of people accessed ordinary community facilities, only one person in residential homes and 2 in the secure unit had developed any kind of relationship with people in them. It is difficult to understand why this is – there clearly were restricted opportunities, but most people were rated as being average or above average in socialisation skills. It may be that they were not very confident or that their skills were not of a sufficient level to develop casual relationships in this context. It may also be due to the level of staff supervision that they required.

The analysis also shows that the opportunities for developing social contacts do not appear to be more limited for people in the secure unit. The average size of the social network for people in the secure unit was 33 (range of 30 –45) and that for people in residential homes, 21.3 (range of 4 – 45). Residents in the secure unit came into contact with more staff, more residents and more people through day activities. Contact usually occurred on the campus site. Residents in residential homes were meeting more people who did not live on the same site, although most of these people had learning difficulties. Although people in residential homes had somewhat more friends who did not have a learning difficulty, the majority of these were long standing acquaintances, such as friends of the family or neighbours, that people had met when living somewhere else.

The kind of activities carried out with friends include watching tv , playing games, listening to music, taking part in activities such as trips out, and talking, including talking about problems. Emotional support was often provided by friends who lived in the same home and was usually reciprocal. Residents also helped each other with practical things like using a computer or making Christmas cards.

Areas of support	Residential Homes	Secure Unit
Personal	4.06%	0
Domestic	5.08%	42.93%
Material	24.37%	15.66%
Decision	0	0
Confide	35.53%	31.31%
Company	16.75%	0
Invisible	2.03%	0
Critical	12.18%	10.1%

Table 9.45: Support given to residents by all social contacts

Residents were asked what all their social contacts helped them with and what they helped their social contacts with. Many people found this question hard to answer. Residents often minimised the amount of support they received when compared to their files or staff reports. The range of support reported by residents given to themselves by staff in residential homes was wider than that in the secure unit. In residential homes, residents reported that staff would help them with personal care such as washing their hair or their backs.

Residents in the secure unit were expected to take on responsibility for a wide range of domestic tasks such as cleaning communal areas. This was not the case in the residential homes. Residents in the secure unit said that staff helped them with obtaining cleaning materials etc. Staff also helped residents with washing, bed making etc. in all of the homes. The main aspect of support identified by all residents in the material domain was that of going out. Residents were often only able to go out with staff support.

Residents said that both staff and residents provided emotional support. In the secure unit, more residents than staff provided emotional support to other residents. In the residential homes, more staff provided emotional support to residents than other residents. This is probably linked to the fact that more people in the residential homes viewed staff as their friends than in the secure unit.

Residents identified staff and other residents as keeping them company in the residential homes. They also identified other residents as keeping a watchful eye on them. Residents often took care of other residents that they considered to be more vulnerable or less able than themselves.

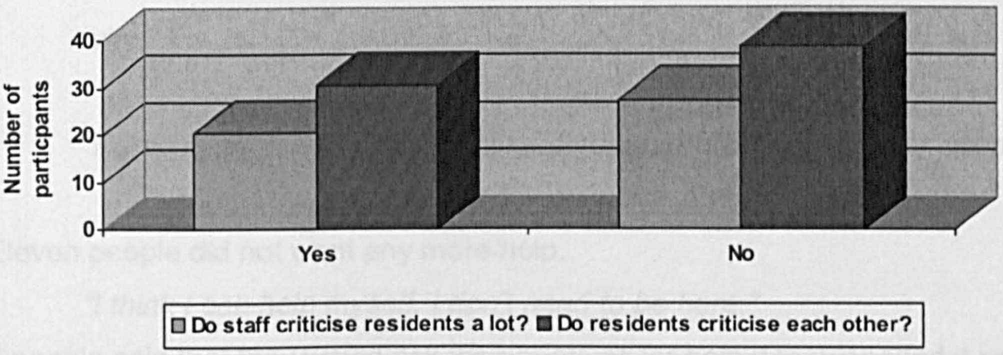


Figure 9.14 : Residents' views on staff and residents criticism

Criticism was experienced from other residents in both the residential homes and the secure unit, and from staff in the residential homes. One resident said that she would prefer it.. "if some staff didn't make annoying remarks to me when things go wrong."

Residents were more likely to identify criticism in general terms than when asked whether they experienced criticism themselves.

Residents said that they helped staff. Residents in the residential homes said that they listened to staff when they had problems, took messages and went to the shops for staff. Residents in the secure unit were less likely to feel that they helped staff – one resident said that he helped staff with computers; another that she helped new staff settle in. Many residents felt that they had reciprocal relationships with staff which consisted of providing practical support.

Would you like more help from staff?	Yes	No	Don't Know
Organisation A	1	2	0
Organisation B	5	2	2
Organisation C	4	0	0
Organisation D	3	7	1
Organisation E	3	0	0
Total	16	11	3

Table 9.46 : Would you like more help from staff?

Sixteen people said they would like more help from staff. The kind of help they wanted was more practical and emotional support. Practical help included things like making beds and going out. One person wanted help with budgeting.

> *"Be with me all the time, take me out. They don't do it here. I don't know why."*
>
> *"Personal problems- talking things through and talking to other people."*

Eleven people did not want any more help.

> *"I think I can help myself. I don't need to be here."*

3 people said that they would ask their relatives for help if they needed it rather than staff. One person said that he would ask the police.

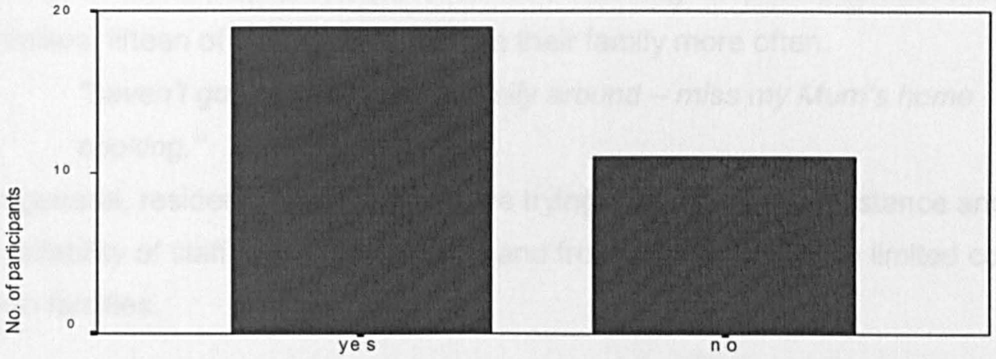


Figure 9.15 : Do staff ever talk down to residents?

63.3% of residents said that staff talked down to them or to other residents. When asked about what they would like to change about the staff, one resident said:

> *"Just a few things need changing – not many – the attitude towards clients. The way they talk to [Sam] and things like that. He's a human being like everyone else."*

Some residents felt that they needed more understanding from staff.

> *"Be more understanding when I'm not in the right mood. Instead of telling me off they need to find out why I'm upset."*
>
> *"To hear me out: don't interrupt me. Try and feel like I've swapped places and see how they feel."*

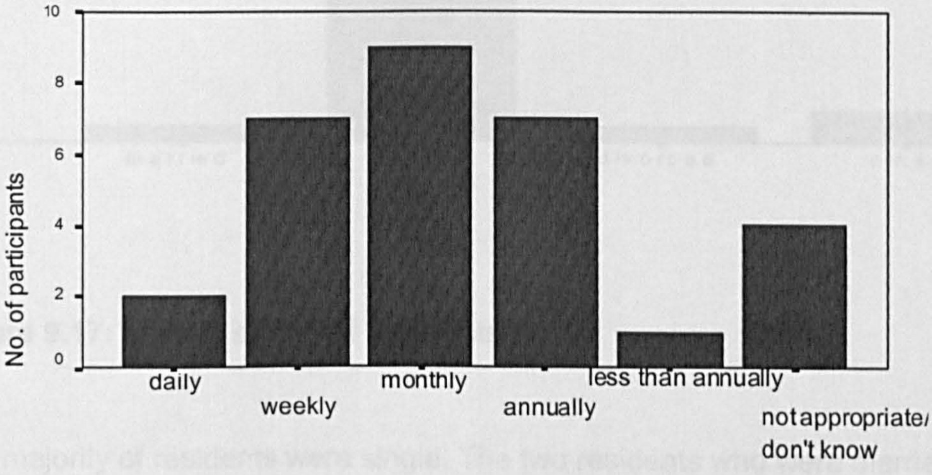


Figure 9.16: How often do you have contact with your family.

Many residents (26) had frequent contact, including telephone contact with their families, fifteen of these wanted to see their family more often.

> *"haven't got my friends and family around – miss my Mum's home cooking."*

In general, residents felt that staff were trying to facilitate this. Distance and availability of staff to escort people to and from family visits often limited contact with families.

> *"I want to but they won't let me go out on my own. I get lost you see. I need a member of staff who knows the way."*

Sometimes it was not felt appropriate for people to visit their family. One woman who had staff support to visit her family every 4 weeks said:

> *"I used to stay overnight – I don't anymore. I don't know why."*

Figure 9.17: Marital status of residents

The majority of residents were single. The two residents who were married or who had been married both lived in Organisation A, the mental health home. Six residents said that they had a girlfriend or boyfriend. One resident said that two female members of staff were his girlfriends and another resident said that he had met his girlfriend in a day centre 10 years ago but he no longer saw her. 6 people wanted to have a girlfriend or boy friend.

> *"I would like to meet girls and not be frightened by them."*

Most people did not want anything to be different about their relationships. Four people did and these were all from Organisation D (the secure unit).

> *"Everlasting friendship."*
>
> *"Yes, I'd like when I mix with the associate people, I wish they'd be more understanding and realise that my illness is great because of the family cycle. I'm trying to break out of the family cycle. I'm not very outgoing."*
>
> *"More friends on the out to get off drugs and realise its bad for them and to have good times without drugs, be happy, think positive."*

(iv) Being happy and contented

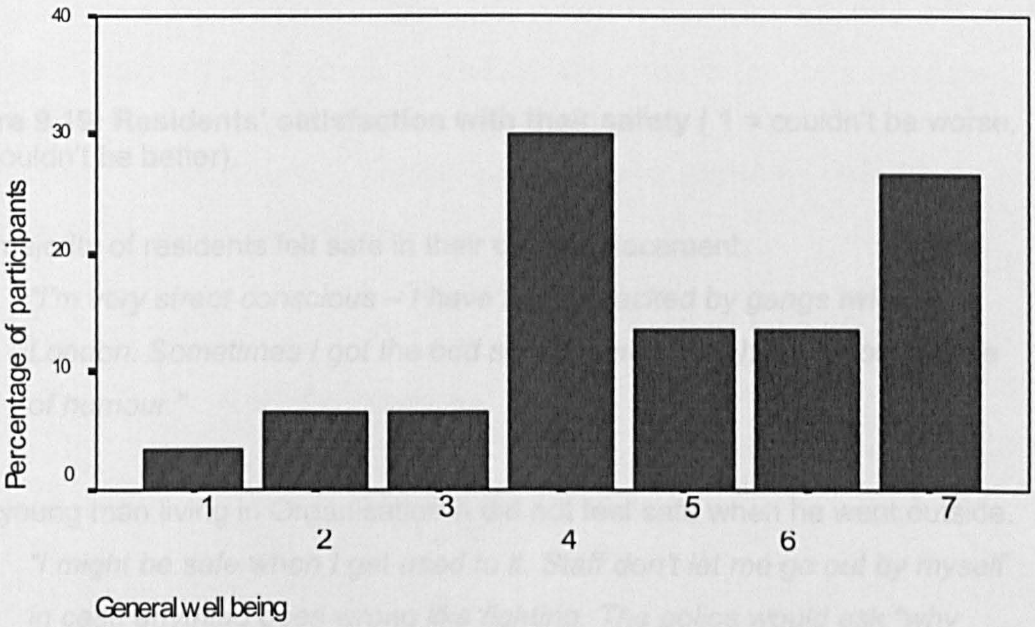


Figure 9.18 : General well-being of all residents

Happiness or contentedness is a hard concept to measure. Residents were asked to rate their general well-being – how happy they were with various aspects of their life, on a scale of 1 to 7, where 1 represents couldn't be worse and 7 couldn't be better. Most residents rated their lives as being okay or better. Only 4 people rated themselves lower than okay. Two people in the secure unit rated themselves at 2 and 3, and two people in Organisation A rated themselves at 1 and 3 respectively.

(v) *Protection from exploitation and abuse*

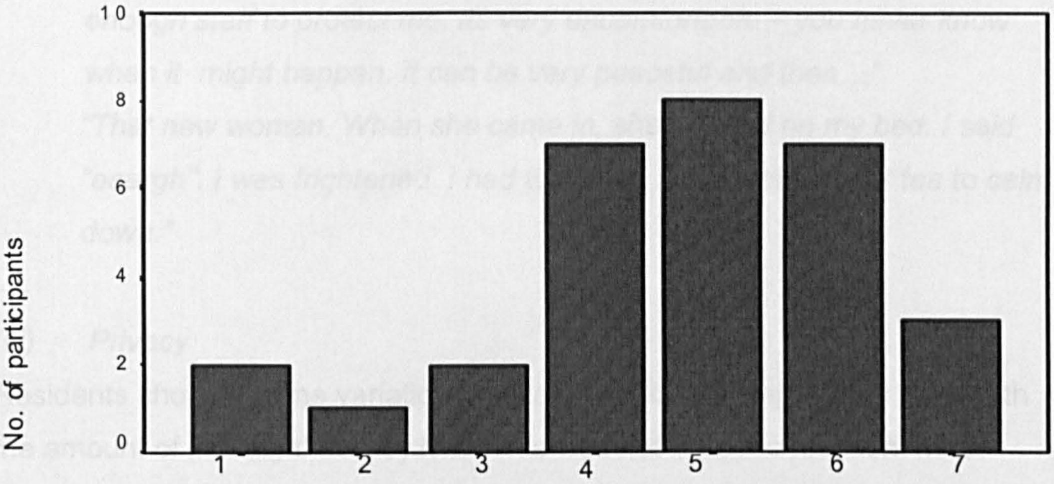


Figure 9.19: Residents' satisfaction with their safety (1 = couldn't be worse, 7 = couldn't be better).

The majority of residents felt safe in their current placement.

> *"I'm very street conscious – I have been attacked by gangs twice in London. Sometimes I got the odd sly comment but I have a good sense of humour."*

One young man living in Organisation A did not feel safe when he went outside.

> *"I might be safe when I get used to it. Staff don't let me go out by myself in case anything goes wrong like fighting. The police would ask "why weren't you with them."*

3 residents in Organisation D, the secure unit, felt at risk from other residents. One resident felt that staff did not do enough to protect residents from each other. The following comments are from different residents about other residents.

> *"No – I don't like it. Just stay in my bedroom."*
>
> *"No –when she hit me the other day she said she would kill me in a couple of days and so I'm on my guard now. All I want to do is go to a nice quiet peaceful house where its more peaceful."*
>
> *"They're not strict about the violence here and that makes me annoyed and upset. I saw W was attacked and she had to go to hospital. The same girl hit me for no reason. I talked to police about it. There's not enough staff to protect me. Its very uncomfortable – you never know when it might happen. It can be very peaceful and then…"*
>
> *"That new woman. When she came in, she jumped on my bed. I said "aaargh". I was frightened. I had to have a couple of cups of tea to calm down."*

(vi) Privacy

Residents showed some variation in opinion as to how happy they were with the amount of privacy that they had. This was not linked to location. Most residents reported that staff knocked on doors etc. before entering. One resident complained that staff would sometimes come into his bedroom or the bathroom when he did not want them to. It may be that the lack of privacy that some people experienced was also linked to having to share their living accommodation with other people.

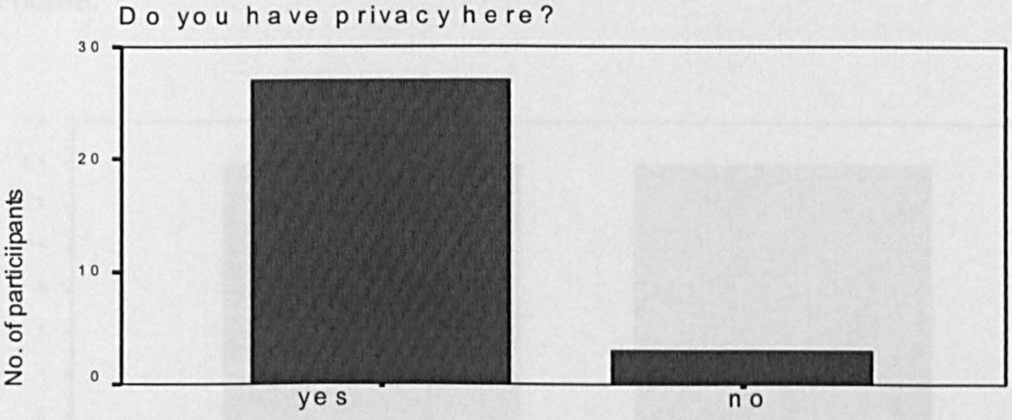


Figure 9.20 : Residents' views on privacy

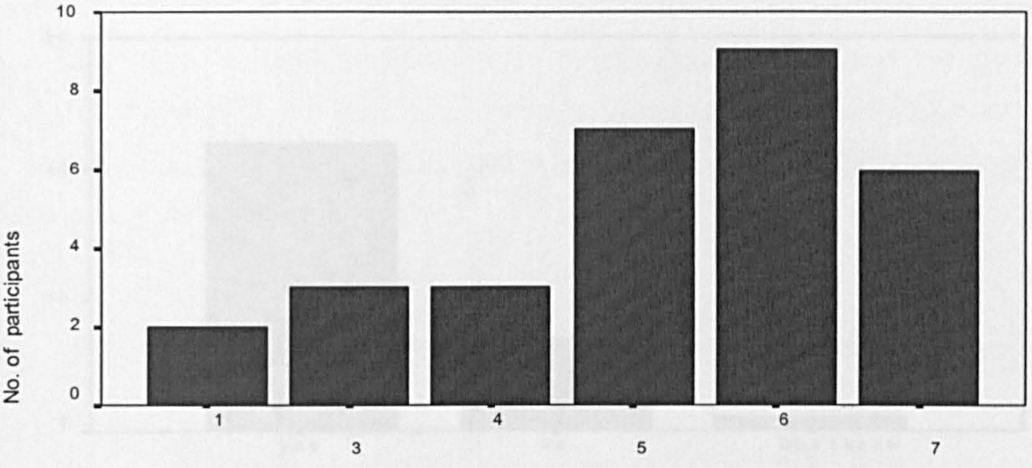


Figure 9.21: Residents' satisfaction with the amount of privacy that they have. (1 =couldn't be worse, 7 = couldn't be better).

(vii) Involvement in decisions about house standards and rules.

Nearly half of residents thought that they could have a say in the rules and nearly half did not. No-one could give an example of rules that they had had a say in. Two people did not know whether they could have a say in the rules. Most residents (21) accepted that there had to be rules, but also thought that staff were strict in enforcing them. Residents (22) mostly knew what would happen if they broke a rule. 82% of residents did think that they could influence change in their home. This disparity seems to indicate that residents thought that rules were the domain of staff and that they could influence other aspects of the home.

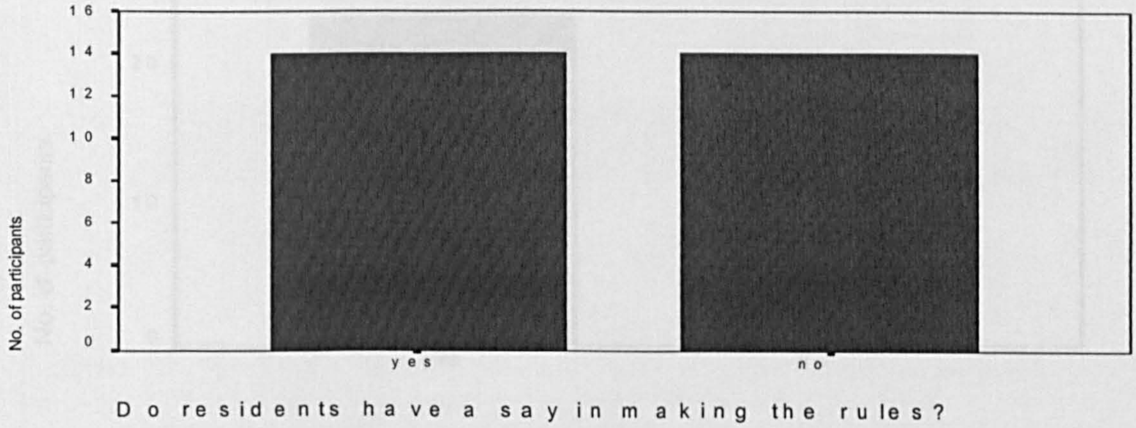


Figure 9.22: Residents' views on participation in rule making

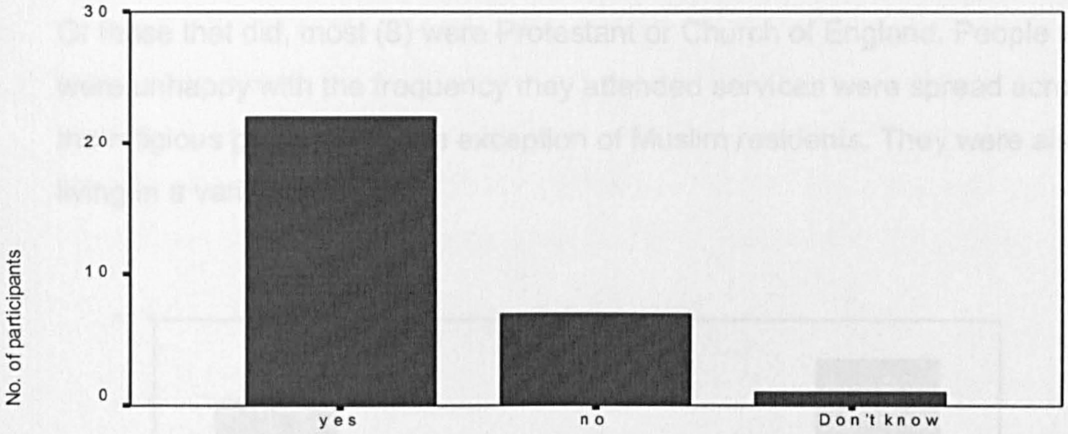


Figure 9.23: Are staff strict about the rules?

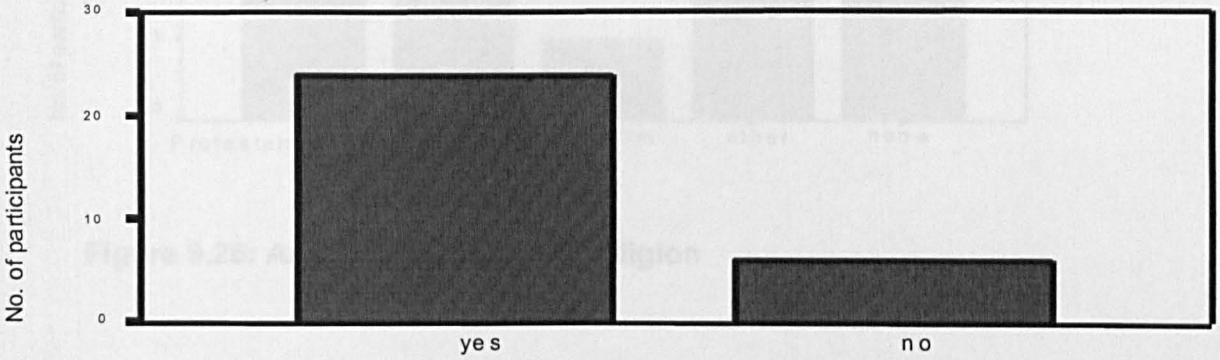


Figure 9.24 : Do residents know what will happen to them if they break a rule?

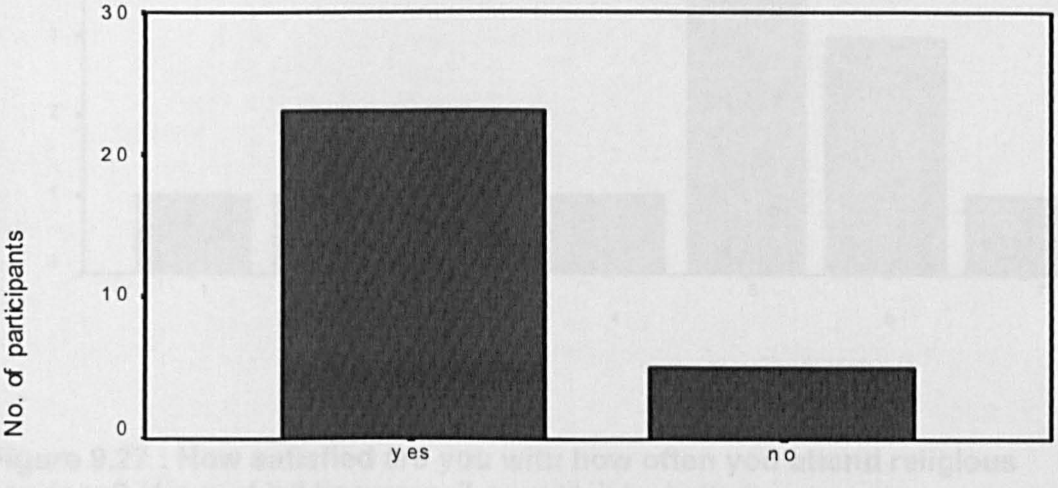


Figure 9.25: **Can residents change things if they really try?**

(iix) Meeting religious needs

Residents were asked what their religion was. 9 people did not have a religion. Of those that did, most (8) were Protestant or Church of England. People who were unhappy with the frequency they attended services were spread across all the religious groups, with the exception of Muslim residents. They were also living in a variety of homes.

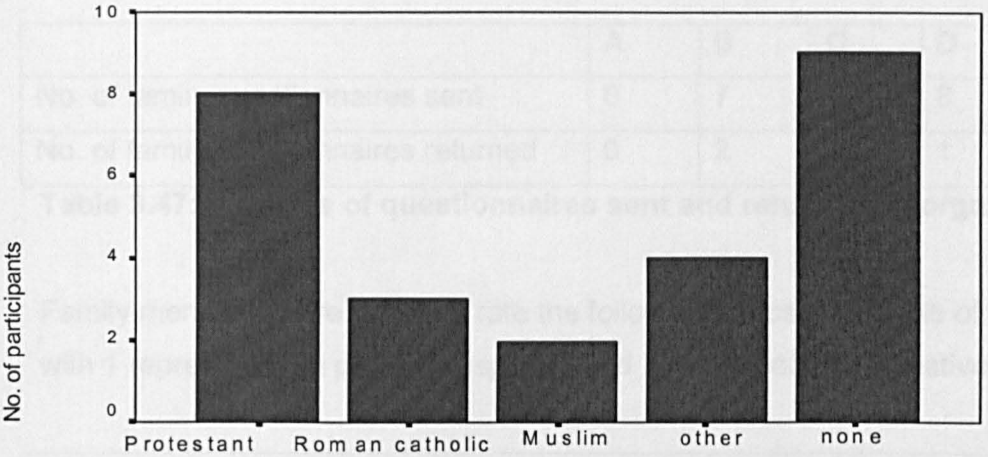


Figure 9.26: Analysis of residents' religion

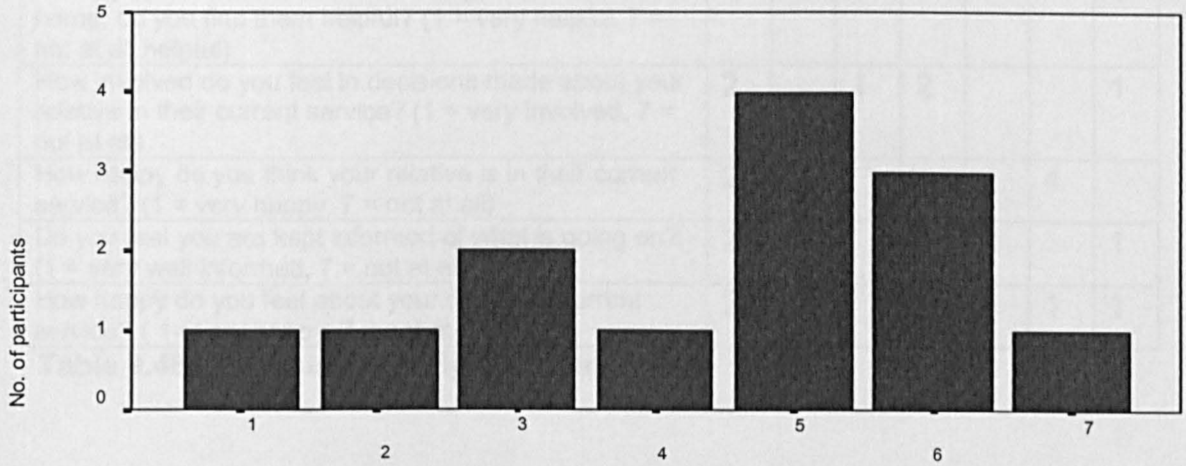


Figure 9.27 : How satisfied are you with how often you attend religious services? (1 = couldn't be worse, 7 = couldn't be better).

9.6 Family Views

Family questionnaires had a very low rate of response. 21 of the 26 service users who had a family agreed that a questionnaire could be sent to their family. One parent from Organisation B rang to say that they were not very involved in their son's care but that they were happy with the home and would not be completing the form. It may be that family members were satisfied with the care or were worried that their involvement may affect their relatives' care.

	A	B	C	D	E
No. of family questionnaires sent	0	7	4	8	2
No. of family questionnaires returned	0	2	3	1	0

Table 9.47: Analysis of questionnaires sent and returned by organisation.

Family members were asked to rate the following topics on a scale of 1 to 7, with 1 representing a positive response and 7 representing a negative one.

