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Deinstitutionalisation and Community-based Care for Adults with Intellectual Disabilities in Hungary: Policy Change, Challenges and Outcomes

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A thesis submitted to University of Kent in fulfilment of requirement for the degree of Doctor of Philosophy

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To the memory of Professor Jim Mansell

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Abstract

This thesis explores the processes of policy change and outcomes of deinstitutionalisation and community living for adults with intellectual disabilities in the context of a post-communist country, Hungary. The dissertation begins by presenting the international perspective. Using multiple theoretical perspectives it investigates how policies changed and what forces drove the process of deinstitutionalisation in different countries. Some common themes and experiences such as scandals, ideologies, policy learning, and the influence of advocacy coalitions are identified. This is followed by a review of the evaluation literature on the individual outcomes of different residential arrangements for people with intellectual disabilities. The second part of the dissertation presents the policy and practice in residential care in Hungary. Various interpretations of recent policy developments are put forward based on theoretical models of policy change, and the critical analysis of a broad range of policies suggests that residential care policies are resistant to change because institutions are a functional part of the policy system. The third part of the thesis describes the results of a field study looking at the quality of different residential arrangements in Hungary for people with intellectual disability using a sample of 15 residential facilities and 120 service users. Data was analysed using statistical methods. Results showed that smaller scale arrangements provided better individual outcomes than institutions, particularly in three areas: material conditions and living standards; living environments; and staff support. However, there were also considerable variations within models and some larger settings provided comparable outcomes to smaller, community-based settings in some domains, such as community participation and choice.In international comparison the outcomes of community-based provision in Hungary were less favourable, particularly for people with more severe disabilities. The thesis concludes with the discussion of the findings and the consideration of implications for national and international policies. It is argued that effective deinstitutionalisation and community living policies should not be based on existing community care policies in Hungary otherwise they risk replacing one set of institutions with another set of smaller scale institutions in the community. Successful policies will also need to address the underlying factors such as discrimination, poverty and the long-term outcomes of the child protection system. A stronger international commitment and surveillance of deinstitutionalisation is also necessary.

Part 1
International Perspective

Chapter 1 Introduction

Deinstitutionalisation, the replacement of large institutions by locally organised small-scale residential services, and more recently by individual residential support for people with intellectual disabilities has been one of the most important paradigm-shifts in adult social services in the past 30 years (Bigby & Fyffe, 2006). It has progressed most in the UK, North-America, Australasia and Scandinavia (Mansell, 2006).

To understand and explain the trends that characterised deinstitutionalisation, it is useful to take a brief look back at the situation in the 1960-70s, which was the "golden age" of total institutions (Tøssebro, 1996). In the United Kingdom the number of places in institutions was steadily rising in the post-war years and reached its peak in the late 1960s with 60-65,000 in a variety of hospital and other residential settings. According to the Government document *Valuing People*, there were 58,850 patients in National Health Service long-stay hospitals and 4,900 people in other residential settings in 1969. The number of people with intellectual disabilities living in long-stay hospitals, psychiatric and special security units in 1970 was estimate at 64,173 in England and Wales, out of which approximately 7,328 were children aged under 16 years (Braddock, Emerson, Felce & Stancliffe, 2001). In Northern Ireland there were over 1,800 people with intellectual disabilities residing in long-stay hospitals in 1962which corresponds to a rate of 1.26 per 1,000 total population (McConkey, 2006).[1] In Scotland the population of intellectual disability hospitals was around 7,000 in 1965, a rate of 1.35 residents per 1,000 total population (Whoriskey, 2003).[2]

In the United States the population of state institutions increased rapidly after the Second World War and reached its highest level in 1967 with 228,500 people with intellectual disabilities accommodated in large institutions for people with intellectual and developmental disabilities or mental illness (Anderson, Lakin, Mangan, & Prouty, 1998; Lakin, Prouty, Polister, & Coucouvanis, 2003a, pp., p. 206). The number of institutions peaked in 1978 with 257 institutions (Braddock & Heller, 1985). Sixty per cent of people accommodated in residential facilities lived in institutions with 1,000+ places (Braddock, 1977) .

Institutional provision for people with intellectual disabilities evolved along similar patterns in Canada, Australia and New Zealand,

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[1] The population of Northern Ireland was 1.42 million according to the 1961 Census. Retrieved from http://www.nisra.gov.uk/archive/demography/publications/annual_reports/historical/1961.pdf (last accessed: 02/01/2012).

[2] The population of Scotland was 5.18 million according to the 1961 Census. Retrieved from: http://www.gro-scotland.gov.uk/files/04table2.5.gif (last accessed: 02/01/2012).

however institutionalisation levels did not reach those in the US or UK. The province of Ontario in Canada opened its first facility in 1867. Its development is illustrative of the general trends: originally designed for 150 residents, in a few decades it reached 1,000 and grew to 2,800 by 1961. Between 1950 and 1970 many new facilities opened across the country. At the height of the institutional era, there were 41 institutions in Canada accommodating over 19 thousand people with intellectual disability – approximately 0.88 residents with intellectual disability per 1,000 total population.[3]) Nearly half of the institutions and more than third of the residents were concentrated in Ontario (Radford & Park, 2003).

On different ideological and socio-economic grounds, the Nordic countries also developed high levels of institutional provision during the expansion of the Scandinavian welfare state between the late 1940s and 1960s. While in Sweden and Denmark this period was more the consolidation of an already existing service system, with a moderate growth in the number of beds, Norway was characterised by a sharp increase in the number of places. There were differences in the patterns of provision: Denmark and later Finland relied on a few large institutions – comparable in size to those found in the USA; Sweden and later Norway developed a more mixed pattern with many smaller facilities. Institutionalisation rates peaked in 1970 with 1.8-1.7 per 1,000 total population in Denmark and Sweden – approximately 9,000-13,600 places respectively (Tøssebro, 1996).

From the 1960s onwards the institutional population started to decline in most countries, first as a result of declining admissions, later due to deinstitutionalisation policies, particularly closures and reprovision/development of services in the community. Two main trends characterised deinstitutionalisation: on the one hand a move from large to small-scale provision, including the closure of large institutions, the decreasing size of community settings and an increase in the number of people supported in their own homes, on the other hand a shift from state provision to more mixed provision, predominantly by private and voluntary organisations (Lakin & Stancliffe, 2007). In some countries, particularly the USA and the Scandinavian countries, there was also a significant expansion of residential services for people with disabilities. Elsewhere provision levels changed little.

Alternative residential services to institutions became more widespread from the the 1970s onwards. In the United Kingdom hostels and large group homes accommodated up to 40 people in the 1970s. Between 1980 and 1992 hospital population nearly halved in England

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[3] The population of Canada was 21.57 million in 1971. Retrieved from: http://www40.statcan.ca (last accessed: 02/01/2012).

and Wales which meant the relocation of some 30,000 people to community-based settings. The mean size of these homes was 11 in 1992. At that time however, more than one third of the institutional population still lived in facilities with 100+ places. Regional variations were also considerable: in Scotland over 57% of people in residential care lived in the 13 facilities with 100+ places and only 31.4% in settings with less than 30 places. In Wales the same figures were 41.8% and 51.4% respectively (Felce, 1996).

The mean size of staffed residential homes in England was 6.3 in 1999 and 45% of the homes were for three or fewer residents (Braddock et al., 2001; Emerson & Hatton, 1998). In Wales the mean size of residential homes was four in local authority and 2.8 in independent sector provision in 1995 (Perry, Beyer, Felce, &Todd, 1998). In Scotland care homes accommodated on average 7.3 residents in 2001; 8.1 in local authority care homes, 9.5 in private homes and 6.7 in the voluntary sector ("Scottish Community Care Statistics", 2001). Currently the most common form of provision is small staffed homes with two to four residents. Supported living arrangements are also increasingly available; among those receiving residential supports approximately half of people with mild intellectual disabilities and one in four of those with moderate intellectual disabilities used supported living services in 2006 (Emerson & Hatton, 2008).

In Northern Ireland 30.1% places were in facilities with six or less places and over 40% in facilities for 16 or more persons (McConkey, 2006). These were predominantly nursing homes or residential care homes where the average number of places was 19 in 2003 (McConkey, 2006; Mulvany, Barron, & McConkey, 2007). In the Republic of Ireland the most common form of accommodation was large residential centres, with a mean size of 41 places (Mulvany, Barron, & McConkey, 2007).

In the United States first admissions to institutions started to decline in 1965, but the depopulation of large institutions started later, in 1968 with a sharp and steady drop. By 1982 the share of people in institutions with 300 or more residents fell to 44% of the total institutional population with intellectual or developmental disabilities. By 2001 this dropped below one percent however this still meant that 27,000 people were living in institutions with 300+ places. The number of residents in facilities for 16 or more people – a more recent US definition of institutions – or nursing facilities has dropped by 55% between 1982 and 2005 (Lakin, Prouty, Polister & Coucouvanis, 2003b; Prouty, Smith & Lakin, 2006). The population of state institutions continued to decline after 2003 (Prouty, Coucouvanis, & Lakin, 2007).

The percentage of people supported in small-scale settings defined as 15 residents or less increased substantially and stood at 26% in 1982 and 83% in 2005 (Prouty et al., 2006). At the same time the number of people living in settings with three or less places increased more than ten-fold and in 2005 they made up over half of people receiving residential services. The number of people supported in their own homes more than doubled between 1995 and 2005 and came to represent nearly one fourth of all residential support recipients (Lakin & Stancliffe, 2007).

Deinstitutionalisation inCanada started in the early 1970s, however traditional and new approaches still co-exist with a sizeable and even expanding institutional provision in some provinces (Crawford, 2005a; Pedlar, Hutchison, Arai, & Dunn, 2000). Although the number of people in 100+ institutions more than halved after 1986, approximately one third of residential service users lived in these facilities in 2002. The number and share of facilities with 50-99 beds also increased between 1986 and 2002, providing for 15% of service users by the end of the period (Crawford, 2005a). Based on a survey of service providers Pedlar et al. (2000) reported that there were 23,855 persons in the residential care system in 1999: 44% in group homes, 33.6% in supported apartments, and the rest in a variety of settings including foster placements.

In Australia deinstitutionalisation started in the 1980s and by 2004 71% of users of accommodation support services lived in a private residence or a domestic scale service, while 26% were in supported accommodation facilities usually with more than seven places (NDA, 2006).

In the Nordic countries there were improvements in institutional living conditions that were accompanied by a decline in the size of facilities from the 1960s onwards (Tøssebro, 1996). In Sweden the number of people in institutions halved between 1980 and 1989, and then halved again by 1993. In Denmark their number dropped by 75% between 1980 and 1991 while in Finland the number of institutionalised persons fell by 45% from 1983 to 1995. Norway started to close its institutions for people with intellectual disabilities in 1985 and completed the process in ten years (Tøssebro, 2003; Tøssebro, Aalto, & Brusén, 1996).

Deinstitutionalisation was not simply the closure of institutions, in fact closures had a relatively minor share in the process while declining admissions and the provision of alternative community-based facilities accounted for most part of the depopulation of institutions (Bigby & Fyffe, 2006; Proutyet al., 2006). Some even suggest that the closure of institutions was driven by competing demands and may be incompatible with effective deinstitutionalisation (Bigby & Fyffe, 2006). Nevertheless, closures were a key and highly symbolic part of the process featuring high on governments' policy agendas. It appears that closures took momentum at the later stages of deinstitutionalisation from the 1980s onwards, when the depopulation of institutions and the availability of alternative services reached a critical level. Then it slowed down again when only a small number of institutions were left. So far Sweden, Norway, New Zealand and England closed all of their large institutions by 2010, other countries still rely on institutional provision to a differing extent (MacArthur, 2003; Tøssebro, 2006).

Braddock and Heller (1985) dated the first closure in the USA to 1970 and noted that the early closures affected "surplus" facilities built for other purposes (such as TB hospitals etc.) and also involved extensive "trans-institutionalisation" of residents. The pace of community-based reprovision gained speed from the late 1980s: more than half of the institutions were closed and others substantially reduced in size by 2006 (Prouty et al., 2006). There were large variations between states: while most states closed one or more facilities, some states did not close any institutions between 1960 and 2005 and had no plans to do so (Prouty et al., 2006, p. 20).

In the United Kingdom the first closures took place in England in the late 1980s: the Starcross Hospital in Exeter closed in 1987, followed by Darenth Park Hospital in London one year later (Korman & Glennerster, 1989). When the *Valuing People* White Paper was published in 2001 there were nearly 4,300 beds in long-stay NHS intellectual disability hospitals and there were still 1,355 beds left in 2007-08 (Kozma, 2009). In Wales the *All Wales Strategy* between 1983-93 and later the government programme *Fulfilling the Promises* included substantial capital investment in hospital resettlement (Felce, 2004). In Scotland progress with hospital closures was initially slower: by 1999 only one long-stay hospital was reprovisioned (Whoriskey, 2003). The Government's review of services for people with intellectual disabilities *The Same As You?'* (2000) envisaged the closure of all long-stay hospitals by 2005, however only 11 out of the 19 long-stay hospitals were closed by the deadline. The remaining hospitals were scheduled to close by the end of 2007[4] ("National Overview – Learning Disability Services," 2006).

In Northern Ireland hospital resettlement has been an official policy objective since the mid-1990s. The three large long-stay hospitals had a population of 440 residents which represented 18% of total residential service recipients and 5.3% of all adults with an intellectual disability in 2002 (McConkey et al., 2006). There were several government plans to resettle these service users in the community, however it has not happened yet. The *Bamford Action Plan*in 2009 extended the deadline to 2013.

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[4] Retrieved from: http://www.nhshealthquality.org/nhsqis/2957.html (last accessed: 02/01/2012)

In Canada the first closures occurred in the 1980s (Brown & Percy, 2003; Lord & Hearn, 1987). Some provinces and territories closed all their institutions, for example Ontario planned to close its remaining three large institutions with approximately 1,000 residents by 2009. At the same time other provinces still retain institutional provision and have no plans for closure. In 2006 there were 28 large institutions across Canada with a total population of around 2,700 persons ("Institution Watch", 2006). There were closures and redevelopments of institutions from the 1970s onwards in Australia as well, but institutional provision still exists in some states (NDA). In New Zealand the last institutions, Braemar Hospital and Kimberley Centre, were closed in 2006.

Norway and Sweden also closed all their institutions by 2000 after a series of gradual improvements and reprovisions in increasingly smaller settings, while Denmark and Finland retained some institutional provision (Tøssebro, 2003; Tøssebro et al., 1996).

While the institutional era was characterised by the monopoly of state services, deinstitutionalisation devolved responsibility for residential support to lower tiers of government, closer to the "community". There were also important changes in the financing of services, including the strengthening of market mechanisms in the provision of care. In some countries, particularly those representing the liberal welfare model, there was a separation of the roles of the purchaser and the provider of services leading to an increased involvement of the independent – voluntary and private – sector and mixed patterns of provision (Esping-Andersen, 1996).

In the UK and Ireland there was a move away from National Health Service (NHS) hospital provision to predominantly independent sector provision purchased by local authorities with social services responsibilities. In England there was a sharp and steady decline in the share of NHS long-stay places within total residential provision after 1976 (Emerson, 2004; Emerson & Hatton, 1998). In 2008 11% of NHS trusts had a total of 1,355 long-stay hospital beds for adults with intellectual disabilities, which represented less than three per cent of total residential provision (Kozma, 2008, 2009). The Government document *Valuing People Now: From Progress to Transformation* proposed the complete transfer of responsibility for commissioning social care for adults with learning disabilities from the health service to local authorities (Kozma, 2009). Parallel to the decline of long-stay hospitals, local authority provision increased by 84% between 1976 and 1989, but fell considerably after 1990 as local authorities increasingly commissioned residential services from the independent sector (Emerson, 2004). In 2006 only nine per cent of council supported residents actually lived in council staffed homes, the majority lived in homes provided by the independent sector and commissioned by local authorities (DH, 2007).

Trends were similar in Scotland and Wales, while Northern Ireland was different. McConkey (2006) reported relatively high levels of statutory and private provision, 21.3% and 46.7% respectively in 2003. In the Republic of Ireland most residential services were managed by voluntary providers (Mulvany et al., 2007).

In the United States there was a shift from state provision to mixed, predominantly private provision. States became purchasers instead of providers of residential services. In 1967 11%, in 1982 49% and in 2005 87% of people receiving residential services for persons with intellectual disabilities were served by non-state, private organisations. Non-state settings represented 98% of the total number of settings in 2005 (Prouty et al., 2006). Similar trends were reported in Canada and Australia where the gradual withdrawal of the federal government from social care left territorial governments with reduced resources and also resulting in the privatisation of residential services for people with intellectual disabilities (Bigby & Fyffe, 2006; Pedlar & Hutchinson, 2000).

In Scandinavia deinstitutionalisation meant the decentralisation or the devolution of responsibility for disability services from county to local levels in the late 1980s and early 1990s (Ericsson, 2004; Tøssebro, 2003) Provision remains predominantly public by statutory providers, with some involvement of large, long-established voluntary agencies in Norway, Denmark and Finland (Tøssebroet al., 1996).

Despite far-reaching changes in some countries, institutions are still the dominant form of service provision in many countries. In Europe approximately 1.2 million people live in residential settings for people with disabilities across Europe, many of them in large institutional facilities. (Mansell, Knapp, Beadle-Brown, & Beecham, 2007).Central and Eastern European countries have been known to provide poor quality care in institutions (Freyhoff, Parker, Coue, & Greig 2004).In 2007 the United Nations Convention on the Rights of Persons with Disabilities made the unjustified segregation of people with disabilities in congregate settings a violation of human rights and called on states to take "effective and appropriate measures" to facilitate full enjoyment of this right, the full inclusion and participation of people with disabilities in the community (ECCL, 2010). Nevertheless very limited progress has been made in the transition from institutions to community-based care (Vann & Siska, 2006, ECCL, 2010).