	1	**2**	**3**	**4**	**5**	**6**	**7**
Would you say that the service they receive is better or worse than the service they received before? (1 = better, 7 = worse)	2	1		2			1
Do you have contact with relatives as often as you would like? (1 = yes , 7 = no)	3					3	
When you have contact with staff at your relatives' home, do you find them helpful? (1 = very helpful, 7 = not at all helpful)	4						1
How involved do you feel in decisions made about your relative in their current service? (1 = very involved, 7 = not at all)	2		1	2			1
How happy do you think your relative is in their current service? (1 = very happy, 7 = not at all)	2					4	
Do you feel you are kept informed of what is going on? (1 = very well informed, 7 = not at all)	2	1		1	1		1
How happy do you feel about your relative's current service? (1= very happy, 7 = not at all)	2	1			1	1	1

Table 9.48: Analysis of family questionnaire

Families were also asked to say how true the following statements were about the current service their relative received. 1 represents very true and 7 not at all true.

	1	2	3	4	5	6	7
Residents have choice over day to day matters	3	1		1			
Residents have plenty of appropriate emotional support	3	1	1	1			
The service provides appropriate regular day activities for residents in sufficient amounts	2	1	1	1		1	
The service supports residents to help them maintain, develop or re-establish relationships with their families	2	2	1		1		
The service protects residents from exploitation or abuse from staff, other residents or relatives	2	2	1		1		
Residents receive sufficient support to enable them to take part in everyday activities and enjoy a busy life	2		2	1		1	
Residents have an active and healthy lifestyle		2		3		1	
Residents look well dressed and healthy	3	1			1	1	
Residents seem happy and content where they are living	2		1		2	1	

Table 9.50: Family members views on the current service

The two most satisfied families were those of residents living in Organisation B. They consistently scored their views as 1 or 2. The things that these family members valued about this home included:

> *"He is like one of the family over there."*
>
> *"He is so well looked after and they phone me if he is not well or other news."*

Neither of them could think of anything they wanted to be improved. They expected their relative to be happy, healthy and busy in the service, and to continue to improve.

The views of the three families from Organisation C varied considerably. One family member was extremely unhappy with the home, one was fairly happy and one was not sure as her son had just moved there. The family member who was unhappy felt that "things were going downhill" since the company changed hands.

> *"The manager is ill informed regarding ASD [autistic spectrum disorder] but he has said that he does not want anyone telling him what to do. Disaster is not far off. The staff are not in agreement with the manager's ideas."*

She wanted to see

> *“attention to diet which is so important for autistic disorder clients”* and *“improved staff.”*

This family member consistently scored the home lowest of all respondents. She subsequently moved her relative.

The family member who liked Organisation C felt that it had

> *“a friendly atmosphere and only two other service users; good understanding of [Robert’s] needs and good level of support by staff.”*

She would like to see “the high turnover of staff” improved and more access to transport. She hope that the service would help her relative

> *“to improve his self-esteem; to gain practical skills to help him gain independence and to learn to meet new people and make new friends.”*

The family member who had a relative in Organisation D felt that her relative was not happy in the secure unit, but that staff were helpful and that she was kept informed. She valued the protection and the emotional support that the service offered:

She would like the food improved and more contact, including home visits. She expected that the service would help her son come off drugs.

Family members who responded to this study were less satisfied in general with the service that their relatives received than those relatives interviewed as part of the Emerson study. This did not necessarily appear to be related to staff as similarly high levels of relatives from both studies (80%) reported that staff were helpful when approached.

Chapter 10

Study 2 : Discussion

Study 2 – "Where I Live" - presents a snapshot of the quality of support and the lives and experiences of people with learning difficulties, mental health needs and offending behaviour living in a variety of settings. The aims of the study were to examine the quality of care and treatment of this group of people. The management of behaviour, development of independent living skills, empowering people to make choices and enabling the development of positive relationships with a network of people are all crucial to meeting the needs of this group of people.

The sample was relatively small because of the difficulties in obtaining permission from organisations and managers to undertake this research. However, this study indicates that the issues for this group of people are very similar to those issues identified in other larger studies, such as the Quality and Costs study (Emerson et al, 1999) and particularly the Twelve Years On study (Cambridge et al, 2001).

Emerson et al examined the quality of care and the costs of a range of residential supports for people with learning difficulties including those living in village communities, residential campuses, group homes and supported living. They concluded that community based provision and village communities offered better care than residential campuses. Benefits associated with living in homes and dispersed housing schemes included being more likely to be supported by qualified staff, having an independent advocate, receiving less institutionalised care, having more friends who do not have learning difficulties and accessing more community based activities. This study found that organisations were often poor in these areas.

Cambridge et al (2001) reported on the twelve year follow up of a study group of 275 people with learning difficulties and people with mental health needs who had left hospitals in the 1980s. All of the study group were based in community based provision. Cambridge et al looked at skills and behaviours, service user's views, social network and costs. The areas of similarity between this study and the Twelve Years On study were:

- The negative and restrictive impact of rules and routine on day to day choices
- Lack of forward planning and future aspirations for residents from residential homes
- High levels of boredom and inactivity for residents in residential homes
- Mixed feelings about co-residents and staff
- Issues about privacy
- Lack of access to advocacy

The study took place over a period in which both the new care standards were being implemented and clearer expectations about person-centred planning were being introduced. The National Care Standards Commission (NCSC) (O'Connor, 2003) has now issued best practice guidance on residential provision for people with learning difficulties and challenging behaviour and many of the findings of this study are at odds with what is considered best practice. This evaluation is based upon current philosophy of what residential homes should provide and may perhaps at times seem unfairly critical.

(i) Managing behaviour

Most residents had been placed in their current accommodation as a result of placement breakdown due to behavioural issues or offending behaviour. In the majority of settings, residents' behaviour was improving or stabilising although sometimes it seemed that this was more by chance than design, due to the lack of clear behavioural plans and risk assessment and management strategies. In Organisation A (mental health home), behaviour was more likely to be managed by on-going medication than in the learning difficulty provision.

Participants in this study were more likely to have episodes of challenging behaviour than those in other studies, e.g. Emerson et al (2000). Like other studies, however, residents had brief episodes of such behaviour and tended to target staff and other residents. Whilst there was variation between organisations in this study, sedation was reported as being more commonly used than physical restraint. This may have been because only one organisation reported having training in control and restraint techniques. In one organisation, the use of sedation took place within the context of a written behaviourally oriented programme. In one organisation it did not.

Emerson et al (2000) found that residents with challenging behaviour were more than 3 times likely to receive anti-psychotic medication than behavioural support. This was not the case in this study, and most organisations seemed to be managing behaviour relatively well, although as stated earlier relevant policies and procedures needed some work in some organisations. The absence of written behavioural plans for people who had challenging or offending behaviour was worrying, and is also not in keeping with NCSC best practice guidance. Most organisations had some behavioural goals as part of their care planning process. These tended to be supported by psychiatry rather than psychology in the residential homes. Emerson et al (2000) suggested that reasons for the lack of such plans also found in his study include:

- Lack of commitment, leadership and poor management procedures
- Ineffective organisation of the care environment
- Conflict between service ideologies, personal beliefs and beliefs about the nature of behavioural practice
- Lack of knowledge amongst service providers
- Insufficient resources, including specialist health providers.

Practice within the organisations in this study (with the exception of Organisations B and D) would suggest that individual planning was not carried out in enough depth in general and that there may have been a lack of expertise or confidence within the staff team to perform this function, particularly in relation to behavioural issues. In all organisations except the secure unit, residents appeared to be placed without a clear plan from the care manager about how the service should perform and what kind of skills etc. the resident should be encouraged to develop.

(ii) Rules, routines and restrictions

Given the nature of the behaviour of many of the residents who agreed to take part in this study, it would be expected that there would be issues about balancing the risks presented by residents with opportunities for user empowerment. Whilst risk assessments may of necessity place restrictions on residents' lives, many restrictions appeared to be those of organisational convenience or history. Organisational policies, rules and architectural features all combined to restrict residents' choice and control over day-to-day activities such as choosing what to eat and when to go to bed.

The social climate measure which looks at the degree of institutionalisation was remarkably consistent across organisations even when comparing small group homes with 3 residents and the secure unit with 40 beds. Studies conducted by Felce and Perry (1994) and Felce (1999) into group homes also found little difference in institutionalised practice between small homes and larger group homes. The scores of the homes in this study were also higher (indicating higher levels of institutionalisation) than those in the Emerson study (1999) for large group homes and especially high in the rigidity of routines domain (30% in this study and 9.1% in the Emerson study). Because of the different nature of the residents across the studies, it is difficult to make like for like comparisons. The majority of residents in the Emerson et al study had higher levels of learning difficulties and physical impairments, and many of the homes were in isolated settings, – rules and routines may not therefore have been relevant in managing residents' behaviours. It may be that a combination of low staffing levels and the severity of difficult behaviours from the residents in this study led to a perception that a safe environment could only be maintained within certain boundaries. The Twelve Years On study found similar patterns of routine impacting on residents' day to day choice of bed times and smoking. Conversely Perry and Felce (2003) found that management practices did not inhibit individualisation in a large study of group homes in the UK and Wales. However, they also found that residents reported less satisfaction with choice in independent sector homes.

Two issues spring to mind – one is that if the home is offering a long-term placement then to deny residents such basic choices is unacceptable. The other is that if the home is offering short-term placements, then residents need to be empowered to make as many decisions as possible about their lives including daily choices. Either way there is little justification for denying residents the opportunities to make basic choices especially if those involve no risk. Whilst it is recognised that organisations need to have structures, there must also be some clarity about the purpose of those services. Choice and flexibility can be built in – organisations B and D, for example, supported some residents in the full range of activities in meal preparation.

(iv) Choices

Residents reported no choice in where they lived, who they lived with and who worked with them. Only one organisation offered some residents some choice in who their keyworker was. Whilst it is recognised that for the secure unit, and in many circumstances, choice may not be possible in identifying a home, there are clearly missed opportunities for increasing the choice of residents in these areas.

Choice in terms of moving on and forward planning was often a missed opportunity. Most residents wanted to move despite liking the placement. Often there was no commitment from the care manager to look for alternative homes unless there were problems. Except for Organisation D, there were no clear pathways into and out of the accommodation with a focused acquisition of skills on the way. Whilst the residential homes, but not the secure unit, need to firm up their individual planning particularly with respect to the future, there also needs to be the development of suitable accommodation for people to move to. Organisations often felt that there was very little more that they could offer a resident and that residents were being de-skilled by remaining but that there was no where for residents to go to. Organisation D was building a half-way house where residents could further develop independent living skills with support from a familiar staff team and Organisation B was considering doing something similar.

As regards activities, residents reported high levels of boredom and inactivity in residential homes, particularly in the evening and weekend. Activities were frequently dependent on staff availability. The Twelve Years On study (Cambridge et al, 2001) also found that not only were people bored, but that they did not like some of the activities that they did, usually domestic tasks. In the secure unit, some people did not like the domestic tasks, but some did. In the residential homes, some people did not like some of the activities they did, but liked meeting some of the people there. These results would suggest that there needs to be more planning around individual interests and choices and a possible re-organisation of staff to support those activities. Mansell et al (2003) warn against identifying resources as being indicative of improving meaningful activity and choices and instead argue that care practices are the most important factor. In particular an "active support model" which promotes clearly defined structures for planning staff and resident activity is central to high quality residential activity (Mansell and Ericsson, 1996).

There was little evidence of this in any organisation, with the exception of Organisation D. Presumably training and supervision would be also be key to the development of a positive culture – again there was limited evidence of commitment to training by the organisations.

Compared to the groups of residents with learning difficulties researched in the Twelve Years On study (Cambridge et al, 2001) and the Quality and Costs study (Emerson et al, 1999), this group of residents were much more able in terms of self-care and independent living skills. However those in residential homes had less opportunities to access work placements etc. This may have been partly due to location - only one of the homes was within easy reach of mainstream shops and transport – the remainder were fairly isolated and residents were dependent upon staff for transport. It may also be because of the restrictions as a result of the risks that people posed due to offending/challenging behaviour or the lack of services for this relatively more able group of people. Whilst keyworkers and organisations can address some of these issues at an individual level, service deficits need to be addressed at a more strategic level.

(v) Interpersonal relationships

The kind of relationships that a resident has with co-residents, staff, family, friends and girl/boyfriends impact substantially on their quality of life. Residents in this study who lived in residential homes had a social network size of 21.3, which is comparable to that of residents' in the Twelve Years On study (22) but of course not that of residents in the secure unit (33). This size compares favourably to that in Emerson study where the average network size was 7.9 for small group homes and 6.3 for large group homes. However, a slightly different methodology was employed by Emerson in gaining information – in that study information was gained from staff, in this study and the Twelve Years On study information came from the resident themselves. The Emerson study also did not include staff numbers in the network – this study and the Cambridge study did. The make-up of social networks across all three studies was very similar, with the exception of a slightly larger group of people from outside learning disability services in both the Cambridge (19%) and Emerson (16% for small group homes) studies.

The majority of residents wanted more help from staff, and some residents wanted staff to change their attitude: to be understanding and to treat some residents better. Residents may have been more critical of staff in this study but for the presence of staff in some of the interviews. Residents also said that staff helped them with domestic, material and emotional issues. The Twelve Years On study found similar themes and also noted difficulties in residents establishing reciprocity in relationships with staff. In this study some residents felt that there was some reciprocity in their relationships. This could have been because of higher ability levels of residents in this study.

Residents experienced criticism from staff and other residents. In this study, some residents complained of violence from co-residents. Forrester-Jones et al (2001) also concluded that bullying significantly impacted on peoples' lives. What was noticeable was that the larger settings enabled people to develop friendship groups and avoid people they did not like. This was not possible in the smaller homes. In the secure unit, where friction was observed between residents, one resident was often moved to another unit in order to avoid interpersonal difficulties.

Residents also sometimes had very strong friendships with other people in the setting. This was particularly the case in Organisation B where people had lived together for a long time.

The Twelve Years On study found that living with people you like and who like you was one of the most important aspects of change as a result of moving out of hospital. In this study, the relationships with both other residents and staff were crucial to whether people liked living in their homes.

(vi) Health Issues

With the exception of Organisation C, regular holistic health checks were much less frequent in this study (7%) than in the Emerson study (57%). Comparisons are shown below with the results of the Emerson study by size of group home. Small group homes in this study have up to 3 residents and so are comparable with Organisation C. Large group homes have 4- 6 residents, much smaller than the homes in this study and so comparisons, whilst still of interest have more limited validity.

Health check	**Organisation A**	**Organisation B**	**Organisation D**	**Organisation E**	**Large Group Homes**
Blood pressure		55%	100%		66%
Mammograms			50%		9%
Cervical Smears			50%		32%
Eye tests	33%	55.5%	80%		68%
Ear tests		88.8%	60%		52%

Table 10.1 Comparison of Frequency of Health Checks with Emerson study

Health check	**Organisation C**	**Small Group Homes**
Blood pressure	75%	70%
Eye tests	100%	63%
Ear tests	75%	41%

Table 10.2 Comparison of Frequency of Health Checks with Emerson Study

Access to dentists also appeared to be less than frequent. Cumella et al (2000) summarise surveys of dental hygiene in people with learning difficulties as consistently identifying more problems requiring dental treatment such as:

- Poor oral and denture hygiene
- A high prevalence of gingival disease
- Untreated dental caries
- Heavy tooth wear as a result of tooth grinding
- Tooth enamel defects

- Delayed eruption of teeth and retained primary teeth

Given that the results vary so widely it is difficult to ascertain whether the variance is due to organisational policy or perceived individual need. What is clear, however, is that in many homes, health checks are widely neglected. At the time of the study, there were no health action plans on file, even in a draft form. NCSC and Valuing People recommend health action plans for all residents.

(vii) Quality care or wasted lives?

The settings in study two were found to provide varying degrees of quality of care using the following indicators:

- Support in managing behaviour
- Development of independent living skills
- Choices
- Positive inter-personal relationships

However there clearly was room for improvement for practice within the homes and in terms of long-term planning for individuals. All settings were effective in minimising or reducing behaviour, but with the exception of Organisation D, and to a lesser extent Organisation B, little attention was paid to maintaining or increasing independent living skills in a planned way. With the exception of Organisation D, residents did not seem to be moving to more independent settings as might be expected. It is not clear how significant the cost of placement was in this – Organisation D costs were considerably higher than the rest of the organisations in the study. It needs to be recognised that there is a financial disincentive in organisations to move people on, particularly where the organisations survives on spot contracts. Placing authorities need to fulfil their duty of care towards those people placed outside the borough rather than maintaining the status quo until a crisis occurs. Similarly, keyworkers need to assertively advocate on behalf of the resident using person centred planning as a tool. This does not negate the need for independent advocates.

It does need to be recognised that settings provide services within a wider social environment. Individual organisations often have little influence over the wider service picture and in many cases appropriate activities including work related activities were not available. However, the lack of robust person centred planning and the negative influence of routines further constrained residents' lives in unnecessary ways. Opportunities to build choice into the operational policies and procedures were not always taken up. Relationships, which were central to the quality of life of residents, could be either positive or negative but contact was often out of the control of the individual resident as was the development of a social network. Despite these factors, residents reported that they were mostly happy with the service provided.

Chapter 11

Conclusion

People with learning difficulties, mental health needs and Asperger's syndrome do commit crimes, and where their disability is identified they are eligible for diversion from the criminal justice system. However, people who are identifed as being disabled do not necessarily receive a service that meets their needs. Some may be returned back to the community without any support or inadequate levels of support and others may be sent to more restrictive settings than prison for terms longer than a prison sentence.

Studies One and Two look at two different options in terms of service delivery for people with mild/borderline learning difficulties, mental health needs or autism who may be at risk of offending or reoffending. The populations studied were remarkably similar in terms of diagnosis and offending behaviour (with the exception of manslaughter). The main differences were in the legislative framework under which people received services – none of the pilot team service users were under sections of the Mental Health Act; age – the residential population were older; history – the residential population had a history of receiving institutionalised services, particularly psychiatric hospital; and ethnic origin – a higher proportion of people, particularly women, from Black and minority ethnic communities were found in residential services, especially secure services.

Caution must be applied when looking at these similarities and differences because of the small numbers in both studies. However, they would suggest that where people end up in the system is pretty random and very much dependent on service structures rather than the individual characteristics or needs of the person. They also suggest that once someone becomes known to services and institutionalised as a result of perceived behavioural problems or needs, it becomes very difficult for that person to move out of institutional models of care. Again this may be because of a lack of alternative models of provision or it could be because of the "reputation" or perceived risk associated with that person. There certainly is anecdotal evidence to support the theory that if someone commits an act which is perceived as possibly criminal, then they are still labeled as a risk even though that act may never have been repeated and was committed many years ago. The difference in ethnic origin is hard to explain : it could be that people from Black and ethnic minorities are more likely to be diagnosed as having primary mental health needs than learning difficulties and as a result of this end up in residential or secure settings. This would suggest that people with learning difficulties are also subject to the institutional discrimination experienced by people from Black and minority ethnic communities in their contact with the criminal justice system and the health and social care system.

The pilot team exposed the weaknesses and limits of the existing service structure in the boroughs which it served. This was both in terms of the willingness of services to work with people from this group and the availability of relevant skills and expertise. Given that the team worked with similar kinds of people to those that ended up in residential and secure provision, and that the team was successful in preventing offending/reoffending behaviour, it would seem that a better way forward for people would be through the provision of community based services which would effectively support people and prevent their long-term incarceration in a variety of institutionalised forms of care where basic choices are restricted. At the moment there is a limited evidence base to support the development of community based teams and support services as an alternative for this group of people mainly because most services are relatively new. However the evidence that exists suggests that this kind of provision is not only extremely effective but also valued by service users and carers because of the positive impact on their lives (Cole, 2000;Waddington et al, 2003).

There is a need for more research into developing a robust evidence base into the effectiveness of community based services for this group of people similar to that currently being developed in more mainstream mental health research. This needs to focus both into the needs of offenders and para-offenders (e.g. the Revolving Doors studies) and into the impact of a flexible person-centred model on such issues as quality of life, skills acquisition, reduction in offending behaviours and crucially cost modelling to evidence value for money (e.g. some of the assertive outreach studies). Key stakeholders such as politicians, clinicians and practitioners who may be more bed-focused and favour risk averse strategies, and commissioners who may favour reactive responses all need to be persuaded of the value of such services. A wider debate which examines the pathways of people with learning difficulties into and out of the criminal justice system also needs to take place in order to properly locate the links with appropriate services. As discussed earlier, there is some good, but very patchy research, into people with learning difficulties and the criminal justice system. Until there is a clear and robust understanding of pathways for people with learning difficulties then it becomes almost impossible to argue for a whole systems approach to effectively supporting a very vulnerable group of people.

Concerns were raised in part one about the expansion of the criminal justice system and secure provision into the community through the development of services which have a potentially authoritarian and restrictive bent such as assertive outreach teams. Concerns were also raised about the creation of a new criminal population through diversion schemes which may identify and label new populations. These concerns do apply to this group of people. People with mild/borderline learning difficulties, mental health needs and Asperger's syndrome often live their lives completely independently of any health and social care services and in many cases may not be known to them. For people with low support needs or a good informal support system this does not pose a problem, but for those with more complex needs, who may not have any informal support system or who may be experiencing a crisis, life may be unbearable without adequate support. These are the people whom one of the service users of the pilot team described as being "in the wilderness." Others may be in contact with services and receive little or inadequate support. Contact with either the criminal justice system or health and social care services may indeed serve to not only stigmatise people and identify a new population of potential offenders but further penalise people when they are seen to fail by continuing to offend, when in reality it is services who fail them. However, it must be recognised that many of these people already come from stigmatised groups in the first place.

Policy Implications

- There is a need for a national policy which brings together some key documents e.g. Reed report, Mansell report and the NSF framework for mental health and develops a framework for integrated community based local services. There needs to be clear guidance and recommendations on the future structure of services.

- PAF indicators for local authorities and targets for PCTs should include measures which reflect the development of such services e.g. PCT spend on out-of-PCT places compared to spend on community based services internally. Strategic health authorities also need to develop local performance indicators for their PCTs which reflect the local make-up of services and issues.

- Joint budgets need to be further developed beyond the Health Act flexibilities to ensure shared ownership of people. Currently, admission to secure provision through the Mental Health Act represents a cost saving to Social Services. There is therefore no shared financial incentive to developing local expertise and reducing admission to such facilities, or indeed speeding up discharge.

- Clear guidance needs to be issued on meeting the needs of people with high functioning autistic spectrum disorders together with appropriate service models. Again, targets need to be developed around this and the NSF for mental health should be expanded to include this area.

- Professional training at all levels should address the needs of this group of people at a foundation level with opportunities for developing specialist knowledge. Post qualification courses which address the needs of health, social care and criminal justice system workers should also be developed.

Practice Implications

- Expertise needs to be developed in dealing with this group of people across both learning difficulty and mental health teams and also across the care and criminal justice systems

- Local protocols should be developed, together with the identification of link workers in all sectors to ensure cohesive working and mutual support

- More flexible person-centred ways of working need to be developed which allow service user needs to lead the pace of working rather than organisational needs

- Services may need to review operational hours and skill mix in order to effectively support service user

- Services need to focus on shared risk management rather than risk averse strategies

Table 11.1 : Keeping People out of the Wilderness : some policy and practice implications.

How then do we get the balance right to ensure that we identify and support people without further contributing to the discrimination, oppression and restrictions that are placed upon their lives because of their diagnosis, label or behaviour? How do we ensure that people are not left out in the wilderness receiving inadequate or no services at all? Table 11.1 suggests some policy and practice implications drawn from the studies, to ensure that people are not left out in the wilderness, or indeed sent out into the wilderness, in ace of inadequate residential provision. The answer would also appear to lie in correctly locating the causes of discrimination within the structures of society, rather than within the individual, and developing services which are based upon supporting people in a non-judgemental individual tailored way to overcome discrimination and enable people to develop the skills that they need to live everyday life successfully and safely. It is suggested that services would need to be:

- Based upon principles of user empowerment, particularly in the management of risk
- User centred, flexible and responsive in their approach
- Based upon a whole team approach to providing a service so that an immediate response to someone does not depend on the service user's case worker being available.
- Use a care programme approach and have a no closure policy
- Offer individually tailored expertise to meet peoples' needs, in particular access to a psychologist or challenging behaviour specialist
- Offer individually tailored practical support packages which enable both an increase in independent living skills and access to mainstream facilities, including employment
- Offer therapeutic input, particularly groups which enable people to deal with sexual relationships and anger management

Such services should challenge and replace the majority of secure and residential provision, not only in terms of meeting the needs of people but also in terms of developing new philosophies and empowering practices. They would also need to have access to the budgets traditionally used for residential provision. One of the most surprising outcomes of study two was the fact that the secure unit was not only developing user empowerment within the legal restrictions and risk management structures that existed, but that in may ways it was more forward thinking and empowering than more traditional and less secure forms of provision. People with learning difficulties, mental health needs and Asperger's syndrome often commit offences because of the restrictions societal structures have imposed upon their lives. Society has a duty to redress the balance and provide adequate services for this complex and vulnerable group of people.

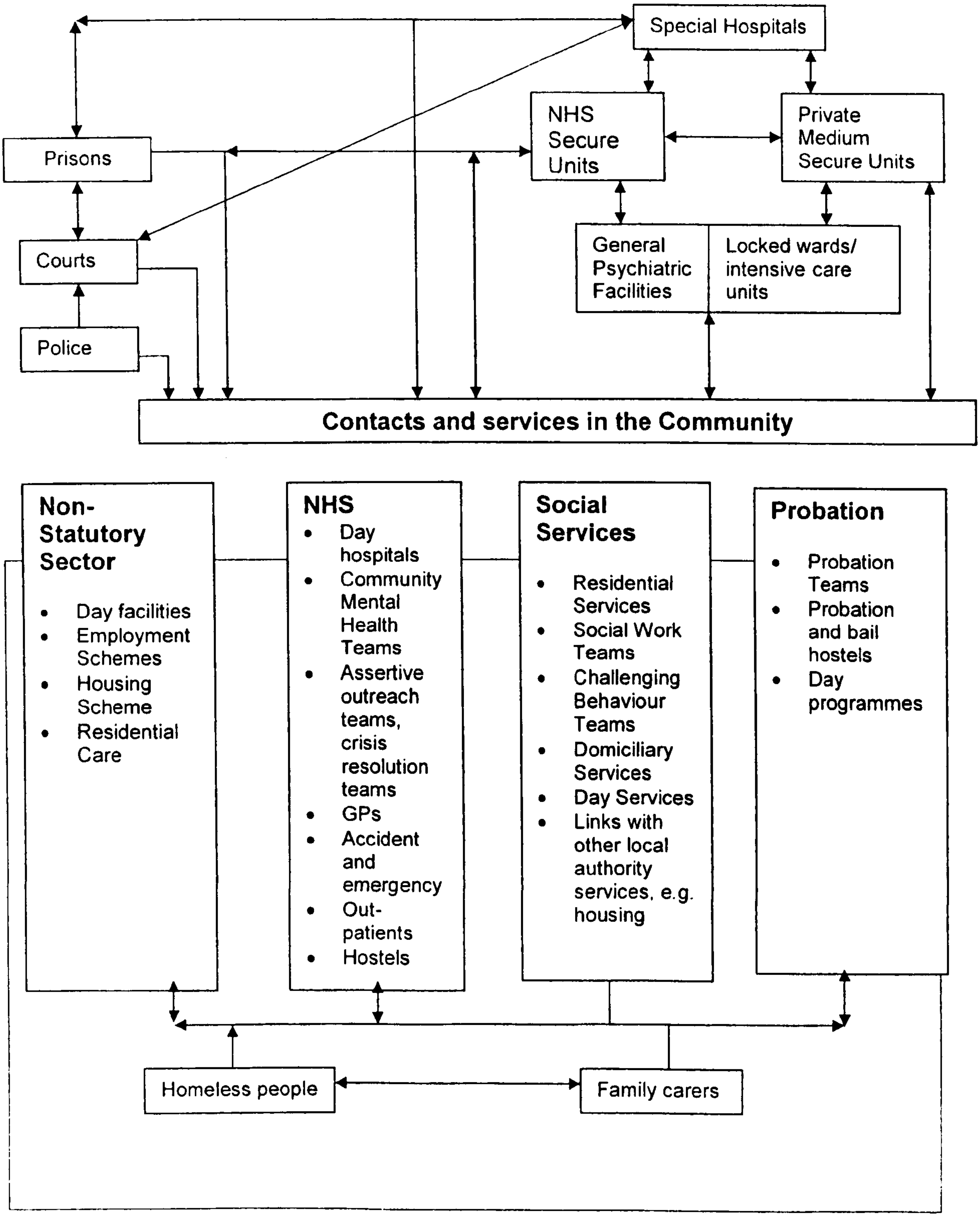
Appendix 1: The Mental Health Act 1983
(Vaughan and Badger 1995)

Mentally disordered offenders may be treated under Part II or III of the Act. Part II relates to the detention of "civil" patients, and mentally disordered offenders may receive treatment as part of diversion.

The relevant sections of Part II are:
Section 2: admission for assessment for a maximum of 28 days
Section 3 : admission for treatment for a maximum of 6 months
Section 4 : emergency admission for a maximum of 72 hours
Section 5 : detention of a patient, already receiving treatment in hospital on an informal basis, for a maximum period of 72 hours
Section 7 : applications for Guardianship
Section 136: authorizes the police to remove from a place to which the public have access, a person who appears to be suffering from mental disorder and to be in an immediate need of care and control, to a place of safety for examination for a maximum period of 72 hours.

Part III provides for:
Section 35: remand to hospital by a court for a report on his/her medical condition
Section 36 : remand to hospital by Crown Court for treatment if suffering from mental illness or severe mental impairment
Section 37: detention in hospital or guardianship made by court following conviction for an offence punishable by imprisonment (hospital order)
Section 38 : detention in hospital for up to 6 months made by court following conviction for assessment (interim hospital order)
Section 41: A Crown Court or court of appeal may make a restriction order when it decides to place an offender on a hospital order, if it appears to the court that it is necessary to protect the public from serious harm
Section 47 : The Home Secretary may transfer a sentenced prisoner to a hospital so that he may be detained for medical treatment
Section 48: The Home Secretary may transfer other prisoners to a hospital so that he may be detained for medical treatment

Appendix 2: Contacts and care options for mentally disordered offenders (adapted from Hagell and Dowling, 1999, p. 74)



Appendix 3
HONOS LD

HoNOS-LD

A Brief Outcome Measure for People with Learning Disabilities and Mental Health Needs

Client name:

Client ID:

Gender **Age:**

Date of assessment DD MMM 200

Name of rater:

Profession of rater:

Location of assessment:

Care status New referral ☐ Current case ☐

Legal status: Informal ☐ Detained ☐

Details of physical conditions:

(e.g. cerebral palsy, epilepsy, sensory impairments, Down's syndrome)

Degree of learning disability: 1 = Mild 2 = Moderate 3 = Severe 4 = Profound ☐

Psychiatric and developmental conditions:

(including autism and offending behaviour and, if available, **ICD-10 codes** ☐ ☐ ☐ ☐

Nature of accommodation: ☐

1 = Lives independently
2 = Family home
3 = Acute hospital
4 = Long-stay hospital
5 = Group home (staffed)
6 = Group home (unstaffed)
7 = Other

KEY

Ratings should be over the past four weeks.
For all the following items rate as follows:

0 = No problem
1 = Mild problem
2 = Moderate problem
3 = Severe problem
4 = Very severe problem
9 = Not known

SUBJECTIVE RATING ☐

1. Behavioural problems – directed to others

Include behaviour that is directed to other persons. Do not include directed towards self (item 2) or behaviour primarily directed at property or other behaviours (item 3). Rate risk as it is currently perceived.

0	No behavioural problems directed to others during the period rated.
1 Mild	Irritable, quarrelsome, occasional verbal abuse.
2 Mod	Frequent verbal abuse, verbal threats, occasional aggressive gestures, pushing or pestering (harassment).
3 Sev	Risk, or occurrence of, physical aggression resulting in injury to others requiring simple first aid or requiring close monitoring for prevention.
4 V sev	Risk, or occurrence, of physical aggression producing injury to others serious enough to need casualty treatment and requiring constant supervision or physical intervention for prevention (e.g. restraint, medication or removal).

☐

2. Behavioural problems – directed to self (self injury)

Include all forms of self-injurious behaviour. Do not include behaviour directed towards others (item 1), or behaviour primarily directed at property or other behaviours (item 3).

0	No self-injurious behaviour during the period rated.
1 Mild	Occasional self-injurious behaviour (e.g. face tapping); occasional fleeting thoughts of suicide.
2 Mod	Frequent self-injurious behaviour not resulting in tissue damage (e.g. redness, soreness, wrist-scratching).
3 Sev	Risk or occurrence of self-injurious behaviour resulting in reversible tissue damage and no loss of function (e.g. cuts, bruises, hair loss).
4 V sev	Risk or occurrence of self-injurious behaviour resulting in irreversible tissue damage and permanent loss of function (e.g. limb contractures, impairment of vision, permanent facial scarring), attempted suicide.

☐

3. Other mental and behaviour problems

This is a global rating to include behavioural problems not described above. Do not include behaviour directed towards others (item 1), or self-injurious behaviour (item 2). Rate the most prominent behaviours present. Include: A. Behaviour destructive to property; B. Problems with personal behaviours e.g. spitting, smearing, eating rubbish, self-induced vomiting, continuous eating or drinking, hoarding rubbish, inappropriate sexual behaviour; C. Rocking, stereotyped and ritualistic behaviour; D. Anxiety, phobias, obsessive, compulsive behaviour; E. Others.

0	No behavioural problem(s) during the period rated.
1 Mild	Occasional behavioural problem(s) that are out of the ordinary or socially unacceptable.
2 Mod	Behaviour(s) sufficiently frequent and severe to produce some disruption of and impact on own or other people's functioning.
3 Sev	Behaviour(s) sufficiently frequent and severe to produce significant disruption and impact on own or other people's functioning, requiring close monitoring for prevention.
4 V sev	Constant, severe problem behaviour(s) producing major disruption of and impact on functioning requiring constant supervision or physical intervention for prevention.

A ☐
B ☐
C ☐
D ☐
E ☐

4. Attention and concentration

Include problems that may arise from underactivity, overactive behaviour, restlessness, fidgeting or inattention, hyperkenesis or arising from drugs.

0	Can sustain attention and concentration in activities/programmes independently during the rating period.
1 Mild	Can sustain attention and concentration in activities/programmes with occasional prompting and supervision.
2 Mod	Can sustain attention and concentration in activities/programmes with regular prompting and supervision.
3 Sev	Can sustain attention and concentration in activities/programmes briefly with constant prompting and assistance.
4 V sev	Cannot participate in activities and programmes even with constant supervision and assistance.

☐

5. Memory and orientation

Include recent memory loss and worsening of orientation for time, place and person in addition to previous difficulties.

0	Can reliably find their way around familiar surroundings and relate to familiar people.
1 Mild	Mostly familiar with environment/person but some difficulty in finding their way.
2 Mod	Can relate to environment/person with occasional support and supervision.
3 Sev	Can relate to environment/person with regular support and supervision.
4 V sev	Not apparently able to recognise or relate to people and environments.

☐

6. Communication (problems in understanding)

Include all types of responses to verbal, gestural and signed communication, supported if necessary with environmental cues.

0	Able to understand first language *(mother tongue)* about personal needs and experience during rating period.
1 Mild	Able to understand groups of words / short phrases / signed communications about most needs.
2 Mod	Able to understand some signs, gestures and single words about basic needs and simple commands (food, drink, come, go, sit, etc.).
3 Sev	Able to acknowledge and recognise attempts at communication with little specific understanding (pattern of response is not determined by nature of communication).
4 V sev	No apparent understanding or response to communication.

☐

7. Communication (problems in expression).

Include all attempts to make needs known and communicate with others (words, gestures, signs). Rate behaviour under items 1, 2, 3.

0	Able to express needs and experiences to others during the period rated.
1 Mild	Able to express needs to familiar people.
2 Mod	Able to express basic needs only (food, drink, toilet, etc.).
3 Sev	Able to express presence of need but cannot specify (e.g. cries or screams when hungry, thirsty and uncomfortable).
4 V sev	Unable to express need or presence of need.

☐

8. Problems associated with hallucinations and delusions

Include hallucinations and delusions irrespective of diagnosis. Include all manifestations suggestive of hallucinations and delusions (responding to abnormal experiences e.g. invisible voices when alone).

0	No evidence of hallucinations or delusions during the period rated.
1 Mild	Occasional odd or eccentric beliefs or behaviours suggestive of hallucinations or delusions.
2 Mod	Manifestations of hallucinations or delusions with some distress or disturbance.
3 Sev	Manifestations of hallucinations or delusions with significant distress or disturbance.
4 V sev	Mental state and behaviour are seriously and adversely affected by delusions or hallucinations with severe distress or disturbance.

☐

9. Problems associated with mood changes

Include problems associated with low mood states, elated mood states, mixed moods and mood swings (alternating between unhappiness, weeping and withdrawal on one hand and excitability and irritability on the other).

0	No evidence of mood change during the period rated.
1 Mild	Mood present but with little impact (e.g. gloom).
2 Mod	Mood change producing significant impact on self or others (e.g. weeping spells, decrease in skills, withdrawal and loss of interest).
3 Sev	Mood change producing major impact on self or others (e.g. severe apathy and unresponsiveness, severe agitation and restlessness).
4 V sev	Depression, hypomania or mood swings producing severe impact on self and others (e.g. severe weight loss from anorexia or overactivity, agitation too severe to allow and time engaged in meaningful activity).

☐

10. Problems with sleeping

Do not rate intensity of behaviour disturbance – this should be included in item 3. Include daytime drowsiness, duration of sleep, frequency of waking and diurnal variation of sleep pattern.

0	No problem during the period rated.
1 Mild	Occasional mild sleep disturbance with occasional waking.
2 Mod	Moderate sleep disturbance with frequent waking, or some daytime drowsiness.
3 Sev	Severe sleep disturbance behaviour or marked daytime drowsiness (e.g. restlessness / overactivity / waking early) on some nights.
4 V sev	Very severe sleep disturbance with disturbed behaviour (e.g. restlessness / overactivity / waking early) most nights.

☐

11. Problems with eating and drinking

Include both increase and decrease in weight. Do not rate pica which should be rated in item 3. This item does not include problems experienced by people who cannot feed themselves (e.g. people with severe physical disability).

0	No problem with appetite during the period rated.
1 Mild	Slight alteration to appetite.
2 Mod	Severe alteration in appetite with no significant weight change.
3 Sev	Severe disturbance with some weight change during the period rated.
4 V sev	Very severe disturbance with significant weight change during the period rated.

☐

12. Physical problems

Include illness from any cause that adversely affects mobility, self-care, vision and hearing (e.g. dementia, thyroid dysfunction, tremor affecting dexterity). Do not include relatively stable physical disability (e.g. cerebral palsy, hemiplegia). Behavioural disorders caused by physical problems should be rated under items 1, 2, 3 (e.g. constipation producing aggression).

0	No increased incapacity due to physical problems during the period rated.
1 Mild	Mildly increased incapacity e.g. viral illness, sprained wrist.
2 Mod	Significant incapacity requiring prompting and supervision.
3 Sev	Severe incapacity requiring some assistance with basic needs.
4 V sev	Total incapacity requiring assistance for most basic needs such as eating and drinking, toileting (fully dependent).

☐

13. Seizures

Include all types of fits (partial, focal, generalised, mixed, etc.) to rate short-term effect on the individual's daily life. Rate the effects of the fits. Do not include behaviour problems caused by or associated with fits (use items 1,2,3).

0	No increased incapacity due to physical problems during the period rated.
1 Mild	Occasional seizures with minimal immediate impact on daily activities (e.g. resumes activities after seizures).
2 Mod	Seizures of sufficient frequency or severity to produce a significant immediate impact on daily activities (e.g. resumes activity after a few hours.
3 Sev	Seizures of sufficient frequency or severity producing a severe immediate impact on daily activities requiring simple first aid for injuries etc. (e.g. resumes activities next day).
4 V sev	Frequent poorly controlled seizures (may be accompanied by episodes of status epilepticus) requiring urgent clinical attention.

☐

14. Activities of daily living at home

Include such skills as cooking, cleaning and other household tasks. Do not rate problems with daily living outside the home (15). Do not rate problems with self-care (16). Rate what is seen regardless of cause e.g. disability, motivation etc. Rate performance not potential. Rate the current level achieved with the existing support.

0	Performs or contributes towards activities of daily living at home.
1 Mild	Some limitations in performing or contributing towards household tasks.
2 Mod	Significant limitations in performing or contributing towards household tasks (e.g. failure to wash or tidy up, difficulty in preparing meals).
3 Sev	Major limitations in performing or contributing towards household tasks (e.g. home neglected, dirty, untidy; no domestic routine).
4 V sev	Gross neglect or danger resulting from no apparent contribution to daily living activities.

☐

15. Activities of daily living outside the home

Include skills such as budgeting, shopping, mobility and the use of transport etc. Do not include problems with activities of daily living at home (item 14). Do not rate problems with self-care (item 16). Rate the current level with the existing support.

0	Regular use of facilities and public amenities (e.g. shopping).
1 Mild	Some limitation in activity (e.g. difficulty with the use of public amenities or transport).
2 Mod	Significant limitation of activity relating to any one of shopping, use of transport, public amenities.
3 Sev	Major restrictions in activity relating to more than any one of shopping, use of transport, public amenities.
4 V sev	Severe restrictions in use of shops, transport, facilities, etc.

☐

16. Level of self-care

Rate the overall level of functioning in activities of self-care such as eating, washing, dressing and toileting. Rate the current level achieved with the existing support. Rate appearance not motivation.

0	Appearance and personal hygiene maintained.
1 Mild	Some deficits in personal appearance, personal hygiene or attention to health (e.g. poor grooming).
2 Mod	Significant deficits in personal appearance, personal hygiene or attention to health causing a problem with social acceptability but not sufficient to pose a risk of health (e.g. body odour, unkempt hair or nails).
3 Sev	Major deficits in personal appearance, personal hygiene or attention to health posing a health risk (e.g. skin rashes, gum infection, not fully dressed.
4 V sev	Gross self-neglect with severe difficulties relating to appearance, hygiene and diet posing a major health risk (e.g. pressure sores)

☐

17. Problems with relationships

Include effects of problems with relationships with family, friends and carers (in residential and day / leisure settings). Measure what is occurring regardless of cause e.g. somebody who is known to have good relationships may still display problems.

0	Positive and frequent contact with family or friend or carers.
1 Mild	Generally positive relationships but some strain or limitations in contact.
2 Mod	Some positive relationships but current disruptions of contact or worsening of relationships.
3 Sev	Difficulties in relationships with risk of breakdown or infrequent contact.
4 V sev	Significant relationships broken down with no current contact.

☐

18. Occupation and activities

Rate the overall level of problems with quality of daytime environment. Take account of frequency and appropriateness of, and engagement with, daytime activities. Consider factors such as lack of qualified staff, equipment and appropriateness with regard to age and clinical condition. Do not rate problems with self-care (item 16).

0	Fully engaged with acceptable range of activities.
1 Mild	Uses reasonable range of activities but some limitation of access or appropriateness.
2 Mod	Uses limited range of activities, limited availability or appropriateness.
3 Sev	Attends daytime activity irregularly.
4 V sev	No engagement with daytime activity.

Appendix 4
ABS –RC 2 Adaptive Behaviour Scale - Residential and Community

ABS-RC:2

Kazuo Nihira, Henry Leland, and Nadine Lambert

Adaptive Behavior Scale–Residential and Community

Second Edition

Examination Booklet

Examinee's Name ____________________

Rater's Name ____________________

Date of Rating ____________________

Setting/Agency ____________________

FOR INFORMATION
ONLY

PART ONE
DOMAIN I.
Independent Functioning

A. Eating

ITEM 1 **Use of Table Utensils**
(Circle highest level)

Uses table knife for cutting or spreading	6
Feeds self neatly with spoon and fork (or appropriate alternate utensil, e.g., chopsticks)	5
Feeds self causing considerable spilling with spoon and fork (or appropriate alternate utensil, e.g., chopsticks)	4
Feeds self with spoon—neatly	3
Feeds self with spoon—considerable spilling	2
Feeds self with fingers	1
Does not feed self or must be fed	0

☐

ITEM 2 **Eating in Public**
(Circle highest level)

Orders complete meals in restaurants	3
Orders simple meals like hamburgers or hot dogs	2
Orders single items, e.g., soft drinks, ice cream, donuts, etc. at soda fountain or canteen	1
Does not order in public eating places	0

☐

ITEM 3 **Drinking**
(Circle highest level)

Drinks without spilling, holding glass in one hand	3
Drinks from cup or glass unassisted—neatly	2
Drinks from cup or glass unassisted—considerable spilling	[illegible]
Does not drink from cup or glass unassisted	0

☐

ITEM 4 **Table Manners**
(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is bedfast and/or has liquid food only, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Throws food	0	1
Swallows food without chewing	0	1
Chews food with mouth open	0	1
Drops food on table or floor	0	1
Does not use napkin	0	1
Talks with mouth full	0	1
Takes food off others' plates	0	1
Eats too fast or too slow	0	1
Plays in food with fingers	0	1

☐

B. Toilet Use

ITEM 5 **Toilet Training**
(Circle highest level)

Never has toilet accidents	4
Has toilet accidents only at night	3
Occasionally has toilet accidents during the day	2
Frequently has toilet accidents during the day	1
Is not toilet trained at all	0

☐

ITEM 6 **Self-Care at Toilet**
(Circle all answers)

	Yes	No
Lowers pants at the toilet without help	1	0
Sits on toilet seat without help	1	0
Uses toilet tissue appropriately	1	0
Flushes toilet after use	1	0
Puts on clothes without help	1	0
Washes hands without help	1	0

☐

C. Cleanliness

ITEM 7 **Washing Hands and Face**
(Circle all answers)

	Yes	No
Washes hands and face with soap and water without prompting	1	0
Washes hands with soap	1	0
Washes face with soap	1	0
Washes hands and face with water	1	0
Dries hands and face	1	0

☐

ITEM 8 **Bathing**
(Circle highest level)

Prepares and completes bathing unaided	6
Washes and dries self completely without prompting or helping	5
Washes and dries self reasonably well with prompting	4
Washes and dries self with help	3
Attempts to soap and wash self	2
Cooperates when being washed and dried by others	1
Makes no attempt to wash or dry self	0

☐

ITEM 9 **Personal Hygiene**
(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is completely dependent on others, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Has strong underarm odor	0	1
Does not change underwear regularly by self	0	1
Skin is often dirty if not assisted	0	1
Does not keep nails clean by self	0	1

☐

ITEM 10 **Toothbrushing**
(Circle highest level)

Cleans dentures appropriately	5
Applies toothpaste and brushes teeth with up and down motion	5
Applies toothpaste and brushes teeth with sideways motion	4
Brushes teeth without help, but cannot apply toothpaste	3
Brushes teeth with supervision	2
Cooperates in having teeth brushed	1
Makes no attempt to brush teeth	0
Does not clean dentures	0

☐

D. Appearance

ITEM 11 **Posture**
(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is bedfast or non-ambulatory, place check in the blank and mark "Yes" for all statements. ______

	Yes	No
Mouth hangs open	0	1
Head hangs down	0	1
Stomach sticks out because of posture	0	1
Shoulders slumped forward and back bent	0	1
Walks with toes out or toes in	0	1
Walks with feet far apart	0	1
Shuffles, drags, or stamps feet when walking	0	1
Walks on tiptoe	0	1

☐

For NRC Examination
ONLY

ITEM 35 **Purchasing**
(Circle highest level)

Buys own clothing	5
Buys own clothing accessories	4
Makes minor purchases without help (candy, soft drinks, etc.)	3
Does shopping with slight supervision	2
Does shopping with close supervision	1
Does no shopping	0

☐

ITEM 36 **Shopping Resources**
(Circle all answers)

	Yes	No
Has charge card for specific stores	1	0
Has general credit cards or other credit arrangements	1	0
Carries appropriate identification	1	0
Can endorse check	1	0

☐

ECONOMIC DOMAIN TOTAL
(add items 31–36) ☐

DOMAIN IV.
Language Development

For Inservice Training Only

A. Expression

ITEM 37 **Writing**
(Circle highest level)

Writes understandable and complete letters or stories	5
Writes short notes or memos	4
Writes or prints whole sentences	3
Writes or prints at least ten words	2
Writes or prints name	1
Cannot write or print any words	0

☐

ITEM 38 **Handwriting**
(Circle all answers)
If item 37 is marked "0," place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Writes backwards	0	1
Reverses some letters	0	1
Writing is generally illegible	0	1
Unable to hold pencil or crayon	0	1

☐

ITEM 39 **Preverbal Expression**
(Circle all answers)
If person is able to say at least a few words, then place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Nods head or smiles to express happiness	1	0
Indicates hunger	1	0
Indicates wants by pointing or vocal noises	1	0
Imitates sounds of objects or animals (choo-choo, bow-wow, etc.)	1	0
Expresses pleasure or anger by vocal noises	1	0

☐

ITEM 40 **Articulation**
(Circle all answers)
If person has no speech at all, then place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Speech is low, weak, whispered, or difficult to hear	0	1
Speech is slowed, deliberate, or labored	0	1
Speech is hurried, accelerated, or pushed	0	1
Speaks with blocking, halting, or other irregular interruptions	0	1

☐

ITEM 41 **Sentences**
(Circle highest level)

Sometimes uses complex sentences containing "because," "but," etc.	3
Asks questions using words such as "why," "how," "what," etc.	2
Speaks in simple sentences	1
Speaks in primitive phrases only or is nonverbal	0

ITEM 42 **Word Usage**
(Circle highest level)

Talks about action when describing pictures	4
Names people or objects when describing pictures	3
Names familiar objects	2
Asks for things by their appropriate names	1
Is nonverbal or nearly nonverbal	0

B. Verbal Comprehension

ITEM 43 **Reading Comprehension**
(Circle highest level)

Reads books suitable for children nine years or older	5
Reads books suitable for children seven or eight years old	4
Reads simple stories or comics	3
Reads various signs, e.g., "NO PARKING," "ONE WAY," "MEN," "WOMEN," etc.	2
Recognizes ten or more words by sight	1
Recognizes fewer than ten words	0

ITEM 44 **Comprehension of Spoken Instructions**
(Circle highest level)

Understands complex instructions involving a decision, "If ___, do this, but if not, do ___."	4
Understands instructions involving a series of steps, e.g., "First do ___, then do ___."	3
Answers simple questions such as "What is your name?" or "What are you doing?"	2
Responds correctly to simple phrases, e.g., "stop," "sit down," "come here"	1
Is unable to understand even very simple verbal communications	0

C. Social Language Development

ITEM 45 **Conversation**
(Circle all answers)

	Yes	No
Uses phrases such as "please" and "thank you"	1	0
Is sociable and talks during meals	1	0
Talks to others about sports, family, group activities, etc.	1	0

ITEM 46 **Miscellaneous Language Development**
(Circle all answers)

	Yes	No
Can be reasoned with	1	0
Obviously responds when talked to	1	0
Talks sensibly	1	0
Reads books, newspapers, or magazines for enjoyment	1	0
Repeats a story with little or no difficulty	1	0
Fills in the main items on application form reasonably well	1	0

LANGUAGE DEVELOPMENT DOMAIN TOTAL
(add items 37–46)

DOMAIN V.
Numbers and Time

ITEM 47 **Numbers**
(Circle highest level)

Performs division and multiplication	6
Does simple addition and subtraction	5
Counts ten or more objects	4
Mechanically counts to ten	3
Counts two objects by saying "one . . . two"	2
Discriminates between "one" and "many" or "a lot"	1
Has no understanding of numbers	0

☐

ITEM 48 **Time**
(Circle all answers)

	Yes	No
Tells time by regular clock or watch correctly to the minute	1	0
Reads time on digital clock or digital watch correctly	1	0
Understands time intervals, e.g., between "3:30" and "4:30"	1	0
Understands time equivalents, e.g., "9:15" is the same as "quarter past nine"	1	0
Associates time on clock with various actions and events	1	0

☐

ITEM 49 **Time Concept**
(Circle all answers)

	Yes	No
Names the days of the week	1	0
Refers correctly to "morning" and "afternoon"	1	0
Understands difference between day-week, minute-hour, month-year, etc.	1	0

☐

NUMBERS AND TIME DOMAIN TOTAL
(add items 47–49) ☐

DOMAIN VI.
Domestic Activity

A. Cleaning

ITEM 50 **Room Cleaning**
(Circle highest level)

Cleans living area or school area well without prompting	3
Cleans living area or school area well with prompting	2
Attempts to clean living area or school area but not thoroughly	1
Does not clean living area or school area at all	0

☐

ITEM 51 **Laundry**
(Circle all answers)

Washes clothing	1	0
Dries clothing	1	0
Folds clothing	1	0
Irons clothing when appropriate	1	0
Can use washer-dryer correctly	1	0

☐

B. Kitchen

ITEM 52 **Table Setting**
(Circle highest level)

Places all eating utensils, as well as napkins, salt, pepper, sugar, etc., in positions learned	3
Places plates, glasses, and utensils in positions learned	2
Places silver, plates, cups, etc., on the table	1
Does not set table at all	0

☐

ITEM 53 **Food Preparation**
(Circle highest level)

Can use microwave correctly to prepare a meal	4
Prepares an adequate complete meal (may use canned or frozen food)	3
Mixes and cooks simple food, e.g., fries eggs, makes pancakes, cooks TV dinners, etc.	2
Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc.	1
Does not prepare food at all	0

☐

ITEM 54 **Table Clearing**
(Circle highest level)

Clears table of breakable dishes and glassware	2
Clears table of unbreakable dishes and silverware	1
Does not clear table at all	0

☐

C. Other Domestic Duties

ITEM 55 **General Domestic Activity**
(Circle all answers)

	Yes	No
Washes dishes well	1	0
Makes bed neatly	1	0
Helps with household chores	1	0
Does household tasks routinely	1	0
Can load and use dishwasher correctly	1	0
Can use small, electric kitchen appliances correctly	1	0

☐

DOMESTIC ACTIVITY DOMAIN TOTAL
(add items 50–55) ☐

For INFORMATION ONLY

DOMAIN VII.
Prevocational/Vocational Activity

ITEM 56 **Job Complexity**
(Circle highest level)

Can perform a job requiring use of tools or machinery, e.g., shop work, sewing, etc.	2
Can perform simple work, e.g., simple gardening, mopping floors, emptying trash, cleaning chalkboard erasers, etc.	1
Can perform no work at all	0

☐

ITEM 57 **Work/School—Job Performance**
(Circle all answers)
If "0" is marked in item 56, place a check in the blank and mark "No" for all statements. ____

	Yes	No
Is a careful worker—avoids accidents to self and others	1	0
Looks after tools, equipment, supplies, etc.	1	0
Works steadily and productively	1	0
Is neat and accurate	1	0

☐

ITEM 58 **Work/School Habits**
(Circle all answers)

	Yes	No
Is late for work/school without good reason	0	1
Is often absent from work/school	0	1
Does not complete jobs without constant supervision/encouragement	0	1
Leaves work station/seat without permission	0	1
Grumbles or gripes about work/school	0	1

☐

PREVOCATIONAL/VOCATIONAL ACTIVITY DOMAIN TOTAL
(add items 56–58) ☐

DOMAIN VIII.
Self-Direction

A. Initiative

ITEM 59 **Initiative**
(Circle highest level)

Initiates most of own activities, e.g., tasks, games, etc.	3
Asks if there is something to do or explores surroundings, e.g., home, yard, school, classroom, etc.	2
Will engage in activities only if assigned or directed	1
Will not engage in assigned activities, e.g., putting away toys, etc.	0

☐

ITEM 60 **Passivity**
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she is totally dependent on others, then place a check in the blank and mark "Yes" for all statements ____

	Yes	No
Needs constant encouragement to complete task	0	1
Has to be made to do things	0	1
Has no ambition	0	1
Seems to have no interest in things	0	1
Finishes task last because of wasted time	0	1
Is unnecessarily dependent on others for help	0	1
Movement is slow and sluggish	0	1

☐

B. Perseverance

ITEM 61 **Attention**
(Circle highest level)

Will pay attention to purposeful activities for more than 15 minutes, e.g., playing games, reading, cleaning up	4
Will pay attention to purposeful activities for up to 15 minutes	3
Will pay attention to purposeful activities for up to 10 minutes	2
Will pay attention to purposeful activities for up to 5 minutes	1
Will not pay attention to purposeful activities for as long as 5 minutes	0

☐

ITEM 62 **Persistence**
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she is totally incapable of any organized activities, then place check in the blank and mark "Yes" for all statements ____

	Yes	No
Cannot organize task	0	1
Becomes easily discouraged	0	1
Fails to carry out tasks	0	1
Jumps from one activity to another	0	1
Needs constant encouragement to complete task	0	1

☐

For Inspection Only

C. Leisure Time

ITEM 63 **Leisure Time Activity**
(Circle highest level)

Organize leisure time activities on a fairly complex level, e.g., going on a fishing trip, arranging to play billiards, scheduling time to do computer games, etc.	4
Has active interest in hobby, e.g., painting, embroidery, collecting stamps, coins, baseball cards, etc.	3
Participates in organized leisure time activity when arranged for him or her	2
Engages in leisure activity on a simple level, e.g., watching TV, listening to radio, etc.	1
Is unable to arrange leisure time activity, even of the simplest nature	0

SELF-DIRECTION DOMAIN TOTAL
(add items 59–63)

DOMAIN IX.
Responsibility

ITEM 64 **Personal Belongings**
(Circle highest level)

Very dependable—always takes care of personal belongings	3
Usually dependable—usually takes care of personal belongings	2
Unreliable—seldom takes care of personal belongings	1
Not responsible at all—does not take care of personal belongings	0

ITEM 65 **General Responsibility**
(Circle highest level)

Very conscientious and assumes much responsibility—makes a special effort; assigned activities are always performed	3
Usually dependable—makes an effort to carry out responsibilities; one can be reasonably certain that assigned activities will be performed	2
Unreliable—makes little effort to carry out responsibilities; one is uncertain that the assigned activities will be performed	1
Not given responsibilities; is unable to carry out responsibilities at all	0

ITEM 66 **Personal Responsibility**
(Circle all answers)

	Yes	No
Usually maintains self-control	1	0
Understands concept of being on time	1	0
Seeks and accepts help on instructions	1	0
Reports (to teachers, supervisor, etc.) if there is a problem	1	0

RESPONSIBILITY DOMAIN TOTAL
(add items 64–66)

DOMAIN X.
Socialization

ITEM 67 **Cooperation**
(Circle highest level)

Offers assistance to others	2
Is willing to help if asked	1
Never helps others	0

☐

ITEM 68 **Consideration for Others**
(Circle all answers)

	Yes	No
Shows interest in the affairs of others	1	0
Takes care of others' belongings	1	0
Directs or manages the affairs of others when needed	1	0
Shows consideration for others' feelings	1	0

☐

ITEM 69 **Awareness of Others**
(Circle all answers)

	Yes	No
Recognizes own family	1	0
Recognizes people other than family	1	0
Has information about others, e.g., job, address, relation to self	1	0
Knows the names of people close to him or her, e.g., classmates, neighbors	1	0
Knows the names of people not regularly encountered	1	0