Most previous research in deinstitutionalisation and community-based care concentrated on English-speaking countries of the Western World. It was also shown that policy change and implementation are complex processes and depend on local circumstances and conditions

(Mansell & Ericsson 1996, Bigby & Fyffe 2006). There is limited information on residential care policies, policy change, structural characteristics of services (Freyhoff, et al. 2004) and service user outcomes in other parts of the world. It is not well understood why despite international attention and support the deinstitutionalisation and community living policies seem to be weak in Central and Eastern Europe. Therefore the purpose of this dissertation is to explore policy change, challenges and outcomes of deinstitutionalisation and community-based care using Hungary, a country in Central Europe as a case study.

The dissertation has three parts. Part 1 presents the international perspective and the research question: Chapter 2 considers deinstitutionalisation from multiple theoretical perspectives and investigates how policies changed and what forces drove the process of deinstitutionalisation in different countries. It draws out some common themes and experiences such as scandals, public support for deinstitutionalisation policies, ideologies, policy learning, and the influence of advocacy coalitions.Chapter 3 looks at the impact of the transition from institutions to community-based settings on the lives of people with intellectual disabilities using these services. The review finds similar experiences in different countries in that small-scale community-based arrangements provide better quality of life outcomes than larger, congregate options in most domains. Nevertheless there is considerable variability in individual outcomes and there are three areas where community-based services do not perform better. Chapter 4 sets out the rationale, the research questions and methods of the dissertation.

Part 2 presents the policy and practice in Hungary and it comprises of three chapters. Chapter 5 offers some background information on the definition, diagnosis and prevalence of intellectual disability, as well as a review of previous research in residential care in Hungary. Chapter 6 describes the development of residential care policies from the late nineteenth century in Hungary and offers three interpretations of recent policy developments based on theoretical models of policy change. It finds that some of the factors and conditions that played a role in driving policy change in countries where deinstitutionalisation is well advanced are different or absent in Hungary. Chapter 7 analyses a broad range of policies from education to employment from a critical perspective and it argues that residential care policies are resistant to change because institutions are a functional part of a broader system that marginalises certain groups.

Part 3 also has three chapters and it describes the results of a field study looking at the quality of residential care for people with intellectual disability. Chapter 8 gives an overview of the methods and summarises the experiences of the implementation of the field work.

Chapter 9 reviews the policy environment of residential provision focusing on physical standards, staffing and funding of services. It considers how certain provisions, implicitly or explicitly, favour large settings over small-scale community-based arrangementsexplores the physical environment and living conditions in residential settings, the characteristics of residents and staff, and the services provided to users. It also compares services in terms of management and care practices, including the management of challenging behaviour, psychotropic medication and user involvement. Chapter 10 offers a more detailed comparison of service users as well as an evaluation of individual outcomes in the different settings. The final chapter 11discusses the main findings considers some of the policy implications of the results.

Chapter 2 Deinstitutionalisation and Community Living: the Policy Perspective

Chapter 1 presented the development of deinstitutionalisation and community-based care from a population level perspective. In less than fourty years the provision of residential services for people with intellectual disability completely transformed in English-speaking Western countries and Scandinavia. There was a move away from state provision in large congregate settings to small scale community-based care. Deinstitutionalisation is a highly complex process of policy change (Mansell, 1996) and it can be described as a paradigm shift (Bigby and Fyffe, 2006) or a 'third order change' (Hall, 1993) that goes beyond "normal policymaking" and represents a radical departure from previous objectives, values and practices.

This chapter looks at the policy process of deinstitutionalisation from three perspectives based on different theoretical frameworks of policy change. It aims to explain deinstitutionalisation by identifying the processes and factors that were driving change in the provision of residential services to adults with intellectual disabilities in different countries in the past 40 years. The same theoretical frameworks will be used to explore policy change and stability in the Hungarian case study in Chapter 6. This chapter is not a case study of policy change or a comparative policy analysis, nor does it address implementation (for reflections on implementation see for example Mansell, 2005; Bigby 2006; Mansell, 2006).

2.1 Theoretical frameworks of policy change

Until the 1980s the dominant approach to policy analysis was the stages approach or process model that conceptualised policy-making as a sequence of distinct stages that follow each other in a given order. The stages were aggregated into different categories; for example Rose (1973) in his dynamic process-model of policy analysis suggested 10 steps or stages:

1. The initial state or the analysis of the situation before the policy.
2. Turning issues into subjects of policy-making; how issues are put on the policy agenda.
3. Advancement of demands or resistance to others' demands, taking into account the variety of stakeholders in the policy process.
4. The characteristics of governmental, political and administrative structures (i.e. whether it is a centralised or a federal state, the different tiers of governments and responsibilities etc.).

5. Exploring resources and constraints; the formulation of policy alternatives is influenced by the (perceived) availability of resources and constraints.
6. Moving from no-decision to decision; issues can be on the policy agenda and debated for long periods without actual decisions. According to Rose governments take decisions for three main reasons: there is an established routine; there is a crisis; or there is no crisis, nor routine but other reason.
7. The determinants and content of governmental choice; a decision is simply an initial statement of intention which is translated into actual policies by subsequent choices.
8. Implementing policies; how policies are put into practice by different levels of governments and organisations.
9. Outputs; what policies achieve and how outputs are defined.
10. The evaluation of impact and feedback.

The stages approach dominated the research agenda until the early 1980s and created a wealth of literature focusing on different stages of the policy process (for example Pressman and Wildawsky's (1973) seminal work on implementation, or Lipsky's (1980) work on street-level bureaucracy). From the late 1980s the stages approach came under increasing criticism, first by Nakamura who claimed that it could not be used as a paradigm (DeLeon 1999), then by Jenkins-Smith and Sabatier (1994) who pointed out four limitations of the stages approach. First, they argued that the model lacked an identifiable causal force that moves the process from one stage to the next. Second, the sequences are often descriptively inaccurate and the stages do not follow in the order suggested by the model. Third, the model has a legalistic, top-down focus and fails to capture the complexity of the actors and processes involved in the policy process. Finally, they argued that the approach is not suitable for empirical hypothesis-testing across stages or within multiple stages.

The first three of these criticisms seem particularly relevant when trying to explain deinstitutionalisation. Chapter 1 has already revealed the complexity of the policy process. Mansell and Ericsson (1996) highlighted the diversity of factors involved in driving the move away from institutions, including ideology (normalisation), changes in the perception of institutions, pressure groups, the availability of mature models and financial pressures. The process was also embedded in the broader context of welfare state restructuring (Bigby and Fyffe, 2006). The stages model fails to explain the diverse set of factors in a coherent model of policy change.

The late 1980s and 1990s saw a drive towards more comprehensive frameworks of the policy process drawing on a variety of disciplines including sociology and social psychology. Three of the newly developed theoretical frameworks seem particularly suitable to explain complex processes of policy change: the model of punctuated equilibrium (Baumgartner & Jones, 1991; True, Jones, & Baumgartner, 2007) that sets out to explain why long periods of policy stability are interrupted by short but intense periods of policy change; the Advocacy Coalition Framework developed by Sabatier (1988) which puts values and policy orientated learning at the centre of the process; and John Kingdon's Multiple Streams framework (Kingdon, 1995) that highlights the idiosyncratic nature of agenda setting. In addition to these frameworks, the theory of policy transfer (Dolowitz & Marsh 2000) is also presented here to aid the analysis of policy change. These approaches offer complementary insights into the policy process highlighting different aspects of the process of agenda setting and policy change. Furthermore they are able to encompass the complexity of actors and levels in the policy process, and they have been successfully used in different political and administrative arrangements (Meijerink 2005; Sabatier 2007: pp 8-10).

Other theoretical frameworks include Ostrom's institutional rational choice (2007), the network model of policy analysis (Marsh & Smith 2000; Adam & Kriesi 2007), institutionalist approaches that postulate that the behaviour of actors is determined by administrative and organisational structures, and 'psychiatric determinism' (Prior 1993). Prior suggested that changes in the social construction – structure and representation - of 'mental disability' were the main driving force behind the transition from institutions to community living rather than external forces, such as financial pressures etc. These approaches focus on a single set of factors and are less suitable to capture the complexity of the process.

The next sections present a brief overview of the main propositions of the three theoretical frameworks and offer an interpretation of deinstitutionalisation based. Using multiple approaches has several advantages: different frameworks work better in different contexts and provide a more complete explanation of policy change by highlighting different aspects of the process (Cairney 2007; p 330).

2.2 *Punctuated Equilibrium: the erosion of institutions*

The model of punctuated equilibrium was developed by Baumgartner and Jones in the 1990s. This approach has been widely used by policy analysts in the US and Europe (True et al. 2007). The framework aims to explain why long periods of policy stability are interrupted by short but intense periods – 'bursts' – of policy change. The argument responds to proponents of incrementalism who see policy change as a marginal adjustment from previous policy.

The framework combines institutional and individual perspectives; structures within which policies are made and the strategies of participants in the policy process. The main source of policy change is thought to be "the interaction of beliefs and values concerning a particular policy, which we term the policy image, with the existing set of political institutions – the venues of policy action" (Jones & Baumgartner 1991, p. 1045). Actors involved in policy-making follow a dual strategy: they aim to manipulate the prevailing policy image through the use of information, rhetoric and symbols and they try to find the most favourable policy venue for their issues.