☐

ITEM 70 **Interaction with Others**
(Circle highest level)

Interacts with others in group games or activities	3
Interacts with others for at least a short period of time, e.g., showing or offering toys, clothing, or objects	2
Interacts with others imitatively with little interaction	1
Does not respond to others in a socially acceptable manner	0

☐

ITEM 71 **Participation in Group Activities**
(Circle highest level)

Initiates group activities (leader and organizer)	3
Participates in group activities spontaneously and eagerly (active participant)	2
Participates in group activities if encouraged to do so (passive participant)	1
Does not participate in or withdraw from group activities	0

☐

ITEM 72 **Selfishness**
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she has no social life or is profoundly withdrawn, place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Refuses to take turns	0	1
Does not share with others	0	1
Gets mad if does not get own way	0	1
Interrupts aide or teacher who is helping another person	0	1

☐

ITEM 73 **Social Maturity**
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she has no social life or is profoundly withdrawn, place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Is too familiar with strangers	0	1
Is afraid of strangers	0	1
Does anything to make friends	0	1
Likes to hold hands with everyone	0	1
Is at someone's elbow constantly	0	1

☐

SOCIALIZATION DOMAIN TOTAL
(add items 67–73) ☐

SUPPLEMENTAL **Menstruation**
(Circle highest level)
(For males, note "No menstruation")

No menstruation	5
Cares for self completely for menstruation without assistance or reminder	5
Cares for self reasonably well during menstruation	4
Helps in changing pads during menstruation	3
Indicates pad needs changing during menstruation	2
Indicates that menstruation has begun	1
Does none of the above	0

☐

For Information Only

ART TWO
OMAIN XI.
Social Behavior

		N	O	F	
ITEM 1	**Threatens or Does Physical Violence**				
	Uses threatening gestures	0	1	2	
	Indirectly causes injury to others	0	1	2	
	Spits on others	0	1	2	
	Pushes, scratches, or pinches others	0	1	2	
	Pulls others' hair, ears, etc.	0	1	2	
	Bites others	0	1	2	
	Kicks, strikes, or slaps others	0	1	2	
	Throws objects at others	0	1	2	
	Chokes others	0	1	2	
	Uses objects as weapons against others	0	1	2	
	Hurts animals	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 2	**Has Violent Temper or Temper Tantrums**				
	Cries and screams	0	1	2	
	Stamps feet while banging objects or slamming doors, etc.	0	1	2	
	Stamps feet, screaming and yelling	0	1	2	
	Throws self on floor, screaming and yelling	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 3	**Teases or Gossips About Others**				
	Gossips about others	0	1	2	
	Tells untrue or exaggerated stories about others	0	1	2	
	Teases others	0	1	2	
	Picks on others	0	1	2	
	Makes fun of others	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 4	**Bosses and Manipulates Others**				
	Tries to tell others what to do	0	1	2	
	Demands services from others	0	1	2	
	Pushes others around	0	1	2	
	Causes fights among other people	0	1	2	
	Manipulates others to get them in trouble	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 5	**Uses Angry Language**				
	Uses hostile language, e.g., "stupid jerk," "dirty pig," etc.	0	1	2	
	Swears, curses, or uses obscene language	0	1	2	
	Yells or screams threats of violence	0	1	2	
	Verbally threatens others, suggesting physical violence	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 6	**Reacts Poorly to Frustration**				
	Blames own mistakes on others	0	1	2	
	Withdraws or pouts when thwarted	0	1	2	
	Becomes upset when thwarted	0	1	2	
	Throws temper tantrums when does not get own way	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 7	Disrupts Others' Activities				
	Is always in the way	0	1	2	
	Interferes with others' activities, e.g., by blocking passage, upsetting wheelchairs, etc.	0	1	2	
	Upsets others' work	0	1	2	
	Knocks around articles that others are working with, e.g., puzzles, card games, etc.	0	1	2	
	Snatches things out of others' hands	0	1	2	☐
	Other (specify) ______________	0	1	2	

SOCIAL BEHAVIOR DOMAIN TOTAL ☐
(add items 1–7)

DOMAIN XII.
Conformity

		N	O	F	
ITEM 8	**Ignores Regulations or Regular Routines**				
	Has negative attitude toward rules but usually conforms	0	1	2	
	Has to be forced to go through waiting lines, e.g., lunch lines, ticket lines, etc.	0	1	2	
	Violates rules or regulations, e.g., eats in restricted areas, disobeys traffic signals, etc.	0	1	2	
	Refuses to participate in required activities, e.g., work, school, etc.	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 9	**Resists Following Instructions, Requests, or Orders**				
	Gets upset if given a direct order	0	1	2	
	Pretends not to hear and does not follow instructions	0	1	2	
	Does not pay attention to instructions	0	1	2	
	Refuses to work on assigned subject	0	1	2	
	Hesitates for long periods before doing assigned tasks	0	1	2	
	Does the opposite of what was requested	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 10	**Has Impudent or Rebellious Attitude Toward Authority**				
	Resents persons in authority, e.g., teachers, group leaders, care personnel, etc.	0	1	2	
	Is hostile toward people in authority	0	1	2	
	Mocks people in authority	0	1	2	
	Says that he or she can fire people in authority	0	1	2	
	Says relative will come to kill or harm persons in authority	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 11	**Is Absent From, or Late For, the Proper Assignments or Places**				
	Is late to required places or activities	0	1	2	
	Fails to return to places where he or she is supposed to be after leaving, e.g., after going to toilet, running an errand, etc.	0	1	2	
	Leaves place of required activity without permission, e.g., work, class, etc.	0	1	2	
	Is absent from routine activities, e.g., work, class, etc.	0	1	2	
	Stays out late at night from home, hospital ward, dormitory, etc.	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 12	**Runs Away or Attempts to Run Away**				
	Attempts to run away from hospital, home, or school grounds	0	1	2	
	Runs away from group activities, e.g., picnics, school bus rides, etc.	0	1	2	
	Runs away from hospital, home, or school grounds	0	1	2	☐
	Other (specify) ______________	0	1	2	
ITEM 13	**Misbehaves in Group Settings**				
	Interrupts group discussions by talking about unrelated topics	0	1	2	
	Disrupts games by refusing to follow rules	0	1	2	
	Disrupts group activities by making loud noises or by acting up	0	1	2	
	Does not stay in seat during class lesson period, lunch period, or other group sessions	0	1	2	☐
	Other (specify) ______________	0	1	2	

CONFORMITY DOMAIN TOTAL ☐
(add items 8–13)

Reference only

DOMAIN XIII.

Trustworthiness

		N	O	F	
ITEM 14	**Shows Disrespect for Others' Property**				
	Does not return borrowed items	0	1	2	
	Uses others' property without permission	0	1	2	
	Loses others' belongings	0	1	2	
	Damages others' property	0	1	2	
	Does not recognize the difference between own and others' property	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 15	**Takes Others' Property Without Permission**				
	Has been suspected of stealing	0	1	2	
	Takes others' belongings if not kept in place or locked up	0	1	2	
	Takes others' belongings from pockets, purses, drawers, etc.	0	1	2	
	Takes others' belongings by opening or breaking locks	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 16	**Lies or Cheats**				
	Twists the truth to own advantage	0	1	2	
	Cheats in games, tests, assignments, etc.	0	1	2	
	Lies about situations	0	1	2	
	Lies about self	0	1	2	
	Lies about others	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 17	**Damages Personal Property**				
	Rips, tears, or chews own clothing	0	1	2	
	Soils own property	0	1	2	
	Tears up own magazines, books, or other possessions	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 18	**Damages Public Property**				
	Tears up magazines, books, or other public property	0	1	2	
	Is overly rough with furniture (kicks, mutilates, knocks it down)	0	1	2	
	Breaks windows	0	1	2	
	Stuffs toilet with paper towel or other solid objects to cause overflow	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 19	**Damages Others' Property**				
	Rips, tears, or chews others' clothing	0	1	2	
	Soils others' property	0	1	2	
	Tears up others' magazines, books, or personal possessions	0	1	2	☐
	Other (specify) ____________	0	1	2	

TRUSTWORTHINESS DOMAIN TOTAL
(add items 14–19) ☐

Demonstration Only

DOMAIN XIV.

Stereotyped and Hyperactive Behavior

		N	O	F	
ITEM 20	**Has Stereotyped Behaviors**				
	Drums fingers continually	0	1	2	
	Taps feet continually	0	1	2	
	Has hands constantly in motion	0	1	2	
	Slaps, scratches, or rubs self continually	0	1	2	
	Waves or shakes parts of the body repeatedly	0	1	2	
	Moves or rolls back and forth	0	1	2	
	Rocks body back and forth	0	1	2	
	Paces the floor	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 21	**Has Inappropriate Interpersonal Manners**				
	Talks too close to others' faces	0	1	2	
	Blows on others' faces	0	1	2	
	Burps at others	0	1	2	
	Kisses or licks others	0	1	2	
	Hugs or squeezes others	0	1	2	
	Touches others inappropriately	0	1	2	
	Hangs onto others and does not let go	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 22	**Has Disturbing Vocal or Speech Habits**				
	Giggles hysterically	0	1	2	
	Talks loudly or yells at others	0	1	2	
	Talks to self loudly	0	1	2	
	Laughs inappropriately	0	1	2	
	Makes growling, humming, or other unpleasant noises	0	1	2	
	Repeats a word or phrase over and over	0	1	2	
	Mimics others' speech	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 23	**Has Unacceptable Oral Habits**				
	Drools	0	1	2	
	Grinds teeth audibly	0	1	2	
	Spits on the floor	0	1	2	
	Bites fingernails	0	1	2	
	Chews or sucks fingers or other parts of the body	0	1	2	
	Chews or sucks clothing or other inedibles	0	1	2	
	Eats inedibles	0	1	2	
	Drinks from toilet stool	0	1	2	
	Puts everything in mouth	0	1	2	☐
	Other (specify) ____________	0	1	2	
ITEM 24	**Has Hyperactive Tendencies**				
	Talks excessively	0	1	2	
	Will not sit still for any length of time	0	1	2	
	Constantly runs or jumps around the room or hall	0	1	2	
	Moves or fidgets constantly	0	1	2	☐
	Other (specify) ____________	0	1	2	

STEREOTYPED AND HYPERACTIVE BEHAVIOR DOMAIN TOTAL
(add items 20–24) ☐

for Information Only

DOMAIN XV.

Sexual Behavior

ITEM 25 Removes or Tears Off Own Clothing	N	O	F
Tears off buttons or zippers	0	1	2
Inappropriately removes shoes or socks	0	1	2
Undresses at the wrong time	0	1	2
Takes off all clothing while on toilet	0	1	2
Tears off own clothing	0	1	2
Refuses to wear clothing when asked	0	1	2
Other (specify) ________	0	1	2

ITEM 26 Engages in Inappropriate Masturbation			
Has attempted to masturbate openly	0	1	2
Masturbates in front of others	0	1	2
Masturbates in group	0	1	2
Other (specify) ________	0	1	2

ITEM 27 Exposes Body Improperly			
Exposes body unnecessarily after using toilet	0	1	2
Stands in public places with pants down or dress up	0	1	2
Exposes body excessively during activities, e.g., playing, dancing, sitting, etc.	0	1	2
Undresses in public places or in front of lighted windows	0	1	2
Other (specify) ________	0	1	2

ITEM 28 Has Sexual Behavior That Is Socially Unacceptable			
Is overly seductive in appearance or actions	0	1	2
Hugs or caresses too intensely in public	0	1	2
Needs watching with regard to sexual behavior	0	1	2
Lifts or unbuttons others' clothing to touch intimately	0	1	2
Has sexual relations in public places	0	1	2
Is overly aggressive sexually	0	1	2
Is easily taken advantage of sexually	0	1	2
Other (specify) ________	0	1	2

SEXUAL BEHAVIOR DOMAIN TOTAL
(add items 25–28)

DOMAIN XVI.

Self-Abusive Behavior

ITEM 29 Has Other Eccentric Habits and Tendencies	N	O	F
Is overly particular about places to sit or sleep	0	1	2
Stands in a favorite spot, e.g., by window, door, etc.	0	1	2
Sits by anything that vibrates	0	1	2
Is afraid to climb or descend stairs	0	1	2
Does not want to be touched	0	1	2
Screams if touched	0	1	2
Other (specify) ________	0	1	2

ITEM 30 Does Physical Violence to Self	N	O	F
Bites or cuts self	0	1	2
Slaps or strikes self	0	1	2
Bangs head or other parts of the body against objects	0	1	2
Pulls own hair, ears, etc.	0	1	2
Scratches or picks self, causing injury	0	1	2
Soils and smears self	0	1	2
Purposely provokes abuse from others	0	1	2
Picks at any sores he or she might have	0	1	2
Pokes objects in own ears, eyes, nose, or mouth	0	1	2
Other (specify) ________	0	1	2

ITEM 31 Has Strange and Unacceptable Habits			
Smells everything	0	1	2
Inappropriately stuffs things in pockets, shirts, dresses, or shoes	0	1	2
Pulls threads out of own clothing	0	1	2
Plays with things he or she is wearing, e.g., shoestring, buttons, etc.	0	1	2
Saves and wears unusual articles e.g., safety pins, bottle caps, etc.	0	1	2
Hoards things, including food	0	1	2
Plays with spit	0	1	2
Plays with feces or urine	0	1	2
Other (specify) ________	0	1	2

SELF-ABUSIVE BEHAVIOR DOMAIN TOTAL
(add items 29–31)

DOMAIN XVII.

Social Engagement

ITEM 32 Is Inactive	N	O	F
Sits or stands in one position for a long period of time	0	1	2
Does nothing but sit and watch others	0	1	2
Falls asleep in a chair	0	1	2
Lies on the floor all day	0	1	2
Does not seem to react to anything	0	1	2
Other (specify) ________	0	1	2

ITEM 33 Is Withdrawn			
Seems unaware of surroundings	0	1	2
Is difficult to reach or contact	0	1	2
Is apathetic and unresponsive in feeling	0	1	2
Has a blank stare	0	1	2
Has a fixed expression	0	1	2
Other (specify) ________	0	1	2

ITEM 34 Is Shy			
Is timid and shy in social situations	0	1	2
Hides face in group situations, e.g., parties, informal gatherings, etc.	0	1	2
Does not mix well with others	0	1	2
Prefers to be alone	0	1	2
Other (specify) ________	0	1	2

ITEM 35 **Has Peculiar Posture or Odd Mannerisms** *N O F*
Holds head tilted 0 1 2
Sits with knees under chin 0 1 2
Walks on tiptoes 0 1 2
Lies on floor with feet up in the air 0 1 2
Walks with fingers in ears or with hands on head 0 1 2 ☐
Other (specify) ________ 0 1 2

SOCIAL ENGAGEMENT DOMAIN TOTAL ☐
(add items 32–35)

DOMAIN XVIII.
Disturbing Interpersonal Behavior

For information only

ITEM 36 **Tends to Overestimate Own Abilities** *N O F*
Does not recognize own limitations 0 1 2
Has too high an opinion of self 0 1 2
Talks about future plans that are unrealistic 0 1 2 ☐
Other (specify) ________ 0 1 2

ITEM 37 **Reacts Poorly to Criticism**
Does not talk when corrected 0 1 2
Withdraws or pouts when criticized 0 1 2
Becomes upset when criticized 0 1 2
Screams and cries when corrected 0 1 2 ☐
Other (specify) ________ 0 1 2

ITEM 38 **Demands Excessive Attention or Praise**
Wants excessive praise 0 1 2
Is jealous of attention given to others 0 1 2
Demands excessive reassurance 0 1 2
Acts silly to gain attention 0 1 2 ☐
Other (specify) ________ 0 1 2

ITEM 39 **Seems To Feel Persecuted**
Complains of unfairness, even when equal shares
or privileges have been given 0 1 2
Complains, "Nobody loves me" 0 1 2
Says, "Everybody picks on me" 0 1 2
Says, "People talk about me" 0 1 2
Says, "People are against me" 0 1 2
Acts suspicious of others 0 1 2 ☐
Other (specify) ________ 0 1 2

ITEM 40 **Has Hypochondriacal Tendencies**
Complains about imaginary physical ailments 0 1 2
Pretends to be ill 0 1 2
Acts sick after illness is over 0 1 2 ☐
Other (specify) ________ 0 1 2

ITEM 41 **Has Other Signs of Emotional Instabilities**
Changes mood without apparent reason 0 1 2
Complains of bad dreams 0 1 2
Cries out while asleep 0 1 2
Cries for no apparent reason 0 1 2
Seems to have no emotional control 0 1 2
Vomits when upset 0 1 2
Appears insecure or frightened in daily activities 0 1 2
Talks about people or things that cause unrealistic fears 0 1 2
Talks about suicide 0 1 2 ☐
Other (specify) ________ 0 1 2

DISTURBING INTERPERSONAL BEHAVIOR DOMAIN TOTAL ☐
(add items 36–41)

SUPPLEMENTAL
Use of Prescribed (Psychoactive) Medications *N O F*
Uses tranquilizers 0 1 2
Uses sedatives 0 1 2
Uses anticonvulsant drugs 0 1 2
Uses stimulants 0 1 2 ☐
Other (specify) ________ 0 1 2

Appendix 5
Life Skills Profile

Life Skills Profile

Instruction:
Please complete the form (on the inside pages) as you assess ____________'s general functioning (i.e. not during crises when he or she is ill, or becoming ill, but his or her general state over the past three months).

Answer all items by circling the appropriate description.

Example:

For example, if you consider that the person generally shows a particular behaviour only 'rarely' you would place a circle as below:

Always Usually [✓ Rarely] Never

For rights, permissions, forms and scoring manuals, contact Professor G. Parker or Dr A. Rosen at the School of Psychiatry, University of New South Wales, The Prince of Wales Hospital, Randwick 2031, Australia.

Answer all items by circling the appropriate description:

1. Does this person generally have any difficulty with initiating and responding to conversation?

No difficulty with conversation	Slight difficulty with conversation	Moderate difficulty with conversation	Extreme difficulty with conversation

2. Does this person generally intrude or burst in on others' conversation (e.g. interrupts you when you are talking)?

Not intrusive at all	Slightly intrusive	Moderately intrusive	Extremely intrusive

3. Does this person generally withdraw from social contact?

Does not withdraw at all	Withdraws slightly	Withdraws moderately	Withdraws totally or near totally

4. Does this person generally show warmth to others?

Considerable warmth	Moderate warmth	Slight warmth	No warmth at all

5. Is this person generally angry or prickly towards others?

Not angry at all	Slightly angry	Moderately angry	Extremely angry

6. Does this person generally take offence readily?

Doesn't take offence	Somewhat ready to take offence	Quite ready to take offence	Extremely ready to take offence

7. Does this person generally make eye contact with others when in conversation?

Appropriate eye contact	Slightly reduced eye contact	Moderately reduced eye contact	Extremely reduced or no eye contact

8. Is it generally difficult to understand this person because of the way he or she speaks (e.g. jumbled, garbled or disordered)?

Not at all difficult	Slightly difficult	Moderately difficult	Extremely difficult

9. Does this person generally talk about odd or strange ideas?

No odd ideas	Slightly odd ideas	Moderately odd ideas	Extremely odd ideas

10. Is this person generally well groomed (e.g. neatly dressed, hair combed)?

Well groomed	Moderately well groomed	Poorly groomed	Extremely poorly groomed

11. Is this person's appearance (facial appearance, gestures) generally appropriate to his or her surroundings?

Unremarkable or appropriate	Slightly bizarre or inappropriate	Moderately bizarre or inappropriate	Extremely bizarre or inappropriate

12. Does this person wash himself or herself without reminding?

Generally	Occasionally	Rarely	Never

13. Does this person generally have an offensive smell (e.g. due to body, breath or clothes)?

Not at all	Smells slightly	Smells moderately	Smells a lo

14. Does this person wear clean clothes generally, or ensure that they are cleaned if dirty?

Maintains cleanliness of clothes	Moderate cleanliness of clothes	Poor cleanliness of clothes	Very poo cleanlines of clothe

15. Does this person generally neglect her or his physical health?

No neglect	Slight neglect of physical problems	Moderate neglect of physical problems	Extrem neglect physic problem

16. Does this person generally maintain an adequate diet?

No problem	Slight problem	Moderate problem	Extren proble

17. Does this person generally look after and take her or his own prescribe medication (or attend for prescribed injections on time) without remindi

Reliable with medication	Slightly unreliable	Moderately unreliable	Extreme unreliab

18. Is this person willing to take psychiatric medication when prescribed by a doctor?

Always	Usually	Rarely	Ne

19. Does this person co-operate with health services (e.g. doctors and/or health workers)?

Always	Usually	Rarely	Ne

Is this person generally inactive (e.g. spends most of the time sitting or standing around doing nothing)?

propriately tive	Slightly inactive	Moderately inactive	Extremely inactive

Does this person generally have definite interests (e.g. hobbies, sports, activities) in which he or she is involved regularly?

nsiderable volvement	Moderate involvement	Some involvement	Not involved at all

Does this person attend any social organisation (e.g. church, club or interest group but excluding psychiatric therapy groups)?

requently	Occasionally	Rarely	Never

Can this person generally prepare (if needed) her or his own food/meals?

uite capable f preparing ood/meals	Slight limitations	Moderate limitations	Totally incapable of preparing food/meals

4. Can this person generally budget (if needed) to live within his or her means?

uite capable f budgeting	Slight limitations	Moderate limitations	Totally incapable of budgeting

25. Does this person generally have problems (e.g. friction, avoidance) living with others in the household?

No obvious problems	Slight problems	Moderate problems	Extreme problems

What sort of work is this person generally capable of (even if unemployed, retired or doing unpaid domestic duties)?

Capable of full-time work	Capable of part-time work	Capable only of sheltered work	Totally incapable of work

27. Does this person behave recklessly (e.g. ignoring traffic when crossing the road)?

Not at all	Rarely	Occasionally	Often

28. Does this person destroy property?

Not at all	Rarely	Occasionally	Often

29. Does this person behave offensively (includes sexual behaviour)?

Not at all	Rarely	Occasionally	Often

30. Does this person have habits or behaviours that most people find unsociable (e.g. spitting, leaving lighted cigarette butts around, messing up the toilet, messy eating)?

Not at all	Rarely	Occasionally	Often

31. Does this person lose personal property?

Not at all	Rarely	Occasionally	Often

32. Does this person invade others' space (rooms, personal belongings)?

Not at all	Rarely	Occasionally	Often

33. Does this person take things which are not his or hers?

Not at all	Rarely	Occasionally	Often

34. Is this person violent to others?

Not at all	Rarely	Occasionally	Often

35. Is this person violent to him or her self?

Not at all	Rarely	Occasionally	Often

36. Does this person get into trouble with the police?

Not at all	Rarely	Occasionally	Often

37. Does this person abuse alcohol or other drugs?

Not at all	Rarely	Occasionally	Often

38. Does this person behave irresponsibly?

Not at all	Rarely	Occasionally	Often

39. Does this person generally make and/or keep up friendships?

Friendships made or kept up well	Friendships made or kept up with slight difficulty	Friendships made or kept up with considerable difficulty	No friendships made or none kept up

Patient/Client or Resident's name: ______________________________

ID Number: ☐☐☐☐

Age: ______________ Sex: M/F (Please circle)

Rater's Name: ______________________________

Date of Rating: ______________________________

Institution or Facility: ______________________________

The LSP has five scales labelled to reflect functional strengths as well as disabilities. Scores similarly reflect that orientation, so that a high score for each scale or for the total LSP would indicate high function or low disability.

Scoring the LSP: All items are phrased so that the most functional rating is the left-hand anchor point, and the most dysfunctional rating is the right-hand anchor point, so that scores for each item should be assigned as '4' (extreme left anchor), '3' or '2' if intermediate and '1' (if extreme right anchor). Scale scores are generated by summing anchor scores as follows:

'Self-care' is the sum of scores for items 10, 12, 13, 14, 15, 16, 23, 24, 26 and 30.
'Non-turbulence' is the sum of scores for items 5, 6, 25, 27, 28, 29, 32, 34, 35, 36, 37 and 38.
'Social contact' is the sum of scores for items 3, 4, 20, 21, 22 and 39.
'Communication' is the sum of scores for items 1, 2, 7, 8, 9 and 11.
'Responsibility' is the sum of scores for items 17, 18, 19, 31 and 33.

The total LSP score is the sum of all item scores.

SCORE

Self-care ______________

Non-turbulence ______________

Social contact ______________

Communication ______________

Responsibility ______________

TOTAL = ______________

Appendix 6:
Lancashire QOL-P

LANCASHIRE QUALITY OF LIFE PROFILE

NAME OR IDENTIFICATION NUMBER ____________

ADDRESS [optional] ____________
____
____

DATE OF INTERVIEW ____________

INTERVIEWERS CODE ____________
If the client DECLINES to be interviewed , state the reasons and stop here. ____________

STARTING TIME ____________

Section 1: Clients personal details.

1.1. The clients age ____________ Yrs 1.1

1.2. The client is male/female M / F 1.2

1.3. The clients ethnic group [enter a number code] ____________ 1.3

1. White..
2. Black Caribbean
3. Black African
4. Black-Other.
5. Indian.
6. Pakistani
7. Bangladeshi.
9. Other.
8. Chinese

1.4. At what age did the client leave full time education? ____________ Yrs 1.4

Section 2: General well being.

2.1. Can you tell me how you feel about your life as a whole today? ____________ LSS 2.1

Section 3: Work/Education.

3.1. Do you have a job? (please ring the correct answer) Y/N/DK 1 2 3 3.1

3.2. [if yes] What is your occupation? ____________ 3.2

3.3. How many hours per week do you work? ____________ 3.3

3.4. How much money are you paid weekly [gross]? £ ____________ 3.4

How satisfied are you with:

3.5. Your job [sheltered employment; occupational or industrial therapy; studies.]? ____________ LSS 3.5

3.6. The amount of money that you make?	LSS	3.6
3.7. Being unemployed or retired?	LSS	3.7

Section 4. Leisure/participation

In the past fortnight, have you: [please ring the correct answer]	Y/N/DK	
4.1. been out to play or watch a sport?	1 2 3	4.1
4.2. been out shopping?	1 2 3	4.2
4.3. been for a ride in a bus, car or train other than for transport to and from work?	1 2 3	4.3
4.4. watched television or listened to radio?	1 2 3	4.4
4.5. In the past year, have there been times when you would have liked to have had more leisure activity but were unable?	1 2 3	4.5
How satisfied are you with:		
4.6. the amount of pleasure you get from things you do at home?	LSS	4.6
4.7. the amount of pleasure you get from things you do outside your home?	LSS	4.7
4.8. the pleasure you get from radio or T.V.?	LSS	4.8

Section 5. Religion

5.1. What is your religion now? [please enter a number code] **1.** Protestant. **3.** Jewish. **5.** Hindu. **7.** None. **2.** Roman Catholic. **4.** Muslim. **6.** Other.		5.1
5.2. How often have you attended religious services in the past month?		5.2
How satisfied are you with:		
5.3. your religious faith and its teachings?	LSS	5.3
5.4. the frequency which you attend services?	LSS	5.4

Section 6. Finances

6.1. What is your total weekly income?	£	6.1
6.2. Which, if any state benefits do you receive?		6.2
6.3. In the past year have you been turned down for any state benefit for which you have applied?	Y/N/DK 1 2 3	6.3
6.4. About how much more money do you need to be able to live as you would wish?	£	6.4
6.5. During the past year, have you ever lacked the money to enjoy everyday life?	Y/N/DK 1 2 3	6.5
How satisfied are you with:		
6.6. how well-off you are financially?	LSS	6.6

6.7. the amount of money you have to spend on enjoyment? ____ LSS 6.7

Section 7. Living situation.

7.1 The client's current residence is [please enter a number code] ____ 7.1

1. Hostel	**5**. Sheltered housing	**9**. Other
2. Boarding out	**6**. Private house [owner occupied]	**10**.None.
3. Group home	**7**. Private house [rental]	
4. Hospital ward.	**8**. Flat	

7.2 How long have you lived here? (Years & Months) ____Yrs____Mths 7.2

7.3 How many other people live here? ____ 7.3

Y/N/DK

7.4 Do your family live here too? 1 2 3 7.4

7.5 In the past year have there been times when you wanted to move or improve your living conditions but were unable to do so? 1 2 3 7.5

How satisfied are you with:

7.6 the living arrangements here? ____ LSS 7.6

7.7 the amount of independence you have here? ____ LSS 7.7

7.8 the amount of influence you have here? ____ LSS 7.8

7.9 living with the people that you do? ____ LSS 7.9

7.10 the amount of privacy that you have here? ____ LSS 7.10

7.11 the prospect of living here for a long time? ____ LSS 7.11

7.12 the prospect of returning to live in hospital ?[if applicable] ____ LSS 7.12

Section 8 Legal and safety

8.1 In the past year have you been Y/N/DK

a. accused of a crime? 1 2 3 8.1a

b. assaulted, beaten, molested or otherwise a victim of violence? 1 2 3 8.1b

8.2 In the past year have there been any times when you would of liked police or legal help but were unable to get it? 1 2 3 8.2

How satisfied are you with:

8.3 your general personal safety? ____ LSS 8.3

8.4 the safety of this neighbourhood? ____ LSS 8.4

Section 9 Family relations

9.1 What is your current marital status?

1. Married **2.** Single. **3.** Widowed **4.** Divorced **5.** Separated. **6.** Other		9.1
9.2 How many children do you have?		9.2
9.3 How often do you have contact with a relative? [enter a number code] **1.** daily **3.** monthly. **5.** less than annually **2.** weekly **4.** annually **6.** not appropriate/don't know		9.3
9.4 In the past year have there been any times when you would have liked to have participated in family activities but were unable?	Y/N/DK 1 2 3	9.4
How satisfied are you with:		
9.5 your family in general?	LSS	9.5
9.6. the amount of contact you have with your relatives?	LSS	9.6
9.7 your marriage? [if applicable]	LSS	9.7

Section 10 Social relations

People differ in how much friendship they need	Y/N/DK	
10.1 Would you say that you are the sort of person who can manage without friends?	1 2 3	10.1
10.2 Do you have anyone you would call a"close friend"[i.e. who knows you very well] ?	1 2 3	10.2
10.3 Do you have a friend to whom you could turn for help if you needed it?	1 2 3	10.3
10.4 In the past week, have you visited with a friend?	1 2 3	10.4
How satisfied are you with:		
10.5 the way that you get on with other people?	LSS	10.5
10.6 the number of friends you have?	LSS	10.6

Section 11 Health.

During the past year have you:	Y/N/DK	
11.1 seen a doctor for a physical illness?	1 2 3	11.1
11.2 seen a doctor for your nerves?	1 2 3	11.2
11.3 been in hospital for your nerves?	1 2 3	11.3
11.4 Do you take medication for your nerves?	1 2 3	11.4
11.5 Do you have any physical handicap which affects your mobility?	1 2 3	11.5
11.6 How old were you when you were first admitted to a psychiatric hospital/ward? [if appropriate]	Yrs	11.6
11.7 In the past year have there been times when you wanted help from a doctor or other professional for your health but were unable to get it?	Y/N/DK 1 2 3	11.7
How satisfied are you with:		

11.8 your general state of health?	LSS	11.8
11.9 how often you see a doctor?	LSS	11.9
11.10 your nervous well being?	LSS	11.10
During the past month did you ever feel:	Y/N/DK	
11.11 Pleased about having accomplished something?	1 2 3	11.11
11.12 that things were going your way?	1 2 3	11.12
11.13 proud because someone had complimented you on something that you had done?	1 2 3	11.13
11.14 Particularly excited or interested in something?	1 2 3	11.14
11.15 "on top of the world"?	1 2 3	11.15
11.16 too restless to sit in a chair?	1 2 3	11.16
11.17 bored?	1 2 3	11.17
11.18 depressed or very unhappy?	1 2 3	11.18
11.19 very lonely or remote from other people?	1 2 3	11.19
11.20 upset because someone criticised you?	1 2 3	11.20

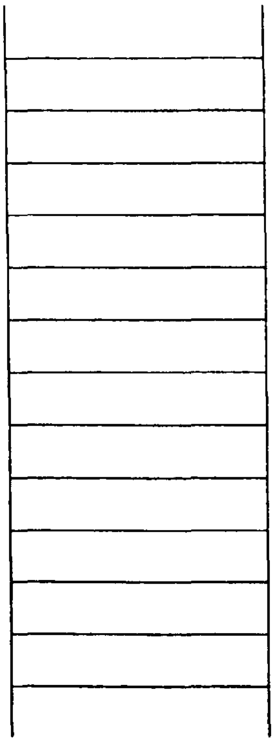
Section 12 Self concept

How satisfied we are with ourselves is also a very important part of our lives. Do you agree that the following statements apply to you:.	Y/N/DK	
12.1 You feel that you're a person of worth at least on an equal plane with others	1 2 3	12.1
12.2 You feel that you have a number of good qualities.	1 2 3	12.2
12.3 All in all you are inclined to feel that you are a failure.	1 2 3	12.3
12.4 You are able to do things as well as most others.	1 2 3	12.4
12.5 You feel that you do not have much to be proud of.	1 2 3	12.5
12.6 You take a positive attitude towards yourself.	1 2 3	12.6
12.7 On the whole, you are satisfied with yourself.	1 2 3	12.7
12.8 You wish you could have more respect for yourself.	1 2 3	12.8
12.9 You certainly feel useless at times.	1 2 3	12.9
12.10 At times you think you are no good at all.	1 2 3	12.10

Section 13 General well being.

During the course of this interview you and I have discussed many of the conditions of your life and how you feel about them. Might we try and sum them up now?

13.1 Can you tell me how you feel about your life as a whole	LSS	13.1
13.2 This is a picture of a ladder. I would like you to imagine that the bottom of the ladder represents the very worst outcome which you could have expected to have in life. The top represents the very best possible outcome you could have expected. Can you please mark[x] where on this ladder you would put your life at present? [Ask client to mark ladder]		



Cantrills ladder score ________ /100 13.2

13.3 How happy has your life been overall? [Please enter a number code]
1. very happy. **2.** pretty happy **3.** not happy. **4.** don't know ________ 13.3

13.4 Can you name anything[s] which would improve the quality of your life?

a ________________ 13.4a

b ________________ 13.4b

c ________________ 13.4c

Section 14 Final remarks

Thank you for having spoken to me in such an honest and open way about your life Y/N/DK

14.1 It is possible that we may wish to contact you again in future, perhaps next year. Would you be willing to be interviewed again? 1 2 3 14.1

Thank you very much for your co-operation

FINISHING TIME ________ 14.2

Section 15 Interviewer comments.

Before filing this questionnaire or proceeding on to the next interview, would you please complete the following section while your impressions of both the client and the setting for the interview are still fresh in your memory.

15.1 How long did the interview take? (Minutes) ________ 15.1

15.2 How reliable or unreliable do you think the clients responses were? [please enter a number code]

1. very reliable **3.** generally unreliable

2. generally reliable. **4.** very unreliable ________ 15.2

15.3 Please complete the QUALITY OF LIFE UNISCALE now. Please mark with an X the appropriate place within the box to indicate your rating of this person's present quality of life

LOWEST quality applies to someone completely dependent physically on others, seriously mentally disabled, unaware of surroundings and in a hopeless position.

HIGHEST quality applies to someone physically and mentally independent, communicating well with others, able to do most things enjoyed pulling own weight, with a hopeful yet realistic attitude

Quality of Life Uniscale

☐

Lowest Highest

Uniscale score ________ /100 15.3

Appendix 7
Personal/team role clarity scale

Please rate your agreement with the following statements about your work by circling the number of your answer on the scale of 0 – 4 .

	Strongly agree	Agree	Neither agree or disagree	Slightly disagree	Strongly disagree
1. I feel uncertain about how much authority I have	4	3	2	1	0
2. I'm not certain of where the team's responsibilities begin and end	4	3	2	1	0
3. I seldom know whether I'm doing my job well or poorly	4	3	2	1	0
4. I know exactly what is expected of me	4	3	2	1	0
5. I know what my responsibilities are	4	3	2	1	0
6. I'm clear about who the team is trying to help	4	3	2	1	0
7. I feel the team has a clear purpose to its work for clients and patients	4	3	2	1	0
8. I'm not sure who I am accountable to for my work with clients and patients	4	3	2	1	0
9. I am not certain what the team's priorities are	4	3	2	1	0
10. I do not feel that the role of the team is clearly defined	4	3	2	1	0
11. I am clear about what my work priorities are	4	3	2	1	0
12. I know exactly what is expected of the team	4	3	2	1	0

13. I feel most of my tasks are clearly defined	4	3	2	1	0
14. It is difficult to tell whether the team is doing its job right or not	4	3	2	1	0

Appendix 8:
Team/Professional Identification Scale

Please rate your agreement with the following statements about your feelings regarding the team by circling the number of your answer on the scale of 0 – 4 .

	Strongly agree	Agree	Neither agree or disagree	Slightly disagree	Strongly disagree
15. I feel strong ties with the team	4	3	2	1	0
16. I don't fit in with other members of the team	4	3	2	1	0
17. I try to hide belonging to the team	4	3	2	1	0
18. I consider the team important to me	4	3	2	1	0
19. I'm embarrassed to say that I am a member of the team	4	3	2	1	0
20. I make excuses for belonging to the team	4	3	2	1	0
21. I see myself as belonging to the team	4	3	2	1	0
22. I'm glad to belong to the team	4	3	2	1	0

Please rate your agreement with the following statements about your feelings regarding your professional identity by circling the number of your answer on the scale of 0 – 4 .

	Strongly agree	Agree	Neither agree or disagree	Slightly disagree	Strongly disagree
1. I'm embarrassed to say that I am a member of my profession	4	3	2	1	0
2. I see myself as belonging to my profession	4	3	2	1	0
3. I make excuses for belonging to my profession	4	3	2	1	0
4. I feel strong ties with my profession	4	3	2	1	0
5. I'm glad to belong to my profession	4	3	2	1	0
6. I don't fit in with any other members of my profession	4	3	2	1	0
7. I consider my profession important to me	4	3	2	1	0
8. I try to hide belonging to my profession	4	3	2	1	0

Appendix 9
Definition of severe challenging behaviour

Individuals who are over 18 years of age and who have a mental disorder, including those with learning difficulties and/or autism and/or mental health needs (currently excluding those in the elderly service and those in the substance misuse services).

Behaviour of such frequency, duration and intensity that the physical safety of the person or others is likely to be placed in serious jeopardy and where all of the following apply:

- The behaviour has occurred over a period of more than 6 months, appears to be chronic and not easily remedied
- The behaviour is likely to be remedied to reoccur (because the causes have not yet been identified and/or cannot be remedied)
- The behaviour has led to conviction in court (or would have done if it were not for the person's learning difficulties and/or mental health needs) but not so serious that the person would be currently accepted by the forensic services. (For self injury, people do not have to meet this court criterion).

The Wolfson study added the following paragraph:

- The behaviour requires detention under secure conditions and/or requires very close supervision and/or frequent restraint (by staff or protective devices)

Appendix 10 : Service Users' Consent Form

Consent Form

My name is ....

Karen Ahmed has spoken to me about her research.

Photo here

She has said that she wants to find out how helpful "*the team*" is. She has said that she would like to me to tell her about the kind of things that I do during the day and where I can go to for help.

I have said that I am happy to talk to Karen about these things.

Karen has explained that it is okay if I change my mind or I get upset and I want to stop..

If I want to, Karen will tell ....that I am upset and would like some support. I will not get into trouble if I do not want to talk to Karen.

Karen has told me that she will be writing about her research. She has promised that she will not use my name.

If there is something I do not understand about what Karen is doing, I can ask her and she will explain.

Signed..

Date ....

Appendix 11

Consent Form (Permission to Speak to Carers).

My name is……………………………………………………………………..

Karen Ahmed has spoken to me about her research.

I know that she wants to find out how helpful "*the team*" is.

She has said that she would like to speak to my ………………… about this.

She wants to ask them questions about the kind of help I get.

I have said that it is okay for Karen to talk to my …………………

If I change my mind, I can leave a message for Karen on 01322 356 154 and she will not talk to my

……………………………………………………

I will not get into trouble if I do not want Karen to talk to my

…………………………..

Signed……………………………………………………..

Date ……………………………………..

Information Sheet

This tells you all about the research that Karen Ahmed is doing.
The research is called " [the name of the team]".

Karen is trying to find out what kinds of services help people with things like:

- Living where they want to
- Going to college/ work
- Not getting into trouble

She would like to ask you about what kind of things you do during the day and where you go to for help. If you agree to talk to Karen, she will give you a consent form for you to sign. You can keep a copy of this form.

Karen will be writing about her research. She has promised that she will not use your name.

You can choose if you want to help Karen with her research. If you change your mind, that is okay.

You can tell Karen who to contact if you get upset and want to talk to someone.

If you do not understand something, you can ask Karen. She will explain it to you. You can ring her on [mobile phone number]. If she is not there, then you can leave a message and she will ring you back.

If you don't like what Karen said or did then you can make a complaint. There is a leaflet which tells you what to do. The complaints leaflet is stapled to this information sheet. You can keep both of these leaflets in case you need to use them.

Karen hopes that you will help her with her research.

Appendix 13
Complaints Procedure

IMPORTANT INFORMATION FOR PEOPLE TAKING PART IN RESEARCH

Thank you for agreeing to talk to Karen Ahmed to help with her research. Karen is a researcher from the Tizard Centre, at the University of Kent. We hope that everything was alright when you talked to Karen.

☺

It is Karen's job to treat people properly. This means she should not make you upset or angry or confused.

☹ 😐 ?

If this did happen, you have a right to complain.

- The first thing you could do is tell Karen herself about it, if you can.

- If you would prefer to talk to someone else straightaway, then you can phone Karen's boss. Her name is Glynis Murphy and her phone number is 01277 764000 extension 7989. ☎

- Or you can write to her at the following address:

✉

Tizard Centre
Beverley Farm
University of Kent
Canterbury
CT2 7LZ

- **If you find it difficult to make a complaint yourself, you can ask someone else to do it for you. Ask someone you trust to help you.**

Glynis will listen to you properly and take you seriously.
She will need to talk to other people. After a short while, she will get in touch with you to let you know what has happened.

☎

If something bad happened when Karen was talking to you, it will help us to know this. We want to learn how to stop this happening again. You will not get into trouble if you report this to us.

✓

If you are not sure whether you have the right to complain, you can contact Glynis anyway just to tell her how you feel.

Thank you.

Tizard Centre Research Ethics Committee

Appendix 14
Service users' interview schedule

Introduction:
It would really help me if you could tell me a little bit about yourself because I don't know you very well.

- Can you tell me what you have been doing over the last few years; what kind of things have been happening to you ?
- Can you tell me about some good things that have happened to you (getting a job, making friends, cooking a meal) and some bad things (e.g. getting into trouble/questioning by the police /being arrested).

1. Who do you see from "the pilot team"?

2. How do you get on with the people that come from "the pilot team"?

3. How often do you see them?
   How often would you like to see them?

4. What do they do with you?
   Do you think that this helps you? If so, how? If not, why not?

5. Would you like them to do anything else with you?
Is there anything in particular you want help with?

6. Does anyone else help you at the moment?
   If yes, what do they do?
   Is there something else that you would like them to help you with?

7. Would you like someone else to help you ?
   What would you like them to help you with?

8. Who helped you before someone came from "the pilot team"?
   What did they do?

9. How would you manage if "the pilot team" closed down?

10. Is there anything else you would like to tell me about "the pilot team"?

Appendix 15
Carers' Interview Schedule

1. How did you find out about the team?
- Who made the referral?

2. When did your son/daughter begin to receive a service from the team?
- Assessment process

3. Please could you describe what they do
a) with your son/daughter
b) with you

- which workers
- frequency of visits

4. Do you think that the team helps your son/daughter?
a) your son/daughter
b) you
If yes, in what way?
If no, why not?

5. What kind of help or service, if any, did your son or daughter receive before the team?

   How did this help differ from that provided by the team?

6. What are your hopes and fears for the future?

   What would happen if the team were not funded?

7. Is there any other help that you or your son/daughter would like that you do not receive at the moment?

8. Is there anything else that you would like help with?

Appendix 16
External Professionals Interview Schedule

1. Have you heard of "the team"? What do you think that it does?

2. Do you know what the eligibility criteria are for "the team"?

3. **For Team Leaders**
   Have you or any of your team members referred anyone to "the team"? If no, why not?
   If yes, why? How easy/difficult was that process?
   What was the outcome of the referral, and were you happy with it?

For Other Professionals

Have you referred anyone to "the team"?
If no, why not?
If yes, why?
Did you consult with colleagues before making the referral? How easy/difficult was that process?
What was the outcome of the referral, and were you happy with it?

4. Do you think that service from "the team" is the best way of meeting its service users' needs? How else could they be met?

5. Do you think that "the team" targets a group of people who do not receive a service elsewhere?

6. Does "the team" target the people who are most in need of a service?

7. What would happen if "the team" did not exist? Where did you refer to before "the team" was set up?

8. What do you think should happen to "the team" at the end of the financial year when the money runs out?

9. Is there anything else that you would like to say about "the team"?

Appendix 17
Interview schedule for team members

1. Can you describe your role within the team?

2. What do you see as being the main aims and objectives of the team and how does your post contribute to those?

3. What do you find most useful about team meetings and what do you find least useful?

4. Who are you accountable to, and for what?

5. Who supervises you?
- What do you find most useful about supervision and what do you find least useful?

6. Can you tell me who carries out the following tasks ?
- Assessment of the referral
- Assessment of the person's needs / functional assessments

How is the assessment carried out ? What tools are used for this process?

7. Who identifies the key areas of work/negotiation with the service user? How is this process carried out?

8. Who provides the agreed areas of treatment/therapy ? How is this done?

9. What do you see as being the role of the case-coordinator?
- How are service users allocated to team members?
- Who would refer on or close the case?

10. Where would you find information on local services and community facilities across both boroughs?

11. How are risks managed in your day to day work?

12. Any there any other tasks which are carried out by the team which you feel are important that I have missed out? What are they, who does them and how?

13. Which team members do you work most closely with? Please give examples of the areas of work that you frequently co-work on.
- Which pieces of work do you have specific responsibility for?

14. What links, if any, do you have with professionals from the same professional group.
- Are these adequate?

15. Which outside agencies do you work most closely with and on what issues?
- Are there any opportunities for co-working?

16. How do you think the team will function in a years' time?
- What do you think the future holds for the team?

17. What theoretical approach underpins your practice and that of the team?

18. Is there any other information which you would like to give me?

Appendix 18
File analysis checklist

Team File Analysis : After team began
First/last 6 months

Name : ....

Issue	Comments	Date	Source
Client reviews: Frequency/actions			
Therapeutic input e.g. groups/anger management			

Locating services: employment/day services/leisure/accommodation			
Support in daily life			
Help with finances			
Other support from team			

Frequency of contact with team			

Other services: Psychiatrist Psychologist Social Worker Support worker Day services Probation officer			
Frequency of contact of service user with other services			
Contact with other services – referrals/ inputs			

Exclusions from other services			
Refusals from other services			
Incidents of challenging behaviour			
Police involvement			

Court appearances and cautions			
Housing			
Risk assessment yes/no Contents of risk assessment			
DISCO assessment results			
Vineland assessment results			
IQ			
Any other assessment results			

Medical investigations – EEG, hormone levels, blood analysis			
Medication			
Social work assessments			
Other assessments			
Follow up needs assessments			
Tertiary panel			

Appendix 19
Number of reviews and case co-ordination meetings

Service user		No. of reviews and case-coordination meetings held in the first 6 months of service	No. of reviews and case-coordination meetings held in the last 6 months of service
1		2.00	2.00
2		1.00	2.00
3		1.00	1.00
4		.00	1.00
5		.00	.00
6		.00	.00
7		4.00	5.00
8		3.00	3.00
9		1.00	1.00
10		1.00	3.00
11		1.00	1.00
12		1.00	1.00
13		2.00	4.00
14		.00	2.00
15		.00	.00
16		2.00	3.00
Total	**N**	**16**	**16**
	Mean	**1.18**	**1.81**
	Median	**1.00**	**1.50**

Appendix 20
Eligibility Criteria for Access to Tulip Assertive Outreach Service

"Criteria for access to Tulip are:

a) **The person lives within the borough of Haringey (East or West), or Enfield (Edmonton or East Enfield)**

b) **The person is between 18 – 65**

c) **The person is experiencing long-term, profound and enduring mental health problems** e.g. do they have a diagnosis, previous hospital appointments or are unknown to the services but in need of help?

d) **The person is hard to reach and engage** e.g. are they from an under-served group such as women who have children and fear their removal or from an ethnic background where admission of mental illness could lead to social exclusion? Are they suspicious of traditional mental health services?

e) **The person requires regular and long-term support related to their mental health**

f) **The person is homeless or living in an unstable housing situation** e.g. they have arrears/debts which jeopardise their housing situation, there are health and safety issues (e.g. domestic violence), they are threatened with eviction, in hospital and homeless, neglect of accommodation or have a history of breakdown in accommodation."

Mental Health Support Services in Haringey : criteria, referral and information on two teams.

Appendix 21
Eligibility Criteria for Access to the Support and Management Team

"At the point of referrals being accepted by the SAM team, cases will be adequately described by the Emerson definition (1987), i.e. "behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary facilities."

Accepted referrals must meet one or more of the following criteria.

1) Crisis
2) Risk of harming self or others, including members of the public
3) Placement breakdown actual or imminent
4) Aversive treatment or management techniques under consideration
5) New perspective needed – old approach reviewed.

Referrals will be considered for dual disability clients where a diverse range of issues apply, e.g. forensic, alcohol/substance misuse, HIV/physical health, provided they display challenging behaviour which meets one or more of the above criteria."

SAM Team Operational Policy (April 2001)

Appendix 22
Satisfaction with Employment

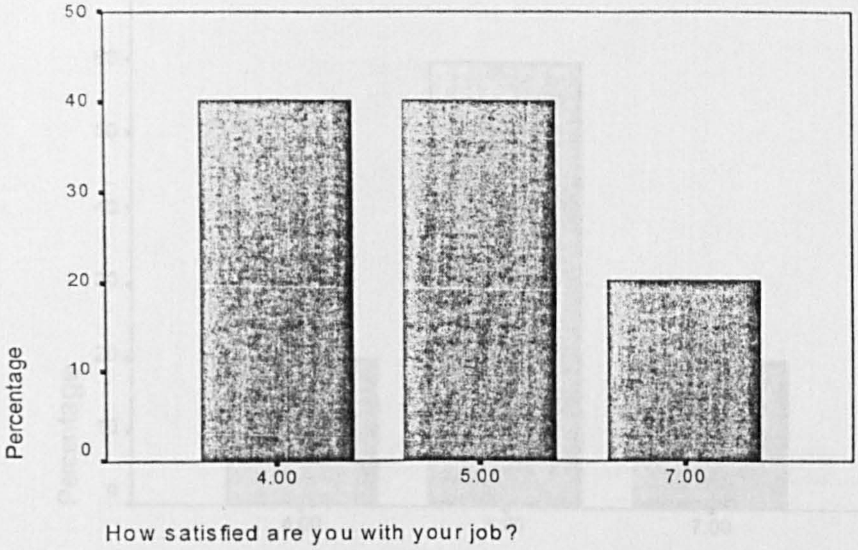


Figure 1: Satisfaction with employment at time 1 (N.B. People in voluntary work and those who went to day centre/college sometimes saw this a being a job). Scores range from 4 (okay) to 7 (couldn't be better).

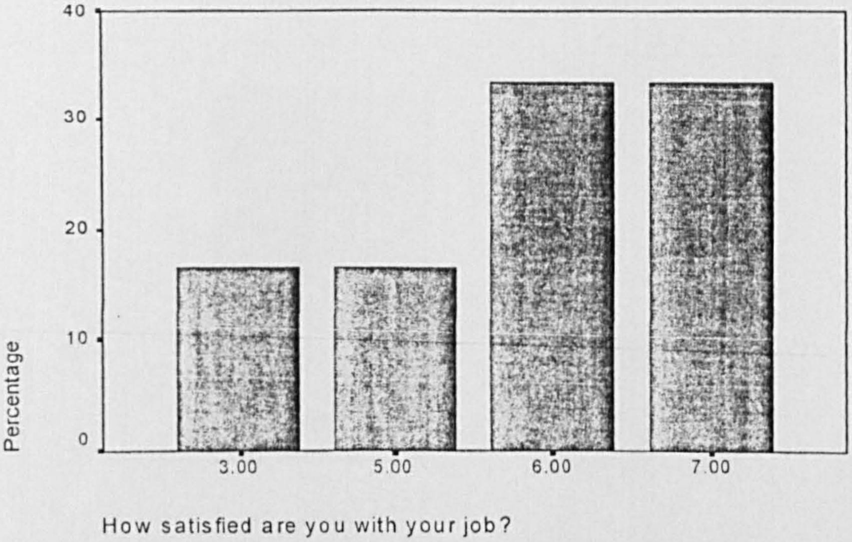


Figure 2 : Satisfaction with employment at time 2. Scores range from 3 (not very good) to 7 (couldn't be better).

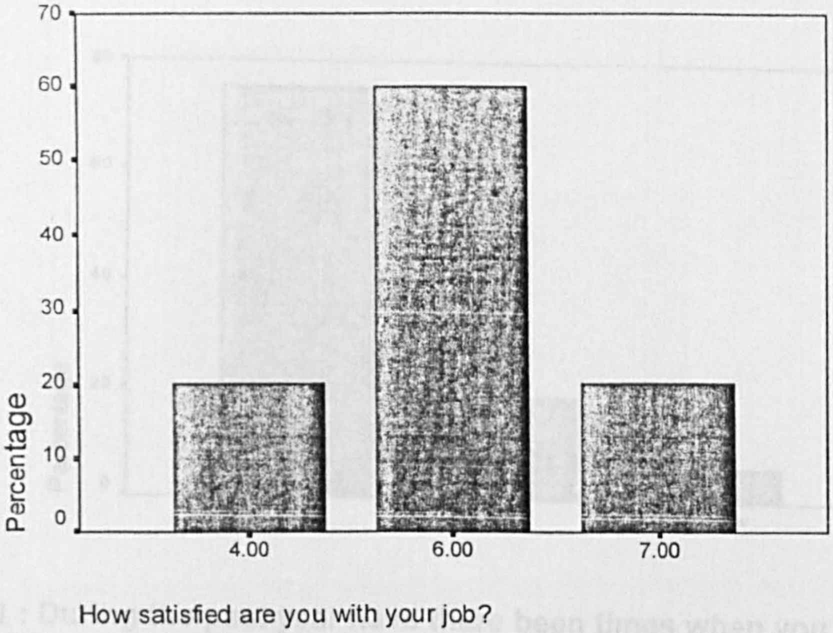


Figure 3: Satisfaction with employment at time 3 (after the service had ended). Scores range from 4 (okay) to 7 (couldn't be worse)

Appendix 23
Satisfaction with Accommodation

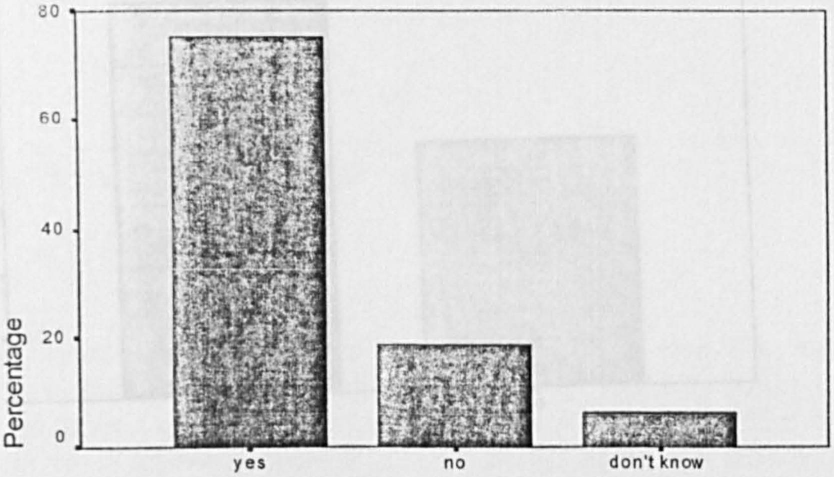


Figure 1 : During the past year have there been times when you wanted to move? (Time 1)

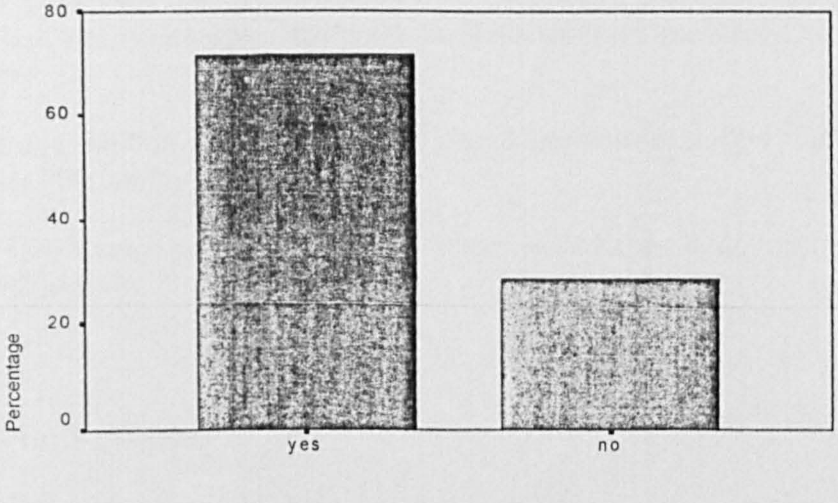


Figure 2: During the past year have there been times when you wanted to move? (Time2)

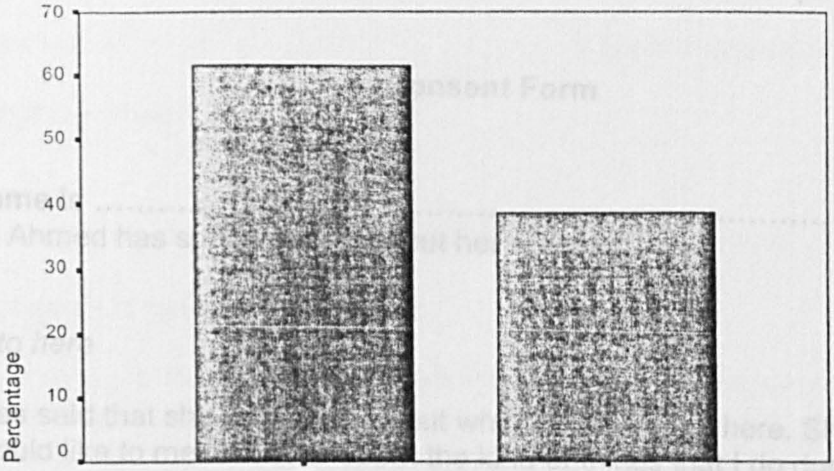


Figure 3: During the past year have there been times when you wanted to move? (Time3 : 6 months after the service had ended)

Appendix 24
Consent Form for Residents

"Where I Live" study **Karen Ahmed (investigator)**

Consent Form

My name is ....
Karen Ahmed has spoken to me about her research.

Photo here

She has said that she wants to find out what it is like living here. She has said that she would like to me to tell her about the kind of things that I do during the day and where I can go to for help. She would also like to look at my files. She has explained that this is where people write down things about me. She would also like to talk to my family.