Policy monopolies are policies dominated by a single image and characterised by stable institutional arrangements (True et al. 2007, p. 159). When there is a disagreement in the perception of the policy it opens up the way for policy change. New policy subsystems may be created "during periods when public understandings of the questions involved is overwhelmingly positive" because specialists can demand autonomy and resources from decision makers (Jones & Baumgartner 1991, p. 1047).

The policy venue and the policy image are strongly linked. It is argued that "[e]ach venue carries with it a decisional bias, because both participants and decision making routines differ" (ibid.). When the policy venue changes, those who previously dominated the policy process may become marginalised and those previously in the minority may find themselves in a dominant position. Thus changes in one aspect can trigger changes in the other. Venue change can also lead to 'subsystem collapse' which is the significant alteration of policy outcomes of an established subsystem by the intrusion of ideas not generally supportive of the prevailing arrangements in the policy process.

The main strategy to gain agenda entrance followed by participants in the minority position is 'conflict expansion', which refers to the efforts of those in the 'losing position' to change the situation by broadening the range of participants and appealing to potential participants not involved in the policy debate. There are three main ways of expanding conflict: the first is termed "the classic loser appeal strategy" by which the minority coalition aims to mobilise new supporters. The second is "action by concerned outsiders, who may or may not be allied with losers in a policy subsystem" and the third is an attempt by decision makers to expand their policy jurisdiction by attacking existing arrangements (p. 1048).

Attention driven choice and disproportionate information processing of decision makers is central to the punctuated equilibrium framework. While information is abundant, attention is limited therefore only some problems make it to the top of the policy agenda and others are ignored. The definition of a policy problem is central in this framework because it determines the level of attention and the nature of the policy response (Cairney 2007).

The punctuated equilibrium framework would explain deinstitutionalisation in terms of changes in the perception of institutions, that were increasingly unacceptable by professionals, parents and the public, together with a shift in the venue of policy action from the state to local levels as shown in Chapter 1. After their 'golden age' in the 1950-60s the monopoly of institutions started to erode in the early 1970s (Tøssebro 2006, Trent 2006). A series of scandals erupted in institutions everywhere. In the words of Butler and Drakeford (2005, p. 5) scandals "are powerful signals that change is occurring, or that the pressure for change has reached unsustainable levels". These scandals revealed the conditions of life in institutions: poor physical conditions, inhumane treatment, neglect and abuse. The visual imagery of the reports resonated with the horrors of the Second World War and parallels were drawn between conditions in institutions and concentration camps. Articles in the popular press (e.g. Blatt and Kaplan 1966) and academic research revealed the detrimental effects of institutionalisation (e.g. Goffman 1961; Edgerton 1967), started to alter the perception of people with intellectual disabilities (for example Tizard's Brookland Experiment) and moved away from the legacy of eugenic ideas (Welshman 2006). Early research on institutional neurosis (Barton 1959) demonstrated that the assumption of psychiatric determinism – behaviour is the product of people's psychiatric state – was false. By the beginning of the deinstutionalisation process it was accepted that behaviour is the product of social forces not just individual characteristics.

Scandals attracted the attention of governments that responded by conducting official investigations that gave real significance to these events (Butler and Drakeford 2005). In Ontario, Canada the Williston Report recommended the closure of institutions in 1971 (Radford & Park 2003). The high-profile scandal in Willowbrook State School in 1972 shaped residential policies for the decades to come in the state of New York (Castellani, 2005; Rothman & Rothman 2005). The first landmark scandal in the UK was that of Ely Hospital in Wales in 1968, which was followed by a number of other cases: the Farleigh Hospital, South Ockendon and Normansfield (Butler & Drakeford 2005). Hospital scandals led to the publication of the White Paper Better Services for the Mentally Handicapped (1971) by the Conservative Government. Scandals also helped the advocates of deinstitutionalisation to expand the conflict and involve potential new participants, mobilise supporters. For example in Scandinavia the media extensively reported on institutional scandals, in Norway an ad hoc action group with celebrities among its members spoke out against poor conditions in institutions (Tøssebro 2006, p. 126).

The most significant impact of scandals were the impetus they provided towards shifting the policy venue from institutions to care in the community (Butler & Drakeford, 2005, p. 133). In England the White Paperenvisaged the expansion of residential social services provided by local authorities from 4,300 to 29,300 places and the reduction of long-stay hospital beds provided by the National Health Service from 52,100 to 27,000 within 20 years (Stevens 2004). The White Paper marked "a decisive switch from care out of the community to care in the community" (Bayley, 1973, p 9 cited in Butler & Drakeford 2005, p 134). Actual progress to implement these targets however was modest. Felce et al. (1998) described this as follows:

> Policy throughout the 1970s and early 1980s may have had a direction set by the principles of *Better Services*, but lacked the organizational and funding mechanisms which were required to engender significant reform. . . . Central government exhorted but did not require action. It devolved responsibility and avoided the wholesale financial implications of a centrally promoted initiative, opting instead to back a number of pilot schemes. (p. 26)

In the US deinstitutionalisation of intellectual disability institutions was debated as early as 1962, when President Kennedy's Committee on Mental Retardation put forward the need for a shift to decentralised community services. The idea of community services was also endorsed by President Nixon who in his statement in 1971 proposed that by 1981 "one-third of the more than 200,000 retarded persons in public institutions" should be enabled "to return to useful lives in the community" (Braddock 1977 p. 11; Ericsson & Mansell 1996). Braddock (1977) points out, the federal government did not formulate a unified policy, even though "policy outputs have explicitly suggested increasing concern with deinstitutionalisation" (p. 8). He highlights the importance of moral support and argues that "the rhetoric, at least, was something to latch on to. This was the genesis of the presidential mandate to deinstitutionalise" (p. 12) and it also signalled a shift in the policy venue, the move away from centralised state provision to community-based care.

The Welsh Office launched the *All-Wales Strategy for the Development of Services for Mentally Handicapped People* (AWS) in 1983 (Perry et al., 1998) which was applauded by the advocates of deinstitutionalisation as a well-formulated and radical policy (Felce et al.,1998, p. 23). The AWS might be seen as a response to the accumulation of signals towards deinstitutionalisation: the hospital scandals, the outcomes of early demonstrations and pilot projects, and feedback from existing policies. It also represented a radical shift in the policy venue:

> The AWS both permitted and established a different path for service reform in Wales. Investment in the community to meet the needs of people living in the community was not only possible through the availability of new resources, but also made a policy priority. Local authority social services as the lead agency and by projecting revenue investment at such a rate that authorities needed to be well organized to respond to the proffered opportunity. The scale of the resources to be made available was more than enough to pump prime change to existing services; innovation and the development of previously unavailable services was also possible.(Felce et al., 1998, pp 27-28)

In Scandinavia the shift of the policy venue for disability services from the central state to local levels was an important element of the policy change and was seen as a pre-requisite for real community-based care. In Sweden the Act of 1993 devolved disability services from county to the municipal level. (Ericsson, 2004). In Norway this occurred in 1987-88 following the influential 1985 Public Committee Report on the situation and living conditions in institutions (Tøssebro, 2003).

In summary, the Punctuated Equilibrium framework explains the origins of deinstitutionalisation: changes in the values and beliefs about people with intellectual disabilities and institutions and the creation of community care, a new policy subsystem. The concept of venue shift is also helpful in explaining deinstitutionalisation as a move away from centralised and/or state provision to smaller scale local provision. However deinstitutionalisation was not a 'burst of policy change' (Cambridge & Ernst, 2006). The framework also fails to explain the incremental nature of the process, the slow progress in implementing community-based care in the 1970s (Bigby & Fyffe, 2006). The closure of institutions and the creation of community-based alternatives started to unfold from the late 1970s onwards, a period that also coincided with the 'crises' of the post-war welfare states (Pierson, 1998).