I have said that I am happy to talk to Karen about these things and that she can look at my files and talk to my family.

Karen has explained that it is okay if I change my mind or I get upset and I want to stop when we are talking.

If I want to, Karen will tell ....that I am upset and would like some support. I will not get into trouble if I do not want to talk to Karen.

Karen has told me that she will be writing about her research. She has promised that she will not use my name.

If there is something I do not understand about what Karen is doing, I can ask her and she will explain.

Signed..Date....................

Appendix 25
Information Sheet for Service Users

"Where I Live" **Karen Ahmed (investigator)**

Information Sheet

This tells you all about the research that Karen Ahmed is doing.

The research is called "Where I Live. "

Karen is trying to find out what it is like living in a home. She wants to know if you:
- Have things to do during the day
- Can choose what you do
- Feel safe

She would like to know if you like living in your home.

She would like to ask you questions about what kind of things you do during the day and who helps you with problems. If you agree to talk to Karen, she will ask you to sign a Consent Form. You can keep a copy of this form.

Karen will be writing about her research. She has promised that she will not use your name. Anything that Karen finds out will be stored in a locked cupboard. She will be the only person that has a key for the cupboard. Any forms that you fill in will have a number on instead of your name. Karen will be the only person that knows what your number is.

You can choose if you want to help Karen with her research. If you change your mind, that is okay. You will not get into trouble if you do not want to talk to Karen.

You can tell Karen who to contact if you get upset and want to talk to someone.

If you do not understand something, you can ask Karen. She will explain it to you. You can ring her on 01227 764000 extension 7269. If she is not there, then you can leave a message and she will ring you back.

If you don't like what Karen said or did then you can make a complaint. There is a leaflet which tells you what to do. The complaints leaflet is stapled to this Information Sheet.

Karen hopes that you will help her with her research.

Appendix 26
Consent Form for Managers

Consent Form

Title of Project : "Where I Live" : the quality of care for people with learning disabilities, mental health needs and challenging behaviour in residential settings.

Name of Researcher: Karen Ahmed

I confirm that I have read the information sheet (copy attached) about the above study and that I have had the opportunity to ask questions in order to obtain clarification about the study.

Karen Ahmed has shown me all the schedules she will be using and explained the purpose of each one. I understand that some schedules will be completed by myself and my staff team and that the majority of schedules will be completed by the researcher. I am aware she will be contacting family members and that, where residents consent, she may require access to residents' files.

I have also been informed about the Complaints Procedure and have been given a copy of this procedure.

I am aware that all information will be kept confidential and anonymised in the final report.

I hereby give my agreement for myself and members of my staff to take part in the research.

Name of Person ....

Job Title ....

Signature...

Date ....

Appendix 27
Staff Consent Form

Title of Project : "Where I Live"
Name of researcher: **Karen Ahmed**

Please initial the box below each statement:

1. I confirm that I have read and understood the information sheet dated January 2002 Version 1 for the above study and had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.

☐

3. I understand that any information I give will be kept completely confidential, unless I disclose any instances of abuse, and will not be reported back to my line manager. I know that any information I give will be recorded anonymously and only the researcher will have access to that data.

☐

4. I agree to take part in the above study

☐

--	--------------	--------------------------
Name of staff member	Date	Signature
--	----------------	--------------------------
Researcher		

Appendix 28
Information Sheet for Professionals

"Where I Live"study **Karen Ahmed (Investigator)**

Information Sheet (Professionals)

The Quality of Care for People with Learning Disabilities, Mental Health Needs and Challenging Behaviour in Residential Settings.

Background

Previous research has established that people with mild/borderline learning disabilities, mental health needs and severe challenging behaviour are often poorly served by community based services. These people, who have very complex needs, often only receive a service when there is a crisis which brings them to the attention of services, and the response is all too frequently to send the person to an out-of-borough specialist residential placement. (e.g. Vaughan, P. (2000) ; Murphy, G. & Fernando, S.(1998)).

Aims

This study is a small scale project which aims to examine the quality of the care and treatment provided in a range of residential out-of-borough settings for people with challenging behaviour, learning disabilities and mental health needs who may be at risk of offending or reoffending.

The Study

It is proposed to look at the quality and outcomes of care provided in various settings using well established and tested measures which have been used in previous studies (e.g. Emerson et al (2001), Cambridge et al (due to be published), Oliver et al (1996)). In essence these explore the way in which the homes are managed, the philosophies on which practice is based, the policies and procedures, training of staff, levels of community integration, service receipt and the response to risks and choices. Settings which are seen to be good quality providers will be focused upon.It is also proposed to measure such outcomes which could affect the capacity of any individual to cope in both community and residential settings such as the incidences of challenging behaviour, the quality of life and the daily living skills of the residents. In selected cases retrospective analyses of files will also be undertaken in order to both validate data and to provide additional longitudinal information.

Settings will be asked to provide basic information about themselves and some background information on the residents. Keyworkers will be asked to complete short schedules about residents. Residents will also be interviewed by the researcher. All residents will be invited to take part in the study. Where there are issues of competence, the researcher will be guided by the setting in determining who should be included in the study.

Consent will be sought from managers and participants with learning disabilities. It is recognised that for people with learning difficulties, consent will need to be discussed and checked before each piece of research takes place. Participants may withdraw from the study at any time.

Outcomes

All settings will be given a summary of findings related to their own settings in June 2003. Any other information produced will be anonymised and will be available to the participating settings from that date.

More Information? Please contact Karen Ahmed on 01227 764000 extension 7269.

Appendix 29
Letter to Relatives

Dear

Re : Where I Live

I am a researcher from the Tizard Centre and I am carrying out some research into the kind of support that people with complex needs receive when they are in a residential home. There have been very few studies in this area and I would like to find out more about this. I will be writing a report for the Oxleas NHS trust on the kind of support that people receive. I will also be producing a report for everyone who has participated in the research and I will send you a copy of this.

.... has agreed that I can contact you to ask you to complete the enclosed questionnaire. I will be writing about the views of resident's relatives, but any information that you give me will be reported anonymously. All information will be stored in an anonymised format and kept in a secure location. If you complete and return the questionnaire then that will be understood as you giving your consent to participate in the study.

I do hope that you will complete the questionnaire as relatives' views form a very important source of information about the experiences of people who are in residential care. Sometimes people worry that if they do or do not participate then their relative's care may be affected. I would like to assure you that because of the independent nature of the research, your relative's care will not be affected by any decision you make about completing the questionnaire.

If you would like to find out more about the research or the questionnaire, you can phone me on 0771 425 9788.

Yours sincerely,

Karen Ahmed

Appendix 30
Provider Organisation Questionnaire (adapted)

Provider Organisation Questionnaire (adapted)

Hester Adrian Research Centre

University of Manchester

1 Organisational Aims and Philosophy

1. Does the organisation have a written statement of philosophy and/or aims?

Yes ☐ No ☐

If YES, please attach written statement

2. Please describe the three most important aims of the organisation

1. ....

....

....

2. ....

....

....

3. ....

....

....

3 (a) Below is a list of 25 statements concerning indicators of the quality of life of people with learning disabilities. Please read all the statements in the list. First, please rate how important each indicator is to a good quality of life, using the five-point scale. Second, please rank the indicators in order of importance, rating the five most important indicators as **1**, the next five most important indicators as **2**, and so on.

Indicator	**Importance of indicator to quality of life**					**Rank Order**
	1 Very Important	**2**	**3**	**4**	**5 Not At All Important**	**Top Five=1 Next Five=2 etc**
Choice over day-to-day matters						
Emotional support from others						
A range of regular scheduled activities						
Good relationships with family						
Respect from others						
Being happy and contented						
Having a job						
Being part of the local community						
Practical support						
Protection from exploitation and abuse						
Good long-term friendships						
Healthy and active lifestyle						
Using local community facilities						
Friendships with people without learning disabilities						
Privacy						
A clean and safe home environment						
Choice over where to live and who to live with						
Involvement in decisions about house standards and rules						
Pursuing interests and hobbies						
Learning new skills						
Having an intimate relationship						
Having responsibility						
Having religious needs met						
Good standard of material possessions						

Good income						

3 (b) If there are any important indicators of quality of life not included in the above table, please provide a brief description of them here.

Indicator 1 ....

Indicator 2 ....

Indicator 3 ....

4 How far do you think the schedules to be used in this project reflect important aspects of quality of life? (please describe, including opinions on omissions from the schedules or alternative ways of finding out about quality of life)

5 Are there any additional comments about organisational aims and philosophy you would like to make?

2 Organisational Developments

RECENT CHANGES

1. Has the residential service changed over the past five years? Yes ☐ No ☐

IF NO, please go to question 6

2. Have new residential services been added in the past five years? Yes ☐ No ☐

IF YES, please describe the number of new places, and the type and location of the new residential services

....

....

....

....

3. Have existing residential services been closed in the past five years? Yes ☐ No ☐

IF YES, please describe the number of places closed, and the type and location of the residential services closed

....

....

....

....

4. Have existing residential services been modified in the past five years? Yes ☐ No ☐

IF YES, please describe the number of places modified, and the type of modifications made

....

....

....

....

5. Please describe any further important changes to the organisation's services in the past five years.

FUTURE PLANS

6. Are there plans for changes in the residential service over the next five years? Yes ☐ No ☐

IF NO, please go to next section

7. Are new residential services planned in the next five years? Yes ☐ No ☐

IF YES, please describe the number of new places to be added, and the type and location of the new residential services

....

....

....

....

8. Are existing residential services planned for closure in the next five years? Yes ☐ No ☐

IF YES, please describe the number of places to be closed, and the type and location of the residential services to be closed

....

....

....

....

9. Are existing residential services to be modified in the next five years? Yes ☐ No ☐

IF YES, please describe the number of places to be modified, and the type of modifications to be made

....

....

....

....

10. Please describe any further important changes to the organisation's services planned for the next five years.

THE ORGANISATION

11. If your organisation was starting from scratch, what would your ideal service be (please describe)?

....

....

....

....

....

....

....

....

....

....

....

....

12. Has your organisation encountered hostility from others (eg. relatives, care managers)? Yes ☐ No ☐.

IF YES, please describe the main sources of hostility and the nature of the hostility experienced

....

....

....

....

13. Has your organisation received support from others (eg. relatives, care managers)? Yes ☐ No ☐

IF YES, please describe the main sources of support and the nature of the support provided

....

....

....

....

3 People Supported by the Organisation

1. How many people with learning disabilities *in total* are supported by this organisation? ....

2. How many people with learning disabilities are long-term residents? ....

3. How many people with learning disabilities attend day services only? ....

4. How many people with learning disabilities are short-term residents? ....

5. Age range of residents ....years to ....years

6. Gender of residents: ....men ....women

7. Ethnic origin of residents ....White ....Black ....Asian ....Other

8. Marital status of residents ....married ....single ....divorced/separated/widowed

9. How many sites are long-term residents living in? ....

10. How many houses/living units are long-term residents living in? ....

11. Please provide a list of houses/living units, and the number of long-term residents living in each house, or please provide a list of current residential provision, giving a breakdown of numbers per house and scheme. Please indicate if any of these houses serve particular groups of people (eg. older people, people with challenging behaviour etc.)

Site	**House name / address**	**Number of residents with learning disabilities**	**Number of staff/co-workers (whole-time equivalent)**	**Number of other residents**	**Particular group served?**

12. Are there any formal policies or criteria defining who *cannot* be supported by the organisation? (eg. children, people with multiple disabilities, people with challenging behaviour etc.)

Criterion 1 ....

Criterion 2 ....

Criterion 3 ....

13. Are there any informal criteria defining who *cannot* be supported by the organisation? (ie who would you find it very difficult to serve at present)

Criterion 1 ....

Criterion 2 ....

Criterion 3 ....

13a. In what circumstances would you request that a resident was no longer supported by the organisation? (e.g. because of violent behaviour, skill levels etc.)

....

....

....

14. Are there any criteria defining particular groups of people who are a specific focus of the organisation? (eg. older people, people with multiple disabilities, people with challenging behaviour etc.)

Criterion 1 ....

Criterion 2 ....

Criterion 3 ....

Criterion 4 ....

15. Is there any information available to describe the skills and abilities of long-term residents, and also aspects of their behaviour (eg. number of people with mild/moderate/severe learning disabilities; number of people with epilepsy/loss of vision and/or hearing; number of people with serious challenging behaviours etc.). If so, please describe this information in the space provided, or attach the information to the questionnaire.

4 Financial and Managing Arrangements

1 Who owns and manages the residential facility?
(please give details)

....

....

....

....

....

2 Have these arrangements changed during the past five years?
(please give details)

....

....

....

....

....

3 How much do residents contribute to the costs of their care per year? Please specify the range of contributions (from the smallest to the largest) and the factors which account for the variations.

Smallest contribution £.................... per year

Largest contribution £.................... per year

Factors which account for variation:

....

....

....

....

....

4 How many residents are principally funded...

by a Local Authority ....

by a Health Authority ....

by the Department of Social Security (DSS) ....

from private sources ....

5 How much is the annual charge per place for residents? £.................... per year

Please describe if there are different annual charges for particular groups of residents

....

....

....

....

....

5 Staff and Volunteers

PAID STAFF

1. *In total,* how many paid staff work in the organisation? ....

2. How many paid staff work full-time (35+ hours per week)? ....

3. How many paid staff work part-time (<35 hours per week)? ....

4. Gender of paid staff: ....Men ....Women

5. Ethnic origin of paid staff ....White ....Black ....Asian ....Other

6. What is the *whole time equivalent* of paid staff in the organisation? ....

7. What is the whole time equivalent of:

Residential care staff	....	Residential domestic staff	....
Day service care staff	....	Day service domestic staff	....
Administrative staff	....	Managerial staff	....
Medical professionals	....	Educational professionals	....

Other (please specify) ....

8. Below is a list of qualifications. Please indicate how many paid staff in your organisation have these qualifications.

Nursing	....	Social work	....
Teaching	....	Doctor	....
Other medical	....	Other professional	....

9. How many days sick leave in total have been taken by paid staff in the last six months? ....

10. How many paid staff have voluntarily left the organisation in the past year? ....

11. How many paid staff have involuntarily left the organisation in the past year? ....
(eg. been sacked, retired, stopped work due to sickness)

12. How are paid staff recruited to the organisation? ....
(please describe) ....
....

13. Are there written equal opportunities policies for recruiting paid staff? Yes ☐ No ☐

14. What recruitment procedures are used to select staff? ....
(please describe) ....
....
....
....

15. Are residents and/or family members involved in recruiting staff? Yes ☐ No ☐

Please describe the nature of this involvement ....
....
....
....
....

16. Are qualifications required for care staff in the organisation? Yes ☐ No ☐

Please describe ....
....
....

17. Is there a written code of conduct for paid staff? Yes ☐ No ☐

18. What procedures are in place for sacking unsuitable staff? ....
(please describe) ....
....

19. Is a period of induction training provided for paid staff? Yes ☐ No ☐

Please describe the duration and content of this training ....
....
....

20. Is on-going training provided for paid staff? Yes ☐ No ☐

Please describe the extent and content of this training ....
....
....

21. Is support provided for paid staff to experience external training? Yes ☐ No ☐

Please describe the extent and nature of this support ....
....
....

22. How would you describe the role or roles of paid staff (for example friends, guardians, teachers, carers etc)?
....

....

....

VOLUNTEERS

23. *In total,* how many volunteers work in the organisation? ....

24. How many volunteers work full-time (35+ hours per week)? ....

25. How many volunteers work part-time (<35 hours per week)? ....

26. Gender of volunteers: ....Men ....Women

27. Ethnic origin of volunteers ....White ....Black ....Asian ....Other

28. What is the *whole time equivalent* of volunteers in the organisation? ....

29. What is the whole time equivalent of:

Residential care volunteers	....	Residential domestic volunteers	....
Day service care volunteers	....	Day service domestic volunteers	....
Administrative volunteers	....	Managerial volunteers	....
Medical professional volunteers	....	Educational professional volunteers	....

Other volunteers (please specify) ....

30. Below is a list of qualifications. Please indicate how many volunteers in your organisation have these qualifications.

Nursing	....	Social work	....
Teaching	....	Doctor	....
Other medical	....	Other professional	....

31. How many days sick leave in total have been taken by volunteers in the last six months? ....

32. How many volunteers have voluntarily left the organisation in the past year? ....

33. How many volunteers have involuntarily left the organisation in the past year? ....
(eg. been sacked, retired, stopped work due to sickness)

34. How are volunteers recruited to the organisation? ....
(please describe) ....
....

35. Are there written equal opportunities policies for recruiting volunteers? Yes ☐ No ☐

36. What recruitment procedures are used to select volunteers? ....
(please describe) ....
....

37. Are residents and/or family members involved in recruiting volunteers? Yes ☐ No ☐

Please describe the nature of this involvement ....
....
....

38. Are qualifications required for volunteers at any level in the organisation? Yes ☐ No ☐

Please describe ....
....
....

39. Is there a written code of conduct for volunteers? Yes ☐ No ☐

40. What procedures are in place for sacking unsuitable volunteers? ....
(please describe) ....
....

41. Is a period of induction training provided for volunteers? Yes ☐ No ☐

Please describe the duration and content of this training ....
....
....

42. Is on-going training provided for volunteers? Yes ☐ No ☐

Please describe the extent and content of this training ....
....
....

43. Is support provided for volunteers to experience external training? Yes ☐ No ☐

Please describe the extent and nature of this support ....
....
....

44. How would you describe the role or roles of volunteers (for example friends, teachers, carers etc)?

....

....

....

6 Aspects of Care

1 Please complete the following table to provide us with an indication of the services or activities provided by the organisation or available to residents.

Service & Activities	**Is this service provided by the organisation?**		**Is this service available to residents although not provided by the organisation?**	
	Yes	**No**	**Yes**	**No**
Sports centre				
Hydrotherapy pool				
Swimming pool				
Social club				
Day centre				
Place of worship				
Education centre/classes				
Special education classes				
Adult education classes				
Visiting teachers				
Classes attached to hospital				
Occupational therapy				
Physiotherapy				
Speech therapy				
Art/drama/music therapy				
Alternative therapist (eg. reflexologist, chiropractor)				
Psychologist				
Psychiatrist				
Community learning disability team				
Social worker				
Support worker				
Doctor/consultant				

Service & Activities	Is this service provided by the organisation?		Is this service available to residents although not provided by the organisation?	
	Yes	No	Yes	No
General practitioner				
Hearing specialist				
Optician				
Chiropodist				
Dentist				
Learning disability nurse				
Community mental health team				
Specialist challenging behaviour support				
Community nurse (eg. district nurse, health visitor)				
Advocate				
Volunteer/befriender				
Shop				
Hairdresser				
Car/minivan				
Other (specify)				
Other (specify)				
Other (specify)				
Other (specify)				
Other (specify)				
Holidays off-campus				
Day trips/outings				
Workshop/workscheme/industry Please list				

7 Making Decisions

1. Please describe how major policy decisions are made within the organisation (eg. priorities for new developments, capital spending)? Please include in your description lines of responsibility and communication between different policy-making groups, and the membership of any policy-making groups.

....

....

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2. Are relatives of residents involved in making major policy decisions?

Yes ☐ No ☐

IF YES, please describe how they are involved

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....

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3. Are residents involved in making major policy decisions?

Yes ☐ No ☐

IF YES, please describe how they are involved

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4. Please describe how organisational decisions are made within the organisation (eg. maintaining safety standards, implementing quality monitoring)? Please include in your description lines of responsibility and communication between different policy-making groups, and the membership of any policy-making groups.

....

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5. Are relatives of residents involved in organisational decisions?

Yes ☐ No ☐

IF YES, please describe how they are involved

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6. Are residents involved in making organisational decisions?

Yes ☐ No ☐

IF YES, please describe how they are involved

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8 Quality Monitoring

1. Within the organisation, are there systems in place to monitor service quality? Yes ☐ No ☐

2. How often does quality monitoring occur? ....

3. Please describe the quality monitoring system used (if written, please also attach to the questionnaire)

....

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4. Is all the organisation covered by the same quality monitoring system? Yes ☐ No ☐

5. Are relatives of residents involved in quality monitoring? Yes ☐ No ☐

IF YES, please describe how they are involved

....

....

....

6. Are residents involved in quality monitoring? Yes ☐ No ☐

IF YES, please describe how they are involved

....

....

....

7. Are the results of quality monitoring available within the organisation? Yes ☐ No ☐

IF YES, please describe who has access to these results

....

....

8. Are relatives of residents informed of the results of quality monitoring? Yes ☐ No ☐

IF YES, please describe how they are informed

....

....

9. Are residents informed of the results of quality monitoring? Yes ☐ No ☐

IF YES, please describe how they are informed

....

....

10. Are the results of quality monitoring fed into decision-making in the organisation? Yes ☐ No ☐

IF YES, please describe how results are fed into decision-making

....

....

....

....

....

....

10. Are quality standards set into contracts with purchasers? Yes ☐ No ☐

11. Are there any other comments concerning quality monitoring within the organisation?

9 Safeguards

1. Is there a written policy concerning basic safety standards in the organisation? Yes ☐ No ☐

IF YES, please describe which aspects of safety are covered by the policy (please also attach)

....

....

....

2. Are there written procedures for implementing policies concerning safety? Yes ☐ No ☐

IF YES, please describe which aspects of safety are covered by the policy (please also attach)

....

....

....

3. Are regular safety checks carried out on:

Electrical appliances	Yes ☐	No ☐	Frequency of checks...............
Fire exits and fire extinguishers	Yes ☐	No ☐	Frequency of checks...............
Structural safety of buildings	Yes ☐	No ☐	Frequency of checks...............
Furniture and furniture layout	Yes ☐	No ☐	Frequency of checks...............
Food preparation and hygiene	Yes ☐	No ☐	Frequency of checks...............

4. Are paid staff trained in safety procedures? Yes ☐ No ☐

5. Are volunteers trained in safety procedures? Yes ☐ No ☐

6. Are residents trained in safety procedures? Yes ☐ No ☐

7. Are there written policies concerned with preventing abuse of residents? Yes ☐ No ☐

IF YES, please describe these policies (please also attach)

....

....

....

8. Are there written policies concerned with preventing exploitation of residents? Yes ☐ No ☐

IF YES, please describe these policies (please also attach)

....

....

....

9. Are there monitoring systems to detect abuse of residents? Yes ☐ No ☐

IF YES, please describe these systems

....

....

....

9. Has any abuse of residents been detected in the organisation in the past five years? Yes ☐ No ☐

IF YES, please describe:
1) the number of residents affected by the instance(s) of abuse/exploitation,
2) the type(s) of abuse/exploitation involved (eg. physical, sexual, financial etc),
3) the perpetrator(s) of the abuse/exploitation (eg. stranger, staff, co-resident etc).

....

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10. Are there systems for paid staff or volunteers to voice concerns over abuse? Yes ☐ No ☐

IF YES, please describe these systems

....

....

....

11. Are there systems for relatives of residents to voice concerns over abuse? Yes ☐ No ☐

IF YES, please describe these systems

....

....

....

12. Are there systems for residents to voice concerns over abuse? Yes ☐ No ☐

IF YES, please describe these systems

....

....

....

13. How many times have these systems been used in the past five years? ....times

14. What has been the result of these systems for residents?

....

....

....

15. Are police checks conducted for newly recruited paid staff? Yes ☐ No ☐

16. Are police checks conducted for newly recruited volunteers? Yes ☐ No ☐

17. Have any accidents involving residents requiring out-patient or in-patient hospitalisation occurred in the organisation in the past five years? Yes ☐ No ☐

IF YES, please describe:
1) the number of accidents,
2) the type(s) of accident (eg. road traffic accident, kitchen burn etc.),
3) whether the resident required out-patient or in-patient hospital treatment

....

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....

18. Have there been any resident deaths in your organisation in the past five years? Yes ☐ No ☐

IF YES, please describe the number of people who have died and the causes of death

....

....

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....

17. Have any accidents involving residents requiring out-patient or in-patient hospitalisation occurred in the organisation in the past five years? Yes ☐ No ☐

IF YES, please describe:
1) the number of accidents,
2) the type(s) of accident (eg. road traffic accident, kitchen burn etc.),
3) whether the resident required out-patient or in-patient hospital treatment

....

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18. Have there been any resident deaths in your organisation in the past five years? Yes ☐ No ☐

IF YES, please describe the number of people who have died and the causes of death

....

....

....

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....

....

....

....

10 Other Policies and Procedures

1. Are there written policies and procedures on the following areas:

	Policy	Procedure		
Equal Opportunitics	☐	☐		
Complaints	☐	☐		
Sexuality	☐	☐		
Residents' Rights	☐	☐		
Intimate/personal care	☐	☐		
Risk assessment	☐	☐		
Behaviour management	☐	☐		
Other areas (please state): **1.**	☐	☐		
2.	☐	☐		
3.	☐	☐		
4.	☐	☐		
5.	☐	☐		

Please attach copies of the policies and procedures.

2. Do you currently have any policies and/or procedures in draft?
If so please list:

....

....

....

3. Please use the space below for any additional information you may wish to add, or any comments you wish to make about the questionnaire. **Thank you for your co-operation.**

Appendix 31
Living Environment Schedule

Living Environment Schedule

Note: the "facility" refers to the whole building or cluster of buildings staffed by the same group, eg in the case of residential communities, the entire community. The "setting" refers to the particular house in which the person concerned lives.

Name of facility ....

Address ....
....
....
....

Name of informant ....

Status of informant ....

Date of questionnaire completed ....

Section One: Setting Information

			Harc Use Only LINE ONE
1a.	Nature of setting		
	Village or residential community	1	☐☐☐ (1-3)
	Supported living	2	
	Staffed House, 24 hour (Specialist)	3	
	Staffed House, 24 hour (Ordinary)	4	(4)
1b.	If *Staffed House*, is this:		
	Linked adjacent housing cluster	1	
	Linked dispersed housing cluster	2	
	Organisationally separate	3	(5)
2.	Size		
	How many long term places are there in this setting?	____	☐☐ (6-7)
	How many of these are currently occupied?	____	☐☐ (8-9)
	How many short term places are there is this setting?	____	☐☐ (10-11)
	How many of these are currently occupied?	____	☐☐ (12-13)
4.	Location		
	Separate road or cul de sac near town	1	
	Separate road or cul de sac rural setting	2	
	Ordinary road - large site	3	(14)
	Ordinary road - ordinary site	4	
5.	Client groups served		
	Learning disability only	1	(15)
	Other (specify)	2	
6.	Groupings - gender		
	How many *males* live in this setting?	____	☐☐ (16-17)
	How many *females* live in this setting?	____	☐☐ (18-19)
7.	Groupings - age range		
	What age is the youngest resident?	____	☐☐ (20-21)
	What age is the oldest resident?	____	☐☐ (22-23)
	What is the majority age band eg 20s, 30s?	____	☐☐ (24-25)
8.	Groupings - how many residents have:		
	Profound or severe learning disability?	____	☐☐ (26-27)
	Moderate/mild learning disability?	____	☐☐ (28-29)
	Borderline or no learning disability	____	☐☐ (30-31)
9a.	Groupings - degree of specialism		
	All have specialist condition	1	
	Mixed specialist conditions	2	
	Mixed	3	(32)

9b If all have specialist condition, is this:
Challenging behaviour 1
Mental health problems 2
Either challenging behaviour or mental health problems 3
Sensory impairment 4 (33)
Physical disabilities 5
Other specialist condition (specify) ....
.... 6

9c. Is the grouping of residents
By policy 1
By default 2 (34)
Don't know 3

10. How many residents go to an external day service?
Average number out Mon-Fri 9.00-16.00 .... ____ (35-36)
Average number in Mon-Fri 9.00-16.00 .... ____ (37-38)

11. How many residents can:
Walk independently .... ____ (39-40)
Use a wheelchair independently .... ____ (41-42)
Speak in sentences .... ____ (43-44)
Sign or speak words or phrases .... ____ (45-46)
Are continent .... ____ (47-48)
Feed independently .... ____ (49-50)
Dress independently .... ____ (51-52)
Wash independently .... ____ (53-54)
Have a severe behaviour disorder .... ____ (55-56)

Building Design

12a. Is the dining room:
Separate 1
Kitchen/dining room combined 2 (57)
Living/dining room combined 3

Is the dining room:

1	*2*	*3*	*4*	*5*	
Very Home Like Small dining area typical of family home, seat 8 or fewer. Family style furnishings and dishes. Good material standard. Residents eat family style				*Non-Home Like* Large area, seats 25+. No subdivision of space. Complete meal brought to residents or cafeteria style serving. Furniture and dishes for large numbers. Barren	(58)

12b. How many living areas are there? ____ Is the main living area: (59)

1	2	3	4	5
Very Home Like				*Non-Home Like*
Typical of family home. Furniture is comfortable and typical of private home. Good material standard and personal touches				Large and poorly furnished. Furniture designed for use by large numbers. No/few personal touches

(60)

12c. How many bathrooms are there? ____ Is a typical bathroom: (61)

1	2	3	4	5
Very Home Like				*Non-Home Like*
Typical of private home - bath, sink, toilet, shower, cabinets, personal towels and toilet requirements. Personal touches, plants etc				Large, to be used by several people at same time. No provision for privacy. No provision for personal storage of toothbrush, shampoo etc.

(62)

12d. How many bedrooms are there? ____ Is a typical bedroom: ☐☐ (63-64)

1	2	3	4	5
Very Home Like				*Non-Home Like*
No more than one adult per room. Private cupboards. Good material standard and personal touches. Carpeted or rugs. Evidence of activity other than sleeping eg books, desk, comfortable chair				4 or more residents per room. Minimal furnishings. Furniture designed for large groups. Crowded. No personal cupboards or just locker. No/few personal possessions. Room just used for sleeping.

(65)

12e. Is the garden (tick here if the home does not have a garden ____): ☐ (66)

1	2	3	4	5
Very Home Like				*Non-Home Like*
Well landscaped with flowers, shrubs, trees. Garden furniture/ equipment appropriate to age of residents available				No landscaping, grass only. No outdoor furniture or equipment or is inappropriate to age of residents. Poorly maintained.

(67)

13a. Are there areas to which residents have no access or access is "out of bounds"? .... Yes 1 No 2 (68)

If *yes*, please specify

....

13b. Is the building fabric (walls, windows, doors) specially strengthened? .... Yes 1 No 2 (69)

If *yes*, please specify ....

13c. Is there special or specially strengthened furniture? ... Yes 1 No 2 (70)

If *yes*, please specify

....

13d. Is the fitting of equipment specially adapted (eg protection of TV)?

.... Yes 1 No 2 (71)

If *yes*, please specify

....

13e. Is there a seclusion or safe room? .... Yes 1 No 2 (72)

If *yes*, please describe ....

....

13f. Are there special arrangements (double handles, deadlocks etc) to lock internal doors or doors to the outside to restrict resident movement (ie to be controlled only by staff)? .... Yes 1 No 2 (73)

If *yes*, please describe ....

....

14a. Do the grounds/garden have a secure perimeter fence and gate?

.... Yes 1 No 2 (74)

14b. How close is the building to the road?

- Remote from the road 1
- Midway 2
- Facing onto road 3

(75)

14c. What size are the grounds?

- Campus 1
- Large domestic 2
- Medium domestic 3
- Small domestic 4

(76)

| 0 | 1 | (93-94)

LINE 2

15. Please list all staff or volunteers working in this setting

Job Title	**WTE** *Whole time equivalent*	**Qualifications**
1. Senior Care Staff		
1		
2		
3		
4		

☐☐☐☐☐☐ (1-6)

☐☐☐☐☐☐ (7-12)

☐☐☐☐☐☐ (13-1

☐☐☐☐☐☐ (19-2

2. Other Care Staff (days)		
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
3. Other Care Staff (nights)		
1.		
2.		
3.		
4.		
5.		
6.		
Other Staff		
1.		
2.		
3.		
4.		
5.		
6.		

☐☐☐☐☐☐ (25-30
☐☐☐☐☐☐ (31-36
☐☐☐☐☐☐ (37-42
☐☐☐☐☐☐ (43-48
☐☐☐☐☐☐ (49-54
☐☐☐☐☐☐ (55-6
☐☐☐☐☐☐ (61-6
☐☐☐☐☐☐ (67-7
☐☐☐☐☐☐ (73-7
0 2 (93-94) LINE
☐☐☐☐☐☐ (1-6)
☐☐☐☐☐☐ (7-1
☐☐☐☐☐☐ (13-

☐☐☐☐☐☐ (19-
☐☐☐☐☐☐ (25-
☐☐☐☐☐☐ (31-
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☐☐☐☐☐☐ (6
☐☐☐☐☐☐ (7
0 3 (93-94) LI
☐☐☐☐☐☐ (1
☐☐☐☐☐☐ (7

16. Please note all Professional Input received at this setting

Discipline/Job title	Hours Per week	
1.		☐☐☐☐ (13-16)
2.		☐☐☐☐ (17-20)
3.		☐☐☐☐ (21-24)
4.		☐☐☐☐ (25-28)
5.		☐☐☐☐ (29-32)
6.		☐☐☐☐ (33-36)
7.		☐☐☐☐ (37-40)
8.		☐☐☐☐ (41-44)
9.		☐☐☐☐ (45-48)
10.		☐☐☐☐ (49-52)

0 4 (93-94)
LINE 5

Working Arrangements: emergency procedures and getting help

21a. Are the residents written up for PRN medication? ..... Yes 1 No 2 (1)

Are staff rotas designed to provide qualified cover for administration? .... Yes 1 No 2 (2)

21b. Do senior care staff have control of a flexible budget to bring in help when necessary? .... Yes 1 No 2 (3)

21c. Is there a staff bank on which senior staff can call to get extra help? .... Yes 1 No 2 (4)

21d. Are there other special arrangements for calling for help? .... Yes 1 No 2 (5)

If *yes* describe ....
....

21e. Is there a written policy for Control and Restraint? .... Yes 1 No 2 (6)

21f. What arrangements are made for training in Control and Restraint?
....
....
What arrangements are made for a refresher course?
....

21g. What % of staff have been trained in Control and Restraint in:
The last 12 months .... ____ ☐☐ (7-8)
The last 1 to 3 years .... ____ ☐☐ (9-10)

21h. Are there arrangements for counselling staff following traumatic incidents? .... Yes 1 No 2 (11)

21i. Are there arrangements for counselling residents following traumatic incidents? .... Yes 1 No 2 (12)

Section Two: Working Methods

1. Person-Centred or Individual Planning

Note: this section refers to formal Individual Planning and *not* to Care Assessment or Care Management arrangements. If Care Assessment or Care Management is the only form of planning around individual clients that occurs, please note this and go on to Part Two.

1a. What arrangements are made to review the needs of each individual, set goals and initiate new service supports?

....

....

....

1b. What percentage of residents have had a meeting in:
The last 6 months .... ____%
The last 12 months .... ____%

1c. Who attended the last meeting?

....

....

1d. Who else was involved?

....

1e. Was this a typical meeting in terms of attendance? Yes/No
If *No* describe ....

....

1f. Are decisions written down? .... Yes/No
And circulated? .... Yes/No

1g. How are decisions communicated to staff? Describe ....

....

....

1h. How is action and progress reviewed between planning meetings?

....

....

1i. How are service users, including those with communication difficulties, involved in the individual planning process?

....

....

General Rating for Part 1

0 There is no operational planning system for individual goals *or* decisions/goals are not recorded or circulated when planning meetings are held

1 There are ad hoc meetings but no regular system. Decisions/goals are recorded and circulated

2 There is an operational planning system with meetings held regularly (at least 50% of residents have had a meeting in the last 6 months, 100% in the last 12 months). Decisions/goals are recorded and circulated

3 As above, plus clear mechanisms for communication/review among staff at regular intervals between planning meetings (13)

Rating for User Involvement

0 Users are not usually or rarely actively involved
1 Some users are actively involved some of the time or through parts of the process
2 Some users actively involved throughout the whole process
3 All users actively involved throughout the whole process . (14)

2. Assessment and Teaching of Clients

2a. Is any form of behavioural assessment or skills checklist used?

.... Yes/No

If *yes* what type and how often?

....

....

2b. How are teaching priorities decided? Describe.

....

....

2c. How are teaching programmes drawn up? Are they written down?

....

....

2d. How are they communicated to staff?

....

....

2e. Does the teaching programme include a standard to be achieved and a section for recording progress?

....

....

2f. How often are teaching programmes reviewed?

....

2g. How are service users (including those with communication difficulties) involved in the process?

....

....

General Rating for Part 2

0 Behavioural assessment is not done regularly and there is no operational system for setting individual teaching programmes or they are not written down

1 Behavioural assessment is done regularly but there is no operational system for setting individual teaching programmes are they are not written down <u>OR</u> Teaching is done but ad hoc and not related to systematic behavioural assessment

2 There is an operational system for deciding teaching priorities and setting teaching programmes (either including behavioural assessment or derived from systematic IP format) which are written down and communicated to staff, and reviewed at least at 3-monthly intervals
3. As above plus clear criteria for success and monitoring of progress. (15)

Rating for User Involvement

0 Users are not usually or rarely actively involved
1 Some users are actively involved some of the time or through parts of the process
2 Some users actively involved throughout the whole process
3 All users actively involved throughout the whole process . (16)

3. Planning Daily/Weekly Activities for Clients

3a. How are the activity opportunities developed for each client decided?

....

3b. What is the range of opportunities covered (eg household, social, leisure, day occupation)?

....

....

3c. Are individual clients involved in choosing their preferred activities? Are likes/dislikes or strengths analyses undertaken?

....

....

3d. How are people with communication difficulties involved in this process?

....

....

3e. Does the planning process result in a written individual timetable of activities? ,.. Yes/No

3f. How is the activity plan communicated to staff?

....

....

3g. Is there a way of monitoring what activities each person is involved in (ie realised opportunities)?

....

3h. How often are individuals' activities reviewed?

....

General Rating for Part 3

0 There is no planning of resident activities beyond the most basic routines such as meals, getting up, dressing, washing etc

1 Assessment of likes/dislikes and discussion of preferred activity is done informally but activity timetable is not written down or is substantially incomplete (less than 50% of the time has activity opportunities)

2 There is an operational system for deciding activity opportunities and setting an activity timetable, which is written down and communicated to staff and covers at least 50% of the time

3 As above plus clear mechanisms for monitoring and review of progress. (17)

Rating for User Involvement

0 Users are not usually or rarely actively involved
1 Some users are actively involved some of the time or through parts of the process
2 Some users actively involved throughout the whole process
3 All users actively involved throughout the whole process . (18)

4. Staff Support of Resident Activity

4a. Is the availability of staff linked to the activity timetables of residents or is there a standard rota? Describe.

....

....

4b. How do staff work out priorities during their shift (ie what needs to be done, who is to be supported to do what)?

....

....

4c. Does the role of staff in relation to helping residents include an emphasis on giving support to residents to be involved in activity?

....

....

4d. Is this aspect of the staff role operationalised in clear performance terms? ....

4e. What training do staff have in how to support resident activity?

....

....

General Rating for Part 4

0 Staff support of resident activity is left to the staff on duty to work out for themselves. The staff role is undefined.

1 The role of staff is defined in support terms and clearly operationalised but staff are left to their own initiative as how to put it into practice

2 There is a written procedure by which staff decide how best time is to be allocated to support residents

3 As above, plus staff role is defined and staff receive related training. (19)

5. Training and Supervision of Staff

5a. What training to staff receive (eg induction or ad hoc in-service training, refresher courses)?

....

....

5b. Do staff receive specific training in Individual Planning?

....

....

5c. Do staff receive training in resident assessment methods and skill teaching techniques?

....

....

5d. Do staff receive training in planning and supporting resident activity?

....

....

5e. Do staff receive training in ways of involving residents in decisions (including residents with communication difficulties)?

....

....

5f. How are staff training needs assessed and reviewed?

....

....

5g. Are there ways of monitoring staff performance?

....

....

5h. What arrangements are there for supervision of individual staff members?

....

....

5i. How often does individual staff supervision take place?

....

....

5j. Is individual staff performance formally appraised? Yes/No
If *yes* how often? ....

General Rating for Part 5

0 There is no formal training for the setting, or basic induction period only

1 Induction training for the setting is given, with opportunities for further training either on staff request or provided on an ad hoc basis.

2 Induction and further training around resident activity (IPs, activity planning, resident assessment etc) is provided regularly

3 As above plus clear mechanisms for staff supervision and appraisal (at least annually). (20)

Group Home Management Interview

The following questions are about daily activities as they happened here *yesterday.*

Please note the number of residents in the facility at the time of interview

....

1. What time did the residents get up yesterday?
    - First resident ....
    - Last resident ....

2. Do they always get up at this time? (21)
    - All yes 2
    - Yes except on specified day 1
    - All no 0
    - Other ....

3. What time was breakfast?
    - Began ....
    - Ended ....

4. Is breakfast always at that time? (22)
    - Always 2
    - Different on specified days 1
    - Different at weekends 0

5. What did residents do after breakfast?

....

....

6a. How many residents went out to work or to a day service?

....

6b. What time did they leave?
First left ....
Last left ....

7a. How did residents get to their work or day service?
Private bus 1
Public transport 2
Walk 3
Other (specify) 4

7b. Do residents travel together?
All in one group 2
Mixed pattern 1 (23)
No more than 3 in a group 0

8. What time did the residents return from their work or day service?
First returned ....
Last returned ....

9. What happened after their return and before supper?
....
....

10. What time was supper?
Began ....
Ended ....

11. Is supper always at that time?
Always 2
Different on specified days 1 (24)
Different at weekends 0

12. What happened after supper yesterday?
....

13. How many residents had a bath yesterday? ....

14. Are there set times when the residents have their baths?
Yes, all scheduled 2
Some scheduled 1 (25)
Individual choice 0

15. What time did the residents go to bed last night?
First resident ....
Last resident ....

16. Do they always go to bed at the same time?
All yes 2
Yes except on specified days 1 (26)
All no 0
Other (specify) ....

17. Are the residents wakened for toileting at night?

All residents 2
Some residents 1 (27)
None 0

18. What rules are there about quiet times eg use of TV or stereos

Strictly scheduled 2
Some time rules 1 (28)
At residents' own discretion 0

19. What is the curfew time for residents to be in the house at night?

Curfew time ....
No curfew time 0

20. Is this the same every night?

Yes 2
Yes, except specified nights 1 (29)
None 0

21. Is the curfew time the same for all residents?

Yes, all 2
Yes, except specified people 1 (30)
No, or none 0

22a. Is the house door ever locked?

Yes 1
No 2

22b. If *yes* how many residents have their own keys?

None 2
Some 1 (31)
All 0

23a. When can relatives visit the residence?

Certain days only 2
Any day but set times 1 (32)
Any time 0

23b. When can friends visit the residence?

Certain days only 2
Any day but set times 1 (33)
Any time 0

24. What rules are there concerning dating?

No dating allowed 2
Allowed under specified conditions or times 1 (34)
No restrictions 0

25. When may residents use their bedrooms?

Only at bedtime or to change 2
Under specified conditions 1 (35)
Any time 0

26. When may residents use the kitchen?

Not at all 2
Under supervision, specified times 1 (36)
Any time 0

27. Are there restrictions on the use of any other area of the residence?

Certain areas restricted always 2
Certain areas restricted certain times 1 (37)
No restrictions 0

28. Where do residents keep their clothes?

Communal storage 2
Shared storage 1 (38)
Private storage 0
Other (specify) ....

29 How many of the residents have books, games, radios, TVs etc of their own?

None 2
Some (give number) 1 (39)
All 0

30. What is done with these items?

Kept but not allowed to use 2
Used but become communal 1 (40)
Used and shared at owner's discretion 0
Other (specify) ....

31. How many of the residents have been clothes shopping in the last month? ....

32. How are meals planned at the residence?

Staff only 2
Staff and certain residents 1 (41)
Residents only 0
Other (specify) ....

33. Who does the shopping?

Staff only or delivery 2
Staff and certain residents 1 (42)
Residents only 0
Other (specify) ....

34. Who shops for residents' clothing and personal articles?

Staff only 2
Staff and certain residents 1 (43)
Residents only 0
Other (specify) ....

35. How many residents:

Have bank accounts ....
Have more than one bank account ....
Have been to the bank in the last month ....

36. How is the banking handled?

Staff only for all 2
Staff and certain residents 1 (44)
Residents only 0

37. How are household chores allocated eg washing up, making beds?

Staff decide who will do 2
Staff and certain residents 1 (45)
Residents decide 0
Other (specify) ....

38. How often are parties or social events held in the residence?
Please enter number of times approximately per year

....

39. Who organizes parties?

Staff only 2
Staff and certain residents 1 (46)
Residents only 0
Other (specify) ....

40a. Do staff invite their friends and relatives to parties too?

Yes 1
No 2

40b. How often do friends and relatives of staff visit?

Rarely 2
Sometimes (once a month or so) 1 (47)
Often (once a week or more) 0

41. Do staff have a chance to eat with residents at meals?

Seldom, usually supervise during meals 2
Some staff, sit but don't eat 1 (48)
All staff frequently 0

42. Do the residents watch TV as a group in the evenings? Do staff sit and watch TV with them?

Seldom, usually supervise only 2
Someone sometimes does 1 (49)
Someone usually does 0

43. How are birthdays celebrated?

Joint parties or no recognition 2
Mixed pattern 1 (50)
Individual presents and parties 0
Other (specify)

44. Can a resident have a pet?

None allowed 2
Common only 1 (51)
Individual pets allowed 0

45. What hobbies or crafts do residents enjoy? Do the staff work on these with them sometimes?

Rarely 2
Someone sometimes does 1 (52)
Someone usually does with at least some residents 0

47. How are the residents' medical needs usually met?

Doctor comes to residence for all 2
Residents all go to same doctor's office 1 (53)
Residents have own personal doctors 0

48. How are residents' dental needs met?

One dentist for all 2
Mixed pattern 1 (54)
Individual dentists 0

49. How many residents have been to stay with a relative for a night or longer during the past 3 months? ....

50. How many residents have been to a friend's house for a meal in the last month? ....

51. How many residents have had friends in for a meal in the last month?
....

52. Please note how many residents have taken part in the following activities in the last month. Also note whether they took part as an individual or as part of the whole group.

Activity	No in last month	Individual	Mixed	Whole Group
Movie				
Restaurant				
Museum				
Church				
Concert				
Play				
Sports event				
Social/recreational club				
Continuing education				
Hairdresser				
Other (specify)				
Other (specify)				

Summary score for over pattern above
Whole group 2
Mixed 1 (55)
Individual 0

53. How many of the residents have been on an outing with staff in the last three months?
None 2
Some 1 (56)
All 0

54. How many residents went away on holiday in the past year?

....

55. Did residents go on holiday individually or as a group?
All went as a group 2
Mixed 1 (57)
Individual trips 0

| 0 | 5 | (93-94)

Appendix 32
Individual Schedule (adapted)

Residential Supports for People with Learning Disabilities

Individual Schedule

Code
☐☐☐

Hester Adrian Research Centre

Background
For HARC use only

Code

B6. Date of Birth ....

.... (1-

8)

B7. Gender

Male 1 (9)

Female 2

B8. Ethnic Origin

Asian (Indian) 1

Asian (Pakistani) 2

Asian (Bangladeshi) 3

Asian (East African)...................................... 4

Asian (Chinese).. 5 ☐☐

Asian (Other).. 6 (10-

Black (Caribbean)... 7

Black (African) 8

Black (Other) 9

White (*Please specify*)................................ 10

....

Some other group *(please specify)*............... 11

....

B8a What is the person's current diagnosis?

Learning disability (mild/borderline).................. 1

Learning disability (moderate) 2

Learning disability (severe)............................. 3

Autism 4

Asperger's 5

Mental health problem.................................... 6

(please specify)

....

Physical/sensory impairment.......................... 7

(please specify)

....

Other 8

(please specify)

B9. Type of residence

Village or residential community........................ 1
Small-scale group home.................................. 2 (12)
Supported living... 3

B10. What is the registration status of the residence?

Small residential care home (3 or fewer people) 1
Registered residential care home (4+ people). 2
Nursing home.. 3
Dual registration (Residential Care Home and
Nursing Home)... 4 (13)
NHS Trust provision....................................... 5
Service user has a tenancy............................. 6
Service user is a home owner.......................... 7
Other (specify)... 8

B11. Are housing and care provided by different organisations?

Yes.. 1 (14)
No.. 2

B12a. Who is the housing managed by?

Social Services... 1
Private (for profit) organisation......................... 2
NHS Trust.. 3 (15)
Voluntary (non-profit organisation)................... 4
Housing Association.. 5
Other (specify).. 6

B12b. Who manages the care provided in the home?

Social Services... 1
Private (for profit) organisation......................... 2
NHS Trust.. 3 (16)
Voluntary (non-profit organisation)................... 4
Housing Association.. 5
Other (specify).. 6

B13. How long has the person been living in this setting. Please enter date of coming to placement

.... ☐☐☐

(17-19)

B. 13a. Is the person on a section of the Mental Health Act (e.g. section 2, 3, 35, 37 or 37/41 or guardianship)? ....

Yes 1
No.. 2

If yes, please specify which and date of section/order

....

B.13b. Is the person subject to the Care Programme Approach?

Yes 1
No.. 2

If yes, please specify the level she or he is currently on:

Level 1.................. 1
Level 2.. 2
Level 3.. 3
Supervision Register 4

B.13c. Does the person have any convictions? .... Yes/No

If yes, please state date, nature of offence and any outcomes:

Date of offence	Nature of offence	Outcome, e.g. caution, sentence

B.13d. Is the person on a probation order?................ Yes/No

B. 13e. Has the resident ever been accused of a crime? Yes/no
If yes, please describe incident/s:

....
....
....
....
....

B14. Does the person's home have the following items?

(20)	Colour television	Yes/No	8
(21)	Black and white television only	Yes/No	8
(22)	Telephone	Yes/No	8
(23)	Washing Machine	Yes/No	8
(24)	Deep-freezer/fridge freezer	Yes/No	8
(25)	Video Recorder	Yes/No	8
(26)	Microwave Oven	Yes/No	8
(27)	Tumble Drier	Yes/No	8
(28)	CD Player	Yes/No	8
(29)	Home Computer	Yes/No	8
(30)	Dishwasher	Yes/No	8
(31)	Central Heating	Yes/No	8

B15. Where did the person live prior to moving into this setting?

Residential special school 1
Residential children's home 2
Family home 3
Foster family home 4
Group Home 5
Hostel 6
Hospital Ward 7
Residential or village community 8
Respite 9
Other, e.g. secure unit, prison (please specify) 10
....

☐☐ (32-3

B16. Residential History: If possible, please record all places that the person has lived in since 1990, including residential schools, hospitals, staffed houses and so on.

Type of setting	Dates the person lived there	
....	....	☐☐
....	....	
....	....	
....	....	
....	....	☐
....	....	
....	....	
....	....	
....	....	☐☐
....	....	
....	....	

(37-3

B17. When did the person move out of family home (please give number of years ago or 99 if not known)

.... ☐☐

B18. Please note the town in which (name's) parents or other relatives live ☐☐☐

....

No Miles..

(41-43)

Case Management

B19a. Is there a keyworker assigned to support the person?
Yes 1
No 2 (44)

If No, go to 20a. If yes, go to B19b.

B19b. For how many months has this keyworker been directly responsible for this person?
☐☐☐

.... months
(45-47)

B19c. How often does the keyworker have formal meetings to review work done with this person with their superior
Weekly 1 (48)
Monthly.. 2
Less Often.. 3
Does not discuss 4

B20a. Does the person have a formal Case Manager?
Yes 1 (49)
No 2
If NO, go to B21a

B20b. How often does the Case Manager see the person?
Monthly 1
Every 6 months 2
Less Often 3 (50
Have not met person 4

B20c. Who is the Case Manager employed by?
Social Services Department 1 (51
Other (specify).. 2

B21a. Is there an Individual Programme Plan (IPP) for this person?
Yes 1
No.. 2 (52)
Don't know.. 3

Case Management

B21b. Does the individual plan have one or more goals stating *who* will *do what* by *when* in the following areas? Please tick all that apply.

(53)	Communication	☐	8
(54)	Self Care	☐	8
(55)	Sexuality and/or relationships	☐	8
(56)	Decreasing difficult or inappropriate behaviour	☐	8
(57)	Job related skills	☐	8
(58)	Academic development (writing, counting etc)	☐	8
(59)	Improving social skills	☐	8
(60)	Increasing self esteem	☐	8
(61)	Expanding social relationships	☐	8

B21c. When were these goals most recently revised? ☐☐

months ago . (62-63)

B21d Does the person have an independent advocate?

Yes 1
No.................................2

If yes please specify which agency:

....
....
....

Health Issues

☐☐☐

H1. Height in metres .... or feet .... inches ....

(64-66)

H2. Weight in kg .... or stone .... pounds .... ☐☐☐
Date last weighed ...../....../......

(67-69)

H3. Has the person been diagnosed as being affected by any of the following?

Autism ....yes/no (70)
Prader-Willi...yes/no (71)
Rett's Syndrome ....yes/no (72)
Cerebral Palsy..yes/no (73)
Down's Syndrome ....yes/no (74)
Fragile-X Syndrome..yes/no (75)
Other (please specify) ....yes/no (76)

H4. Does the person suffer from fits?
No (no medication and no seizures)...........................1
No (has had seizures but now controlled by medication 2
Occasional seizures (less than monthly).....................3 ☐☐
One or more seizures per month.................................4 0 1 (93-9

H5. Health Problems. In the last 12 months, has the person suffered from any of the following problems?

	Yes	No	
Bronchitis	1	2	(1)
Arthritis	1	2	(2)
Sciatica, lumbago or recurring backache	1	2	(3)
Persistent skin trouble eg eczema	1	2	(4)
Asthma	1	2	(5)
Recurring stomach trouble or indigestion	1	2	(6)
Constipation	1	2	(7)
Poor bladder control	1	2	(8)
Poor bowel control	1	2	(9)
Piles	1	2	(10)
Persistent foot trouble eg bunions	1	2	(11)

Health Issues

H15a. Does the person smoke?

Yes (go to H15b) 1
No (go to H16)...2
(34)

H15b. If *yes* how many cigarettes (roll-ups, cigars or pipes) does the person smoke a day?

☐☐

(35-36)

H15c. Has the person ever had advice about giving up smoking?

Yes 1 (37
No...2

H16. In an average week, how many of the following does the person drink?

Pints of beer, lager or cider ....pints ☐☐ (38-3
Glasses of sherry, wine, vermouth .... glasses ☐☐ (40-4
Shots of spirits or liqueurs ....shots ☐☐ (42-4

H17. Is (name's) use of alcohol considered to be a problem?

Yes 1 (44
No...2

If *yes* please give details

....
....
....

Interview Schedule
Supplementary Information on Challenging Behaviour

Name of resident concerned: ....

Setting ....

Code ....

Name of person completing schedule
....

Status of person completing schedule ....

Date schedule completed..

Challenging Behaviour

C2. What form does the challenging behaviour most commonly take?
Brief episodes of challenging behaviour 1 (15)
Sustained or prolonged episodes of
challenging behaviour.. 2

C3a. How frequently have episodes of challenging behaviour occurred within the past month?
Hourly 1
Once or more a day 2
Once or more a week 3 (16)
Less often 4
Not at all 5

C3b. If not at all in the last month, how long is it since the last incident? ☐☐

.... months

(17-18)

C4. What/who is *usually* the recipient of the person's challenging behaviour? Please choose one only.
Usually a staff member.. 1
Usually another person with learning disabilities . 2
Usually a stranger 3 (19
Causes harm to self only....................................... 4
Inanimate objects only... 5
No usual type of victim 6
Other, e.g. children (please specify).................... 7

....

C5a. Immediately an episode of challenging behaviour occurs, what is the *usual* level of intervention that is needed to control the behaviour? Choose one number only.

No intervention, behaviour ceases spontaneously .. 1
No intervention, behaviour is tolerated or accepted 2
Is ignored as part of an agreed programme 3
Verbal response from member of staff 4 (20
Physical intervention (with or without verbal response) by a member of staff 5
Physical intervention by more than one member of staff 6
Other e.g. calling the police (Please specify) 7

....

C5b. What is the *maximum* level of intervention which may be needed to control the behaviour? Choose one number only.

No intervention, behaviour ceases spontaneously.... 1
No intervention, behaviour is tolerated or accepted 2
Is ignored as part of an agreed programme............. 3 (21
Verbal response from member of staff 4
Physical intervention (with or without verbal response) by a member of staff 5
Physical intervention by more than one member of staff... 6
Other e.g. calling the police (Please specify) 7

C6. Are any of the following used for immediate control of the person's challenging behaviour?

a) Physical Restraint
Usually.. 1
Sometimes 2 (23
Rarely 3
Never 4

b) Seclusion
Usually.. 1
Sometimes.. 2 (24
Rarely 3
Never.. 4

c) Sedation (prn or medications `as required')
Usually 1
Sometimes 2 (25
Rarely 3
Never 4

C6a. Does the person have complete freedom to come and go as he or she pleases?

Yes 1
No 2

If no, is s/he allowed out at all? .... Yes/no
Does the person have to be accompanied by staff to go out?
Yes/no
Can s/he only go out at certain times and to certain places?
Yes/no
Please specify when and where:
....
....
....

C6b. Has the person ever engaged in any behaviour which you think would be a criminal offence (such as stealing, physical aggression, sexual assault)?

Yes 1
No 2

If yes, please give details of these behaviours:

Date	Details of behaviours

C6b. Have the police ever been called in response any of these incidents?

Yes 1
No 2

If yes , please describe what happened as a result:

....
....
....
....

If no, please say why not:

....
....
....
....

If no, were any consequences arising from the incidents? (e.g. withdrawal of activities etc.)

....
....
....
....
....

C6c. What do you think causes ~~these~~ behaviours?

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....
....
....

Appendix 33
Individual Resident's Interview (adapted)

The Quality and Costs of Residential Provision for People with Learning Disabilities

Individual
Resident Interview

Code Number

___ ___ ___

Hester Adrian Research Centre
The University of Manchester
Oxford Road
Manchester
M13 9PL

Background Information

Note: this page will be removed from the questionnaire at HARC to ensure confidentiality

Name of resident: . . . .

Address of residence: . . . .

. . . .

. . . .

Name of Interviewer: . . . .

Date of Interview: . . . .

Notes for Interviewers

This interview schedule seeks to obtain the views of the resident regarding their overall lifestyle and support from services. The schedule contains a list of topics to be covered in the following general areas:

- the residence that they live in
- their day activities (day service, employment, education)
- social and recreational activities
- friendships and relationships
- support from services
- choice
- risks

All the topic areas are covered in the interview using simply phrased, open-ended questions. The questions listed in the interview schedule do not have to be followed in order but can vary according to the flow of conversation. Also interviewers can rephrase questions if necessary. Probe questions are listed in the event that the resident does not respond to the main questions.

The resident's responses should be written down in the appropriate section in as much detail as possible. At the end of each section, make a global rating of the section based on the resident's responses using the following scale (this can be done after the interview on the basis of your notes):

0	No clear response
1	Very positive responses overall
2	Mildly positive responses overall
3	Neutral/mixed responses overall
4	Mildly negative responses overall
5	Very negative responses overall

Accommodation

How long have you been living here?

Where did you live before you came here?

Do you like living here more than ......?

What do you like most about living here?
- Physical aspects of home
- People you live with
- The staff
- Neighbours
- Location of residence

What do you *not* like about living here?
- Physical aspects of home
- People you live with
- The staff
- Neighbours
- Location of residence

What would you like to be different about your home?