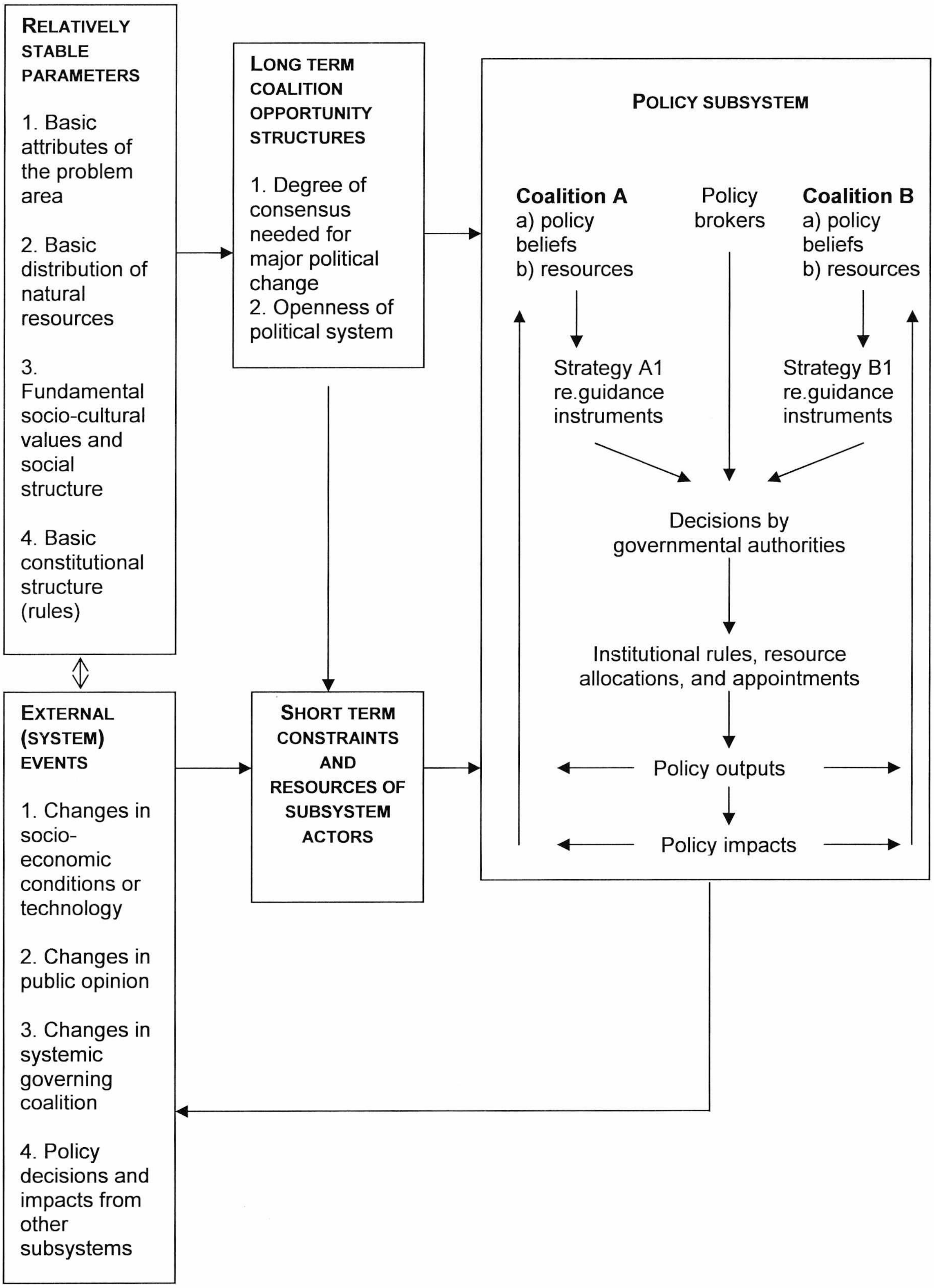
2.3 The Advocacy Coalition Framework: policy learning and welfare state restructuring

The Advocacy Coalition Framework (ACF) was first put forward by Sabatier in the 1980s and since then revised several times on the basis of research experience (Sabatier 1988; Sabatier 1998; Sabatier & Weible 2007; Weible, Sabatier,& McQueen, 2009). This approach puts policy coalitions, policy learning and external (system) events or shocks in the centre of policy change.

The framework is based on four premises: First, technical information – information regarding the extent and the aspects of the problem, its causes, possible solutions and their impact – is an important part of the policy model. Second, the process of policy change and the impact of policies can only be understood and assessed over a longer period of time. Thus the time perspective of the analysis should be at least a decade. Third, the most useful unit of analysis is the policy subsystem or domain. This consists of "actors from a variety of public and private organizations who are actively concerned with a policy problem or issue" and who regularly try to influence public policy in that area (Sabatier 1998, p. 99). Fourth, public policies can be conceptualised as belief systems. Public policies or programmes incorporate implicit theories about how to achieve their objectives. "They involve value priorities, perceptions of important causal relationships, perceptions of world states (including the magnitude of the problem), and perceptions/assumptions concerning the efficacy of various policy instruments" (Sabatier 1998, p. 99).

The model of ACF is presented in Figure 2.1 and Table 2.1 presents the revised hypotheses of the framework.

Figure 2.1 Diagram of the Advocacy Coalition Framework



Source: Sabatier et al. 2007, p. 202

Table 2.1 Revised hypotheses of the Advocacy Coalition Framework

Hypotheses concerning advocacy coalitions

1. On major controversies within a *mature* policy subsystem when policy core beliefs are in dispute, the line-up of allies and opponents tends to be stable over periods of a decade or so.

2. Actors within advocacy coalition will show substantial consensus on issues pertaining to the policy core, although less so on secondary aspects.

3. An actor (or coalition) will give up secondary aspect of his (its) belief system before acknowledging weaknesses in the policy core.

4. Elites of purposive groups are more constrained in their expression of belief and policy positions than elites from material groups.

5. Within a coalition, administrative agencies will usually advocate more moderate positions than their interest-group allies.

Hypotheses concerning policy change

6. The policy core attributes of a governmental programme in a specific jurisdiction will not be significantly revised as long as the subsystem advocacy collation that instituted the programme remains in power with that jurisdiction – except when the change is imposed by a hierarchically superior jurisdiction.

7. Significant perturbations external to the subsystem (e.g. changes in socio-economic conditions, public opinion, system-wide governing coalitions, or policy outputs from other subsystems) are a *necessary, but not sufficient,* cause of change in the *policy core* attributes of a governmental programme.

Hypotheses concerning policy learning, particularly *across* coalitions

8. Policy-oriented learning across belief systems is most likely when there is an intermediate level of informed conflict between the two coalitions. This requires that:

a) Each has the technical resources to engage in such a debate; and that

b) The conflict between secondary aspect of one belief system and core elements of the other or, alternatively, between important secondary aspects of the two belief systems.

9. Problems for which accepted quantitative data and theory exist are more conducive to policy-oriented learning across belief systems than those in which data and theory are generally qualitative, quite subjective, or altogether lacking.

10. Problems involving natural systems are more conducive to policy-oriented learning across belief systems than those involving purely social or political systems because in the former many of the critical variables are not themselves active strategists and because controlled experimentation is more feasible.

11. Policy-oriented learning across belief systems is most likely when there is a forum which is:
a) Prestigious enough to force professionals from different coalitions to participate; and
b) Dominated by professional norms.

12. Even when the accumulation of technical information does not change the views of the opposing coalition, it can have important impacts on policy – at least in the short run – by altering the views of policy brokers.

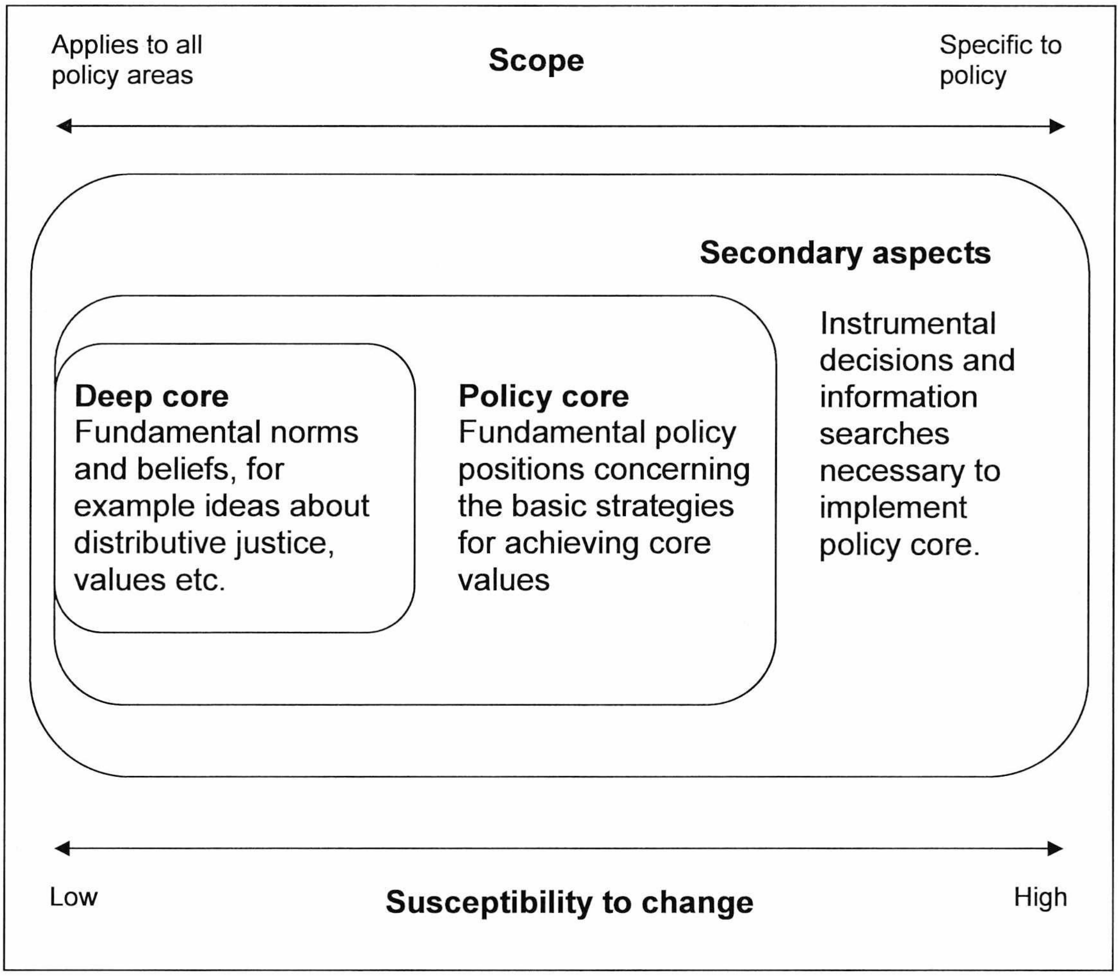
Note. Adapted from Sabatier, 1998, p. 106

The ACF distinguishes two sets of exogenous variables: relatively stable parameters and external (system) events. The stable parameters include the basic attributes of the policy area, constitutional structure, socio-cultural values and natural resources of a political system. They are rarely subject of coalition strategies because they are very difficult to change, however they clearly affect behaviour. The other set of external variables includes dynamic (system) events that are more likely to change. These are seen as "critical prerequisite to major policy change" (Sabatier, 1998, p. 103). They represent major socio-economic changes and changes in technology, e.g. rise of social movements; changes in public opinion; changes in the governing coalitions; and policy decisions and impacts from other subsystems.

The ACF model assumes that actors can be aggregated into one to four but most often two advocacy coalitions. Coalitions are distinguished by a shared set of normative and causal beliefs, i.e. belief systems and coordinated activity over time. Coalitions include interest group leaders, agency officials, policy-makers from various levels of government, scientists/researchers and often the representatives of the media.

Belief systems are organised into "a hierarchical, tripartite structure, with higher/broader levels constraining more specific beliefs" (Sabatier 1998, p. 103). *Deep core beliefs* include basic ontological and normative beliefs and values. These are very resistant to change and are rarely debated in the policy process. These are external to the policy subsystem (e.g. they are product of one's education etc.) however they serve as a foundation to form policy core beliefs. *Policy core beliefs* are the "glue" of coalitions and include general assumptions regarding the policy subsystem. These are somewhat more likely to change in the longer term, particularly in the light of new information and evidence. The secondary aspects of belief systems hold a large set of more specific assumptions and beliefs regarding the problem and its possible solutions. These are assumed to be readily altered in light of new evidence, experience, or even out of strategic considerations (See Figure 2.2).

Figure 2.2 The structure of belief systems



*Note.*Adapted from Parsons, 1995 (p. 197) and Sabatier 1991 (p. 145)

Coalitions adopt one or more strategies with the objective of influencing the behaviour of various governmental institutions. These involve the use of guidance instruments that include changes in legislation, budgets, personnel or information with a view to "altering the behaviour of various governmental institutions in an effort to realize its policy objectives" (Sabatier, 1998, p. 104). Coalitions possess a range of resources that include formal legal authority to make policy decision, public opinion, information, volunteers and activists, financial resources, and skilful leadership (Sabatier & Weible, 2007, p. 203).

Advocacy coalitions in the same policy subsystem normally have conflicting strategies that are moderated by policy brokers whose aim is to find a "reasonable compromise" (p. 104). If this is successful, the process results in a governmental decision and various policy outputs. The outputs then produce an impact on the targeted problem as well as they have a variety of side effects. On the basis of information arising from implementation, advocacy coalitions may revise their beliefs, particularly the secondary aspects, and strategies.

Residential provision for people with intellectual disabilities had been typically dominated by a single institutional coalition; however from the 1960s onwards coalitions for community-based services and deinstitutionalisation emerged and challenged the dominant approach. Two groups of actors – professionals and advocacy groups – were particularly important in promoting change. In the UK for example deinstitutionalisation was described as "a largely professionally- and managerially-led enterprise" (Mansell & Ericsson, 1996, p. 244). Staff and professionals in institutions on the other hand were interested in maintaining the status quo and opposed reforms. In the United States closures often met with the organised opposition of staff who were public employees and enjoyed higher payments and more extensive benefits than their colleagues in community-based services. Workers were rarely redeployed from institutions to the community in the USA. Elsewhere, for example in the UK and in Scandinavia, the transfer of staff was more common practice. Institutions often proposed themselves as "centres of expertise" or "resource centres" and claimed to 'normalise environments' to save their existence (Stainton 2006, p. 142).

Advocacy groups underwent major changes both in terms of their resources and strategies. Parents have been important players in deinstitutionalisation from the early phases in a number of ways. Self-advocacy groups of people with intellectual disability and their participation in policy formulation are more recent and less well explored. The US, the UK and Canada have large and influential parent associations. They are present in the policy arena in a dual role as users and providers of services. Castellani (2005) writes that "the postwar emergence of parent-advocacy organizations providing services began the fundamental duality of institutional versus community approaches" (p. 42). Initially these organisations demanded access to and the expansion of special education for children with intellectual disabilities, and achieved considerable success (Castellani, 2005; Stainton 2006). From the 1970s onwardsthey increasingly emerged as providers of community-based services, including day- and residential care.

Some authors highlighted the cleavages within the associations regarding deinstitutionalisation, particularly the closure of institutions (see e.g. Hayden, 1998; Castellani, 2005; Rothman & Rothman, 2005). While parent groups demanded better access to community-based services for their children, they saw the reprovision of institutions as an enterprise that took away much needed resources from the development of new capacities (Castellani 2005). Elsewhere, for example in the UK national parents' groups had a less prominent role in deinstitutionalisation that was led mainly by professionals and managers (Mansell & Ericsson 1996, p. 244).

Parental attitudes to deinstitutionalisation have received considerable attention in the literature. Heller, Bond, and Braddock (1988) surveyed changes in family attitudes during the closure of a US institution. Opposition to closure initially was high (81%) and strong among parents. Even though most of them agreed with the principles of normalisation, they wanted their relative to stay in the institution because they were concerned about the possible negative effects, especially the transfer trauma. However opposition quickly faded and at the second survey most parents expressed their satisfaction. Larson and Lakin (1991) reviewed studies on parental attitudes focussing on changes in attitudes associated with the relocation from institutions to community-based settings. They identified four main reasons for parental opposition:

- Institutions were seen by many parents as the right environment for their offspring, they were thought to provide safe environment and staff considered to have the necessary expertise;
- At the same time, available community alternatives were seen as undesirable, providing poor quality of care, unsafe and with high staff turnover.
- Often, the process of closure and relocation was seen as poorly designed and implemented.
- Finally there were concerns regarding the adverse impact on the relocation on the families themselves, such as the increased burden of care or financial involvement.

Larson and Lakin reported an overwhelming (90%) satisfaction with institutions while family members were living there. Over half of the relatives opposed relocation that later turned into strong support for community living. A discrepancy between pre- and post-move attitudes was highlighted: lower satisfaction with institutions and higher support for relocation was reported retrospectively. Similar findings were put forward by Tøssebro and Lundeby (2006) who investigated changes in family attitudes in a longitudinal survey between 1989/90 and 2004. Before the move 57% of the relatives expected community services to be worse than institutions and only 17% expected improvements. After relocation however, around three quarters of the relatives thought that their family members were better off and around 15% thought they were worse off in the community, and these views remained consistent between 1994 and 2001.

Self-advocacy groups are more recent than parent associations. The first groups were formed in Canada and in the US by people with intellectual disabilities living in institutions in the early 1970s (Miller & Keys 1996). The movement quickly spread to other continents and today they are found in most European countries. Self-advocacy organisations have increasingly been involved in policy and service planning issues, for example local Learning Disability Partnership Boards were introduced in England by the Valuing People White Paper in 2001; however a recent study found that public involvement in intellectual disability services was superficial and characterised by passive rather than active participation (Riddington, Mansell & Beadle-Brown, 2008).

The importance of policy advocacy is highlighted by the example of the United States where despite some federal policy pressures (i.e. legislation and funding) there was no single federal deinstitutionalisation policy or a prescribed model. Braddock and Fujiura (1991) found that strong advocacy groups (measured as per capita membership), together with commitment to civil rights legislation predicted a substantial share of the variation in community services spending in American states. Parish (2005) compared deinstitutionalisation in two states – Michigan and Illinois – with similar demographic, socio-economic and political characteristics but different residential care systems. While Michigan was characterised by small-scale community-based provision, Illinois retained institutions. She found that leadership and socio-political factors, such as political culture were crucial in implementing successful deinstitutionalisation policies. Obstacles – the opposition of service providers, neighbourhoods, parents' and professional organisations – and incentives – federal funding – were similar in both states, nevertheless in Michigan a strong advocacy coalition emerged for deinstitutionalisation between the various stakeholders including the Arc, the state administration and legislation. Parish termed this a "central vision" (p. 229) which seemed to be lacking in Illinois where the pro-institution coalition was better organised and had more resources.