Notes: ....

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Accommodation Section Notes cont

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Overall Rating for Accommodation Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Day Activities

Where do you go during the day (day service/employment/education)?

What do you do at .... ?

What do you like about ......?
    Activities
    People

What do you *not* like about ......?
    Activities
    People

Do you ever get bored with ......?

What would you like to be different about what you do during the day?

Notes: ....

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Social and Recreational Activities

What have you done in the evenings (in the last four weeks)?

Who do you do these things with?

Do you like what you do in the evenings?

Do you ever get bored in the evenings?

What would you like to be different about what you do in the evenings?

What have you done at the weekends (in the last four weeks)?

Who do you do these things with?

Do you like what you do at weekends?

Do you ever get bored at weekends?

What would you like to be different about what you do at weekends?

Notes:

Social and Recreational Activities Section Notes

Overall Rating for Social and Recreational Activities Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Friendships and Relationships

Do you have any friends?

Where did you meet them?

What do you do with your friends?

How often do you see them?

Would you like to see them more often?

Would you like to make more friends?

Do you have any family?

How often do you see them?

Would you like to see them more?

Have you got a girlfriend/boyfriend?

What would you like to be different about your friends and relationships?

Notes: ....

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Friendships and Relationships Section Notes

Overall Rating for Friendships and Relationships Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Support From Services

Who do you ask if you need any help with anything?

Do you get as much help from staff as you would like?

Would you like more help from staff?

What would you like to be different about the way staff help you?

IPP Meetings

Do you ever have meetings with staff about what you do during the day or where you live?

Do you go to the meetings? If not, why not?

If you do, do you feel able to say what you want?

Do staff listen to you?

Is everything explained to you?

Who helps you in these meetings?

What would you like to be different about the meetings?

Notes: ....
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Support from Services Section Notes

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Overall Rating for Support from Services Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Choice Section Notes Cont

Overall Rating for Choice Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Risks

Do you feel safe living here?

Do you feel safe when you go out?

Is anyone ever unpleasant/nasty to you?

Does anyone ever make you feel scared?

Notes: ....

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Risks Section Notes Cont

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Overall Rating for Risks Section (please circle)

No response	Very Positive	Mildly positive	Neutral/ mixed	Mildly negative	Very Negative
0	1	2	3	4	5

Risks (2)

Has anyone ever said that you have scared them?

Has anyone ever said that you have hit them?

Has anyone ever said that you have stolen something from them?

Has anyone ever said that you have hugged them, kissed them or touched them when they did not want you to?

Notes:

Overall rating for risks section (please circle)

No response	Very positive	Mildly positive	Neutral/ mixed	Mildly negative	Very negative
0	1	2	3	4	5

Appendix 34
Risks and Choices interview

Interview Schedule

Risks and Choices

Name of Resident Concerned : ....

Setting: ....

Code ....

Date of Interview ....

Name of Informant..

Relationship to Resident..

Hester Adrian Research Centre

LINE 8

Accidents and Injuries

R1a. Has the person suffered any *major* accidents or injuries which have required admission to hospital in the last five years?

Yes 1
No..2

(8)

R1b. If *yes*, please describe.

....
....
....

R2a. Has the person suffered any accidents or injuries in the home which have required medical attention over the last year?

Yes 1
No..2 (9)

R2b. If *yes*, please describe.

....
....
....
....

R3a. Has the person suffered any accidents or injuries whilst out of the home over the last year?

Yes 1
No..2 (10)

R3b. If *yes*, please describe.

....
....
....
....

R4a. Risks in the home: do you feel that the person is at risk in the home in any way, for example, drinking cleaning fluids, falling down stairs, danger of burns from cooker, and so on?

No..1
Yes, but no support for concern.......................................2
Yes, some support for concern...3 (11)
Yes, solid evidence exists to support concern.................4

R4b. Please describe risks in the home and outline evidence which you feel supports concern regarding these risks

....
....
....
....

R5a. Traffic: do you consider the person to be at risk of suffering a road traffic accident?

No..1
Yes, but no support for concern.......................................2
Yes, some support for concern...3 (12)
Yes, solid evidence exists to support concern.................4

R5b. Please outline evidence which you feel supports concern regarding risk of a road traffic accident

....
....
....
....

R6a. Other risks outside the home: do you consider the person to be at risk in any other way outside the home, for example, getting lost, danger from water?

No..1
Yes, but no support for concern.......................................2
Yes, some support for concern...3 (13)
Yes, solid evidence exists to support concern.................4

R6b. Please outline evidence which you feel supports concern regarding other risks outside the home

....

....

....

....

Abuse and Exploitation

R7a. Have there been any documented instances of physical or sexual abuse of the person in the last 5 years?

Yes 1
No 2 (14)

R7b. If *yes*, please describe.

....

....

....

R8a. Do you feel that the person is at any risk of physical or sexual abuse by <u>other service users</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (15)
Yes, solid evidence exists to support concern 4

R8b. Please outline evidence which you feel supports concern regarding risk of abuse

....

....

....

R9a. Do you feel that the person is at any risk of physical or sexual abuse by <u>people in the local community</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (16)
Yes, solid evidence exists to support concern 4

R9b. Please outline evidence which you feel supports concern regarding risk of abuse

....

....

....

R10a. Do you feel that the person is at any risk of physical or sexual abuse by <u>staff working in the service</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (17)
Yes, solid evidence exists to support concern 4

R10b. Please outline evidence which you feel supports concern regarding risk of abuse

....

....

....

....

R11a. Do you feel that the person is at any risk of physical or sexual abuse by <u>any others not mentioned above</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (18)
Yes, solid evidence exists to support concern 4

R11b. Please outline evidence which you feel supports concern regarding risk of abuse

....

....

....

....

R12a. Do you feel that the person is at any risk of exploitation by <u>other service users</u> (eg having money or possessions taken; being coerced or encouraged to take part in inappropriate activities)?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (19)
Yes, solid evidence exists to support concern 4

R12b. Please outline evidence which you feel supports concern regarding risk of exploitation

....
....
....
....

R13a. Do you feel that the person is at any risk of exploitation by <u>people in the local community</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (20)
Yes, solid evidence exists to support concern 4

R13b. Please outline evidence which you feel supports concern regarding risk of exploitation

....
....
....
....

R14a. Do you feel that the person is at any risk of exploitation by <u>staff working in the service</u>?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (21)
Yes, solid evidence exists to support concern 4

R14b. Please outline evidence which you feel supports concern regarding risk of exploitation by staff

....

....

....

....

R15a. Do you feel that the person is at any risk of exploitation by any others not mentioned above?

No 1
Yes, but no support for concern 2
Yes, some support for concern 3 (22)
Yes, solid evidence exists to support concern 4

R15b. Please outline evidence which you feel supports concern regarding risk of exploitation

....

....

....

R16a. Has the person been subjected to verbal abuse or teasing by members of the public or children whilst outside the home?

Yes... 1
No 2 (23)

R16b. If *yes* please describe ....

....

....

....

....

....

....

R17a. Has (name's) home been vandalised in any way in the past?

Yes... 1
No 2 (24)

R17b. If *yes* please describe ....

....

....

....

....

....

R18a. Has the person ever been the victim of a crime such as burglary or theft?

Yes..1 (25)
No 2

R18b. If *yes* please describe ....

....

....

....

....

Risks
(addition)

R. Do you feel that the person is at risk of physically abusing other service users?

No 1
Yes, but no support for concern..2
Yes, some support for concern..3
Yes, solid evidence exists to support concern...............................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that the person is at risk of physically abusing people (including) in the local community?

No 1
Yes, but no support for concern..2
Yes, some support for concern..3
Yes, solid evidence exists to support concern...............................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that the person is at risk of physically abusing staff working in the service?

No 1
Yes, but no support for concern..2
Yes, some support for concern..3
Yes, solid evidence exists to support concern...............................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that the person is at risk of sexually abusing other service users?

No	1
Yes, but no support for concern	2
Yes, some support for concern	3
Yes, solid evidence exists to support concern	4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that the person is at risk of sexually abusing people (including children) in the local community?

No	1
Yes, but no support for concern	2
Yes, some support for concern	3
Yes, solid evidence exists to support concern	4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that the person is at risk of sexually abusing staff working in the service?

No	1
Yes, but no support for concern	2
Yes, some support for concern	3
Yes, solid evidence exists to support concern	4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....

....

....

Do you feel that the person may verbally abuse people (including children) in the local community?

No 1
Yes, but no support for concern...2
Yes, some support for concern..3
Yes, solid evidence exists to support concern....................................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....

....

....

Do you feel that the person is at risk of damaging property either in the home or in the local community?

No 1
Yes, but no support for concern...2
Yes, some support for concern..3
Yes, solid evidence exists to support concern....................................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....

....

....

Do you feel that the person is at risk of stealing in either the home or the local community?

No 1
Yes, but no support for concern...2
Yes, some support for concern..3
Yes, solid evidence exists to support concern....................................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Do you feel that this person presents any other kind of risks?

No 1
Yes, but no support for concern...2
Yes, some support for concern...3
Yes, solid evidence exists to support concern..................................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....
No
....
1
Yes, but no support for concern...2
Yes, some support for concern...3
Yes, solid evidence exists to support concern..................................4

Please outline evidence which you feel supports the concerns regarding the risk of abuse.

....
....
....

Resident's Lifestyle

L1. Resident Choice

In what ways is the person supported in making choices with regard to the following areas of their life?

Rating Scale:

1 Nothing mentioned
2 Some procedure(s) mentioned but unlikely to give person much real choice
3 Some procedure(s) mentioned through which person can express preferences but final say does not rest with person
4 Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.

	1	2	3	4	(26)
The timing of their evening meal	1	2	3	4	(27)
Where they eat their evening meal	1	2	3	4	(28)
The leisure activities they take part in indoors eg TV, radio	1	2	3	4	(29)
Going out eg pub, cinema	1	2	3	4	(30)
The time they go to bed in the evening	1	2	3	4	(31)
The clothes that they purchase	1	2	3	4	(32)
The clothes they wear each day	1	2	3	4	(33)
Household routines eg shopping for food, housework rotas	1	2	3	4	(34)
Keeping pets	1	2	3	4	(35)
Who they live with	1	2	3	4	(36)
Where they live	1	2	3	4	(37)
Recruitment of staff	1	2	3	4	(38)
Staff performance review	1	2	3	4	(39)
The firing of unsuitable staff	1	2	3	4	(40)
Involvement with girlfriends or boyfriends	1	2	3	4	(41)
Their haircut	1	2	3	4	(42)
Their day time activities	1	2	3	4	(43)

Holidays: where they go, who they go with and when they go	1	2	3	4	(44)
The time they spend in the bath or shower	1	2	3	4	(45)
Their employment	1	2	3	4	(46)
Access to a private area	1	2	3	4	(47)
Moving home in the future	1	2	3	4	(48)
The furnishings in their home	1	2	3	4	(49)
The furnishings in their bedroom	1	2	3	4	(50)
Personal possessions	1	2	3	4	(51)

L3. Are there any particular reasons why choice has to be limited for this person, for example, choices tend to be inappropriate, choice has to be constrained due to challenging behaviour or person cannot communicate preferences?

....

....

.... **(58-59)**

....

....

Day Time and Leisure Activities

L2. Please note the activities that the person has taken part in in the last 4 weeks. Under *other*, include any other activities not listed and any *hobbies* that the resident takes part in.

Activity	**This setting**	**Other Setting**	**Who with?** (i.e. staff, family, other people with learning disabilities, neighbours, alone or other)?	**Number of times in past 4 weeks**
Had guests to stay (no. of nights)				
Had family or friends round for a meal				
Been to a social club				
Been on an overnight stay to family or friends (no. of nights)				
Had trips out with family or friends				
Been to a café				
Been to a pub				
Been to a hairdresser				
Been shopping				
Been to a place of religious worship				
Been to a sports event				
Been to a cinema				
Been to a concert or play				
Been on a bus				
Been to their bank				
Been on holiday (*in the last 12 months*).				
Other (specify)				
Other				
Other				
Other				

Appendix 35
Social Network Grid

Social Network Guide - Interviewer's Notes

Forrester-Jones and Cambridge 1998

1. Map

Preamble: I am interested in the people you know and who they are. Look at this cake (circle), I've split it into different pieces and we will write the names of people you know in each segment (piece).

1) Who do you live with?

2) I am interested in (like to know) what you normally do during the week and whom you see.
Prompt: What did you do today?, yesterday? Do you do anything different during the weekend? What about in the evenings?

3) What about your family? Who are you in contact with (see, phone, letter).

4) Is there anyone you have been in touch with (by telephone or letter) who hasn't been mentioned yet?

5) Is there anyone we have missed out whom you feel is important to you?

2. Grid

Researcher writes in the initial of people identified into the appropriate boxes on the questionnaire. Then asks the respondent further questions about each individual. ***Codes are provided on grid and are as follows:***

Codes for Area of Life (social context):

- *1 - household (includes people living under the same roof)*
- *2 - residential care staff (those caring for user in household)*
- *3 - visiting specialist / professional*
- *4 - employment / day support*
- *5 - clubs / vol org / churches*
- *6 - shops, pubs, cafes*
- *7 - neighbours*
- *8 - family (those not living in household)*
- *9 - other friends*
- *10- social acquaintances / others*

Codes for Network Membership:

- *1 - user*
- *2 - staff (paid carers)* includes visiting specialist / professionals
- *3 - key worker* /care manager
- *4 - ex-staff*
- *5 - volunteers / advocates*
- *6 - service contacts*
- *7 - boyfriend / girlfriend / partner / spouse*
- *8 - other family*
- *9 - social acquaintances*
- *10 - other friends*
- 11 - ME

Preamble: I'd like to learn more about the people in your network (life). I'm going to write down their initials, and then ask a few questions about the ways in which they help you.

Social Support
For the following questions, the codes are:

1 - Always
2 - Some
3 - Hardly / Never

6) Do any of these people help you with (refer to grid):

- Personal = washing and bathing
- Household = household chores, e.g. cooking, shopping, etc.
- Material = give you money, cigs, help with transport - give you lifts to the shops, etc.
- Decision and feedback = help you make decisions (choices)
- Confide = could you go to them if you were upset or wanted to tell secrets / worries
- Company = companionship - keep you company (like being together)
- Invisible = watch out for you (keep an eye on you) (look out for you).

Critical
7) Is this person ever critical of (nasty or bad to) you or do they ever upset you?

Reciprocity
8) Do you ever (do anything) (help) for (specify name) *or*
do they just (do things) (help) for you *or*
do you (do things for) (help) each other?

Codes for 8) Direction:
1 - Y - T
2 - T - Y
3 - Both ways
4 - Not reciprocal

Frequency
9) About how often do you see this person? Daily, weekly, monthly, yearly?

Codes for 9) How Often:
1 - daily
2 - weekly
3 - monthly
4 - few a year
5 - less than a year.

Duration
10) How long (many years) have you known this person? Less than 1 year, 1-5 years, 5+ years?

Codes for 10) How Long Known:
1 - less than 1 year
2 - 1 -5 years
3 - 5+ years

11) How closes are you to this person? (Is this person a best friend). Very close, (a friend), quite close or (just someone you know) not very close.

Codes for 11) Closeness:
1 - very close
2 - quite
3 - not very close.

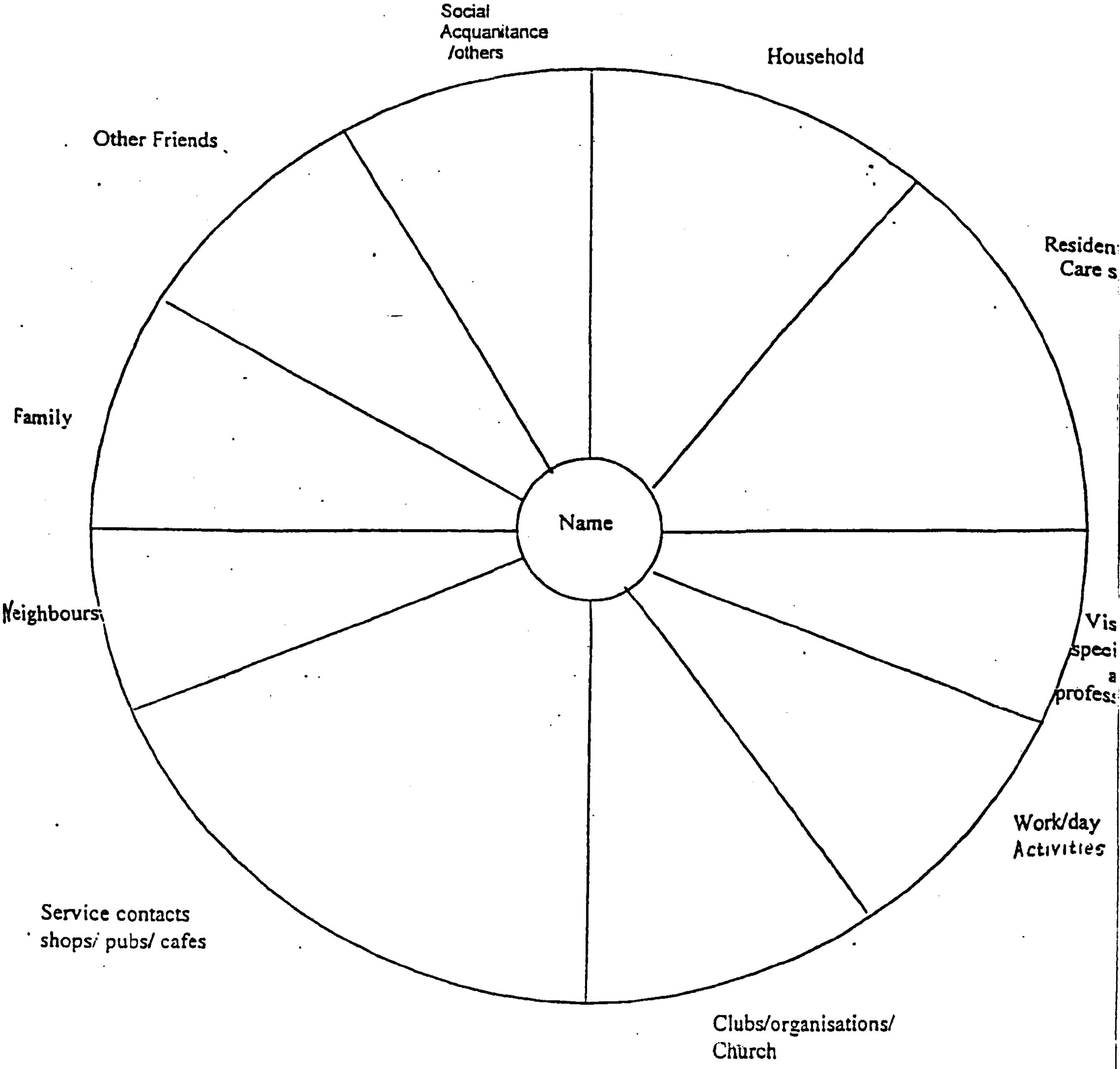
FOR REMAINING QUESTIONS PLEASE REFER TO THE "SOCIAL NETWORK GUIDE - SPECIAL RELATIONSHIPS" FORM IN INTERVIEW PACK.

Density
12) Can you tell me who knows whom? By that I mean that they talk to each other (e.g. does Jim know Paul?) (Staff member will be able to help, likely that clusters of people, e.g. household and staff, will all know each other). To save time, interviewer might be able to place Grid next to Matrix and go through asking "who knows who" without writing names on matrix, but by corresponding numbers.

Social Network Map

Date
Respondent
Interviewer

User ☐
User & Staff ☐
Staff ☐



L5. **Social Network Grid** *Please see preceding instruction sheet. Use Rows 11-15 for any people who are important in the person's life but who was not included in the Social Network Map eg because they have had no recent contact with the person.*

Initials	**Does person have learning dis-ability?** 1. Yes 2. No	**Area of life** 1. Household ✓ 2. Other family ✓ 3. Work/Day Service ✓ 4. Organizations ✓ 5. Other friends ✓ 6. Neighbours ✓ 7. Formal Services ✓ 8. Other	**Concrete Support** 1. Hardly ever 2. Sometimes 3. Almost always	**Emotional Support** 1. Hardly ever 2. Sometimes 3. Almost always	**Information/ Advice** 1. Hardly ever 2. Sometimes 3. Almost always	**Critical** 1. Hardly ever 2. Sometimes 3. Almost always	**Direction of Help** 1. Goes both ways 2. You to them 3. Them to you	**Closeness** 1. Not very close 2. Quite close 3. Very close	**How often seen** 1. Few times year 2. Monthly 3. Weekly 4. Daily	**How long known** 1. Less than year 2. From 1-5 years 3. 5 years or more	
1											(43-52)
2											(53-62)
3											(63-72) LINE 11 | 1 | 0 | (93-94)
4											(1-10)
5											(11-20)
6											(21-30)
7											(31-40)
8											(41-50)
9											(51-60)
10											(61-70) LINE 12 | 1 | 1 | (93-94)
11											(1-10)
12											(11-20)
13											(21-30)
14											(31-40)
15											(41-50)

LTD.

How much contact has the person had with their family over the past
3 months?

☐☐

[illegible]mber of visits by family to (name's) home...

☐☐

Number of visits by the person to family home .... (53-54)

☐☐

Number of telephone calls (approximately)... (55-56)

☐☐

Number of letters received by the person.. (57-58)

Appendix 36
Sheltered Care Environment Scale

Sheltered Care Environment Scale
(Form R)

Address of Residence

....

....

....

How long have you lived or worked here (months)?

☐☐☐

Are you a member of staff or a resident?

....

If staff, please give position

....

There are 63 questions here. They are statements about the place in which you live or work. Based on your experiences here, please answer these questions yes or no. Ask yourself which answer is generally true.

Circle *yes (1)* if you think the statement is true or mostly true of this place

Circle *no (2)* if you think the statement is false or mostly false of this place
Please answer every question.

Thank you!

				Harc Use Only
				Setting ☐☐☐ (1-3)
1.	Do residents get a lot of individual attention?	Yes 1	No 2	(4)
2.	Do residents ever start arguments	Yes 1	No 2	(5)
3.	Do residents usually depend on the staff to set up activities for them?	Yes 1	No 2	(6)
4.	Are residents careful about what they say to each other?	Yes 1	No 2	(7)
5.	Do residents always know when the staff will be around?	Yes 1	No 2	(8)
6.	Is the staff strict about rules and regulations?	Yes 1	No 2	(9)
7.	Is the furniture here comfortable and homely?	Yes 1	No 2	(10)
8.	Do staff members spend a lot of time with residents?	Yes 1	No 2	(11)
9.	Is it unusual for residents to openly express their anger?	Yes 1	No 2	(12)
10.	Do residents usually wait for staff to suggest an idea or activity?	Yes 1	No 2	(13)
11.	Are personal problems openly talked about?	Yes 1	No 2	(14)
12.	Are activities for residents carefully planned?	Yes 1	No 2	(15)
13.	Are new and different ideas often tried out?	Yes 1	No 2	(16)
14.	Is it ever cold and drafty here?	Yes 1	No 2	(17)
15.	Do staff members sometimes talk down to residents?	Yes 1	No 2	(18)
16.	Do residents sometimes criticise or make fun of this place?	Yes 1	No 2	(19)
17.	Are residents taught how to deal with practical problems?	Yes 1	No 2	(20)
18.	Do residents tend to hide their feelings from one another?	Yes 1	No 2	(21)
19.	Do some residents look messy?	Yes 1	No 2	(22)
20.	If two residents fight with each other will they get into trouble?	Yes 1	No 2	(23)
21.	Can residents have privacy whenever they want?	Yes 1	No 2	(24)
22.	Are there a lot of social activities?	Yes 1	No 2	(25)
23.	Do residents usually keep their disagreements to themselves?	Yes 1	No 2	(26)
24.	Are many new skills taught here?	Yes 1	No 2	(27)
25.	Do residents talk a lot about their fears?	Yes 1	No 2	(28)
26.	Do things always seem to be changing around here?	Yes 1	No 2	(29)
27.	Do staff allow the residents to break minor rules?	Yes 1	No 2	(30)
28.	Does this place seem crowded?	Yes 1	No 2	(31)
29.	Do a lot of residents just seem to be passing time here?	Yes 1	No 2	(32)

Appendix 37
Family Questionnaire

Family Questionnaire

Code

☐☐☐

Name of relative concerned

....

Name of family member completing questionnaire:

....

Address

Street: ....
Town: ....
County: ....

Contact telephone no if possible:

....

Relationship to relative concerned

....

Please note that all information you give is <u>strictly confidential</u>

This questionnaire should be returned using the Freepost envelope provided

Should you wish to ask any questions about filling in the questionnaire, please contact Karen Ahmed on 0771 4259788

Hester Adrian Research Centre
The University of Manchester
Oxford Road
Manchester
M13 9PL

1a. Where did your relative live before moving to their current service?

Type of residence (eg group home) ....

....

Town ....

1b. How long did they live there? ....

2. Would you say that the service they receive now is better or worse than the service they were receiving previously?

Much better Much Worse

1 2 3 4 5 6 7

3a. Did you encounter any specific opposition from anyone whilst trying to secure your relative's current placement?

Yes (please describe below) 1
No 2

3b. If yes, please describe who or what the problems were

....
....
....
....
....
....
....
....
....

4a. Whilst trying to secure your relative's current placement, did you receive any particular encouragement from anyone?

Yes 1
No 2

4b If yes, please describe who was supportive and in what ways:

....
....
....
....
....
....
....
....

Harc Use Only
LINE ONE

Code
☐☐☐ (1-3)
Setting
☐☐☐ (4-6)
Type prior res
☐☐ (7-8)
Miles from home
☐☐☐ (9-11)
Time in prior res
☐☐ (12-13)
Relationship
☐☐ (14-15)
(16)
(17)
☐☐ (18-19)
☐☐ (20-21)
☐☐ (22-23)
☐☐ (24-25)
(26)
☐☐ (27-28)
☐☐ (29-30)
☐☐ (31-32)
☐☐ (33-34)

5. Do you have contact with your relative as often as you would like?

Yes No

1 2 3 4 5 6 7 (35)

6. When you have contact with staff or volunteers at your relative's current service, do you find them helpful?

Very helpful Not at all helpful

1 2 3 4 5 6 7 (36)

7. How involved do you feel in decisions made about your relative in their current service?

Very involved Not at all involved

1 2 3 4 5 6 7 (37)

8. How happy do you think *your relative* is in their current service?

Very happy Not at all happy

1 2 3 4 5 6 7 (38)

9. Do you feel you are kept well informed of what is going on?

Very well informed Not informed at all

1 2 3 4 5 6 7 (39)

10. How happy do *you* feel with your relative's current service?

Very happy Not at all happy

1 2 3 4 5 6 7 (40)

11. <u>Please rate how true you feel the following statements are of your relative's current service</u>:

i. Residents have choice over day to day matters such as what they wear, what they eat, what they do with their money and so on.

Very true Not at all true

1 2 3 4 5 6 7 (41)

Appendix 38
Services provided and available to residents

Service & Activities	Is this service provided by the organisation?		Is this service available to residents although not provided by the organisation?	
	Yes	No	Yes	No
Sports centre		4	3	1
Hydrotherapy pool		4	2	1
Swimming pool		4	4	
Social club		4	1	3
Day centre	2	2	3	1
Place of worship		4	3	1
Education centre/classes	1	3	3	1
Special education classes	1	3	3	1
Adult education classes	4		3	1
Visiting teachers	2	2	1	3
Classes attached to hospital	4	0	1	3
Occupational therapy	1	3	2	
Physiotherapy	2	2	2	
Speech therapy	2	2	2	
Art/drama/music therapy	2	2	2	
Alternative therapist (eg. Reflexologist, chiropractor)	2	2	2	
Psychologist	4			
Psychiatrist	3	1	1	
Community learning disability team	2	2	2	
Social worker	3	1	1	
Support worker	4			
Doctor/consultant	3	1	1	
General practitioner	2	2	2	
Hearing specialist	1	2	2	

Service & Activities	Is this service provided by the organisation?		Is this service available to residents although not provided by the organisation?	
	Yes	No	Yes	No
Optician	1	3	3	
Chiropodist	2	2	2	
Dentist		4	4	
Learning disability nurse	2	2	2	
Community mental health Team	1	3	3	
Specialist challenging behaviour support	2	2	2	
Community nurse (eg. District nurse, health visitor)	1	3	3	
Advocate	2	2	2	
Volunteer/befriender				
Shop	1	3		
Hairdresser	1	3		
Car/minivan	2	2		
Snoozelum	1			
Counsellor	1			
Holidays off-campus	1	3		
Day trips/outings	3	1		
Workshop/ workscheme/industry		4	2	

Appendix 39
Quality of Life Domains Identifies by Managers

Indicator	Importance of indicator to quality of life				
	1 Very Important	**2**	**3**	**4**	**5 Not At All Important**
Choice over day-to-day matters	4				
Emotional support from others	3	1			
A range of regular scheduled activities	3	1			
Good relationships with family	2	1	1		
Respect from others	3	1			
Being happy and contented	3	1			
Having a job		1	2	1	
Being part of the local community	2		1	1	
Practical support	2	2			
Protection from exploitation and abuse	4				
Good long-term friendships		2	1	1	
Healthy and active lifestyle	1	1	1	1	
Using local community facilities	1	2		1	
Friendships with people without learning disabilities	1	2		1	
Privacy	4				
A clean and safe home environment	4				
Choice over where to live and who to live with	3		1		
Involvement in decisions about house standards and rules	4				
Pursuing interests and hobbies	2	2			
Learning new skills	2	2			

Having an intimate relationship		2	1	1	
Having responsibility	2	2			
Having religious needs met	4				
Good standard of material possessions	1	2	1		
Good income	1	2		1	

Table : Importance of quality of life domains

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