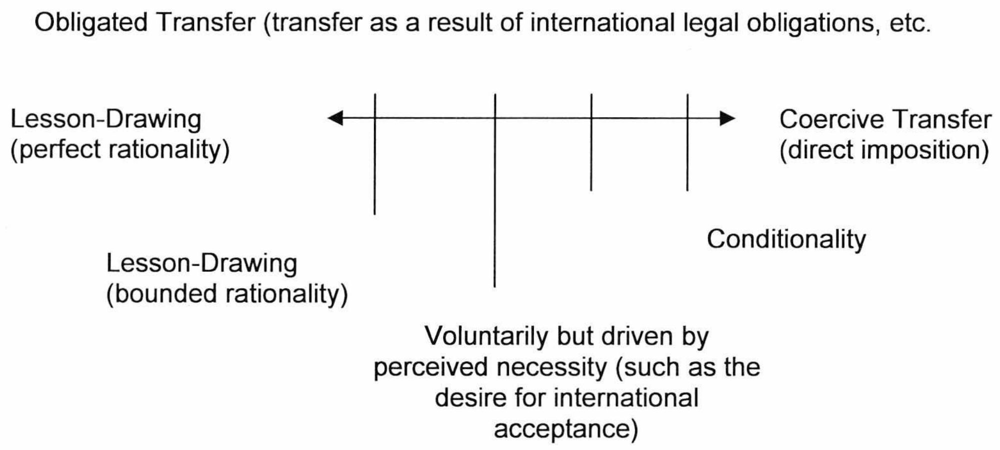
The ACF identifies four paths to policy change: policy learning, external subsystem events, internal subsystem events and negotiated agreements involving two or more coalitions (Weibleet al., 2009). The first two seem particularly relevant here. Policy-oriented learning is defined as "relatively enduring alterations of thought or behavioural intentions which result from experience and/or new information and which are concerned with the attainment or revision of policy objectives" (Sabatier, 1998, p. 104). Policy-oriented learning is usually limited to minor or technical aspects and happens over a longer period of time because actors resist information that questions their deep core or policy core beliefs.

Policy learning can also happen through the influence of ideas and models originating outside the immediate policy context (Bulkeley, 2006). Policy transfer is one of the main approaches within this body of literature.[5] The conceptual framework for analysing policy transfer was developed by Dolowitz and Marsh (1996; 2000) and it looks at the following areas:

- Who is involved in the policy transfer process?
- What is transferred?
- From where are lessons/policies drawn?
- What is the degree of transfer?
- Is the transfer successful or failed?

Policy transfer is defined as "knowledge about policies, administrative arrangements, institutions and ideas in one political system (past or present) is used in the development of policies, administrative arrangements, institutions and ideas in another political system" (Dolowitz & Marsh, 2000, p. 5). Policy transfer is conceptualised along a continuum between voluntary lesson-drawing and direct imposition of a policy or a programme by a supranational organisation (see Figure 2.3). Lesson drawing is a rational process and is often used as a "political weapon" to legitimise proposed changes; policy entrepreneurs present them as politically neutral truths. Lessons can be drawn from a variety of sources, including the country's own past, other policy areas or administrative levels in the same country, or from abroad.

Figure 2.3 The policy transfer continuum



Note. Adapted from Dolowitz & Marsh, 2000, p. 13.

There can be multiple actors involved in the process of policy transfer, including elected officials (e.g. members of parliament), political parties, civil servants, pressure groups, policy entrepreneurs/experts,

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[5] Other – largely overlapping – perspectives include europeanisation, policy convergence and policy diffusion however these are not discussed here.

and supranational institutions or transnational organisations (corporations, think tanks, international NGOs etc.).

Policy transfer does not necessarily mean the adoption of complete policies; it can be limited to certain aspects, such as the goals, the structure or the content of the policy, policy instruments, administrative techniques or institutions implementing a policy, and ideology, ideas, attitudes and concepts behind a policy. Dolowitz and Marsh (2000) distinguish four degrees of transfer: *copying* is a complete and direct adoption of a policy – with or without changes. *Emulation* is when ideas and concepts behind a policy are transferred but the policy itself is not. The third category is *combination* whichrefers to a mixture of policy elements transferred from different sources. And finally, *inspiration* when the policy does not draw on the original policy, only shares an ideological base.

Policy transfer can be constrained by the complexity of policies and issues, access to information, resources and administrative/institutional structure in the receiving entity. It sometimes fails to achieve its aims for various reasons: it is based on insufficient information, key elements are left out or the borrowing context is too different from the lending context.

Policy learning and lesson drawing within and between countries provided important resources for the policy process of deinstitutionalisation: it helped to to formulate an alternative vision of services, provided guidance for policy making and facilitated the choice between policy options. There were two main sources of policy-learning: the ideas of normalisation and demonstration projects/experiments.

Normalisation and Social Role Valorisation have been described as the most influential ideas in shaping services for people with intellectual disabilities in the past 40 years (Flynn & Lemay, 1999). The Normalisation principle emerged in Scandinavia in the late 1960s. Its roots go back to the early Nordic welfare state which was based on the principle of equality and aimed to ensure a high standard of living for all its citizens. Perrin (1999) suggests that it is "a general philosophy about how we should view human beings" and provides general direction for social policies. It was originally formulated by Nirje (1969) as "Making available the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream society" (cited in Perrin, 1999). Nirje later reformulated it as "Making available to all persons with intellectual disabilities or other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed *the same as* the regular circumstance and ways of life of society" (Perrin, 1999).

Influenced by the Scandinavian ideas and Goffman's work on symbolic interactionism Wolfensberger in the United States re-defined

Normalisation as "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible". (Wolfensberger, 1972 cited in Emerson, 1992) In the early 1980s he reformulated these principles as Social Role Valorisation and used them as an ideological basis to develop evaluation materials (PASS and PASSING) for services to measure compliance with Normalisation. (Emerson, 1992) Normalisation and SRV quickly spread in the US and in the other English-speaking countries. In the UK Normalisation was introduced in the 1970s and "from the late 1970s onwards consolidated its influence on service reform" (Felce, 1996; p. 134). Wolfensberger (1999) argued that without the influence of Normalisation residential care would have taken a different path of development and would have retained institutions, although in improved infrastructure and smaller scale.

Innovation and pilot programmes developed good practices that informed policy-making and were rolled-out more broadly. In the UK these high-profile early experiments were particularly important in providing input for policy making; starting with Tizard's work with children with disabilities, the Wessex experiment, the Andover and NIMROD[6] projects between 1981 and 1986 (Felce 1996; Felce et al., 1998, pp 13-14), and the Care in the Community Programme in England launched in 1983 (Renshaw, Hampson, Thomason, Darton, Judge, & Knapp, 1988). National resource centres were set up in a number of countries; the establishment of the National Institute on Mental Retardation in 1967 (currently the Roeher Institute) in Canada is often seen as a milestone in Canadian disability policy (Radford & Park, 2003) or the Institute on Community Integration in the US. Finally there was a considerable involvement of academics and university research centres, particularly in the US and UK. From the 1980s onwards a substantial body of applied research has emerged from these centres providing evidence and input for policy making together with an increased interest in interventions and the development of individuals with an intellectual disability.

By the 1980s various models of community-based residential services and demonstrated good practice were available. There was also empirical evidence that these consistently achieved better outcomes and in some countries (e.g. the US) they even proved to be cheaper. Demonstration and pilot projects were carried out in every country. Mansell and Ericsson (1996) argued that the "availability of mature models" including adequate administrative mechanisms to develop community-based settings gave new impetus to the process in the 1980s. A considerable amount of trans-national learning and

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[6] New Ideas for the Care of Mentally Retarded people in Ordinary Dwellings

exchange of practices was taking place that was also facilitated by the shared language and cultural background of the English-speaking countries, but it also involved Scandinavia (Flynn & Lemay 1999; Tøssebro 2006, p. 126). Publications of the King's Fund in England were an example of this;the project paper "An Ordinary Life" (1980) proposed the adoption of the 'core and cluster' model for residential provision developed in Nebraska, and "acted as a focus for the conceptualization, design and implementation of community services throughout the 1980s" in England (Felce et al., 1998b, p. 12).

Nevertheless policy-learning in itself seldom leads to policy change. A central proposition of the ACF if that "changes in the *policy core* aspects of a governmental program require a perturbation in non-cognitive factors external to the subsystem" (Sabatier, 1998, p. 105). These 'events' or 'shocks' bring about policy change by substantially altering the composition and resources advocacy coalitions and thus changing the balance of power. They include changes in socioeconomic conditions, public opinion, governing coalitions, and other subsystems (Weible, et al. 2009).

This seems to explain why the development of community care and the reprovision of public institutions gained momentum in the early 1980s with the first planned closures taking place. This coincided with the perceived crises of the welfare state under the neo-conservative governments in the liberal welfare states. Deinstitutionalisation has been embedded in the context of welfare state restructuring "characterised by an ideological shift to reliance on markets, reduced collective commitments to vulnerable populations, and a more minimalist residual role for the state in the provision of welfare" (Bigby & Fyffe, 2006, p. 568).

A large number of the institutions were built in the nineteenth century, many of them for other purposes and reconverted for use as intellectual disability institutions. Decision-makers were faced with the reality of poor physical conditions and buildings likely to require significant capital investments already in the short run if they were continued to be in use and brought up to the standards demanded by interest groups and the public. Mansell and Ericsson (1996) suggested that the pressure on institutional costs were important driving factors. They argued that "decisions about resource allocation came to the fore in this period, and that they interacted with evidence of feasibility of the policy and practice of community services" (p. 245). Furthermore, these years also coincided with a boom of real estate prices in some countries (e.g. USA, UK) that made institutional sites more attractive for investment and closure a more feasible option. While in some countries, such as the United States, community-based services were seen as cheaper alternatives to institutional provision, elsewhere (e.g. the United

Kingdom) they were regarded as 'better value for money', an increasingly important principle in public services since the 1980s.

The importance of the 'neo-liberal shift' is perhaps most clearly illustrated by the example of the United States where deinstitutionalisation became a federal objective in 1976 following a recommendation made by the General Accounting Office Investigation proposing cuts in public spending by states (Braddock, 1977). As put by Trent (1994) "the federal policy of deinstitutionalisation resulted from an ironic convergence of developments: a combination of civil-libertarian advocacy groups joined with state officials hoping to trim the ever rising costs of state institutions" (p. 5).

Similar conclusions were put forward by Parish (2005) in her comparative study of Michigan and Illinois. She found that economic recession and budgetary constraints in Michigan facilitated the development of community-based services:

> One of the main selling points for the development of community homes was their cost; replacing institutional services with community homes represented considerable financial savings. Michigan's dire finances apparently presented a unique opportunity for advocates, who capitalized on the potential savings represented by developing community homes as less costly alternatives to institutions. (p. 224.)

Rizzolo, Heller and Braddock (2005) created a "political socio-economic model" to explain variation in the utilisation of state-institutions among states. The independent variables included state wealth, political culture, legislative professionalism, advocacy, state spending on home and community based services and nursing homes for the elderly. The full model accounted for 57% of the variation in the utilisation of state institutions, with the most powerful dimensions being political culture and state wealth. These variables were positively associated with institutionalisation: wealthier states could afford dual systems, while states with less resource tended to rely on community-based provision.

In the USA there was another source of external pressure towards deinstitutionalisation: advocates successfully used the Federal Court to force policy change. The decisions of the Federal Court demanded the improvement conditions, forced the closure and reprovision of public institutions in the community from the 1970s onwards. Hayden (1998) identified 71 cases before 1997, the majority of which were filed as class-action on behalf of people living in large state institutions by individuals with intellectual and developmental disabilities, parents' organisations, self-advocacy groups or joint groups as plaintiffs. Due to the characteristics of the US legal systems these decisions had important spill-over effects on policy-making in all states.[7]

The Advocacy Coalition Framework emphasises the role of learning within policy communities and external events in policy change. This model fits nicely with existing ideas on the driving forces of deinstitutionalisation (see Mansell & Ericsson 1996). It also explains dynamics of the process: the initial failure to reduce the population of institutions despite a commitment to community care and normalisation, and their rapid decline in the 1980s. The main source of policy change in the first wave of deinstitutionalisation (Bigby & Fyffe, 2006) was policy learning and policy change was limited to secondary aspects: institutions still existed alongside community-based services, although they were smaller and better-resourced, and people moving out of institutions were relatively more able. It was the perceived crisis of the welfare state that brought about major policy change and shifted the balance from predominantly institutional to community-base care.

2.4 The Multiple Streams Framework (MSF): windows of opportunity for deinstitutionalisation

The Multiple Streams Framework adds another dimension to the explanation by highlighting the idiosyncratic nature of deinstitutionalisation. The MSF attempts to answer "why important people pay attention to one subject rather than another, how their agendas change from one time to another, and how they narrow their

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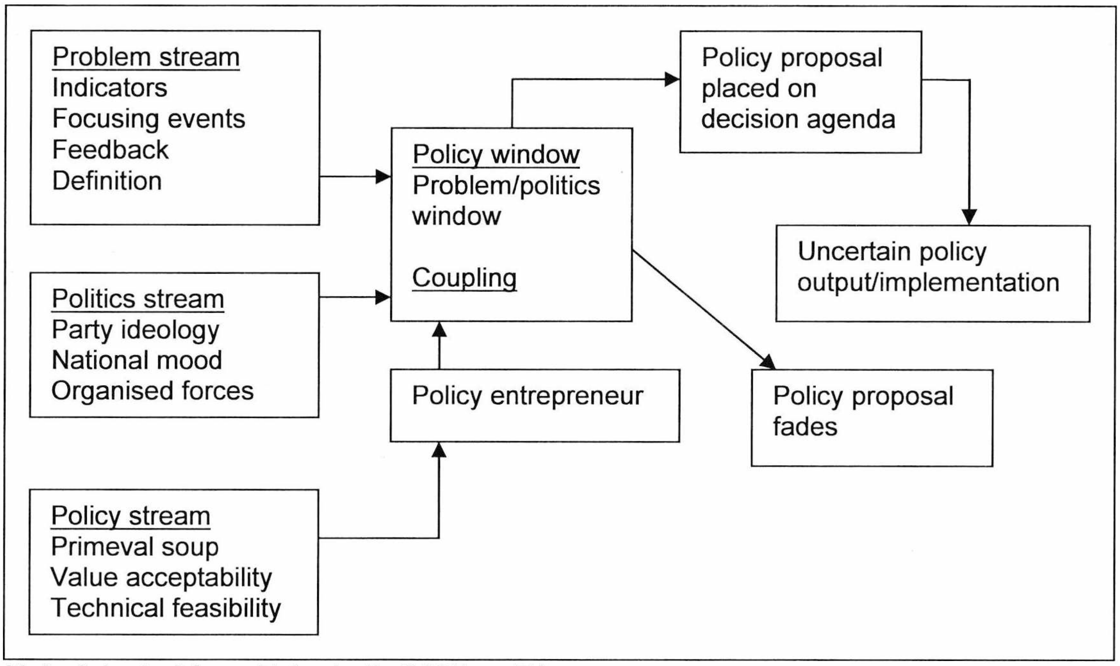
[7] The first landmark ruling was in the case Wyatt *vs.* Stickney brought against the Partlow State Hospital in Alabama in 1970. The decision established minimum standards for residential care of people with intellectual disability and the right to the least restrictive conditions. (Wyatt *vs.* Stickney: a Landmark Decision, retrieved from http://www.adap.net/Wyatt/landmark.pdf last accessed: 02/01/2012) The next case attracting nation-wide attention was the New York State Association of Retarded Children, Inc. vs. Rockefeller, or more commonly known as Willowbrook. The case started in 1973 and resulted in the reprovision of residential services in community-based settings for over 3,000 former Willowbrook residents, and eventually ended with the closure of the institution in the 1990s (Rothman & Rothman, 1995). The first case that demanded the complete closure of an institution was the Pennhurst vs. Haldermann case in 1974. Plaintiffs claimed that institutions are inherently inadequate to provide acceptable conditions and treatment for people with intellectual disabilities. The ruling ordered the closure of Pennhurst and the placement of it residents in the community. In the 1990s new types of class-action litigations emerged, the primary aim of which is to force States to expand services to people on waiting lists and ensure access to services (Rizzolo, et al., 2003). The most recent landmark ruling was in what is known as the Olmstead case in 1999. The Supreme Court ruled that "it is a violation of the Americans with Disabilities Act for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting" (Fox-Grage, Coleman, Folkerner, 2003, no page number).

choices from a large set of alternatives to a very few" (Kingdon, 1995, p. 2). In other words, the multiple streams framework deals with policy making when there are many potential ways of dealing with problems, and aims to explain why certain ideas are pushed forward at the expense of other – potentially equally good - ideas (Zahariadis, 2007, p. 66). Figure 2.4 presents a diagram of the Multiple Streams Framework.

Figure 2.4 Diagram of the MS Framework



*Note.*Adapted from Zahariadis 2007, p. 71

Kingdon makes a distinction between a 'condition' and a 'problem': "Conditions become defined as problems when we come to believe that we should do something about them" (p 109). Thus problems are largely perceptual and always carry an element of subjectivity. There are three main factors that contribute to the interpretation of a condition as a problem:

- values;
- comparisons with others (countries, groups, sectors etc.);
- the category of the problem, how the problem is positioned.

However, the recognition of a problem is not necessarily sufficient to get an item on the agenda.

Problems capture the attention of people through different channels in the problems stream: indicators, focusing events such as a crisis or a disaster, and the personal experiences of important policy makers. Focusing events very rarely can put an issue on the policy agenda by themselves, they need accompaniment by either reinforcing an already existing perception of a problem or alter the definition of a problem. For example the Kennedy family's interest in intellectual disability through their personal experience with Rosemary, the sister of John F. Kennedy and Robert F. Kennedy, was an important contribution to deinstitutionalisation in the US. Trent (2006) wrote:

> In September 1965, Robert F. Kennedy, a United States senator from New York, strongly criticised two of the state's largest facilities (...). As a senator, Kennedy had little influence over the state government (...) but (..) Kennedy's criticism gained the attention of the press and the state's public officials. (p. 116)

The policy stream consists of ideas, alternatives and proposals 'floating around' in the primeval soup of a policy community – a metaphor borrowed from evolution theory. Policy communities are defined as a group of specialists in a given policy area who interact with each other and are familiar with each other's ideas. The emergence of new ideas – "mutation" as Kingdon puts it – is relatively rare, more commonly existing ideas are recombined into new structures or policy proposals.

Proposals survive if they are technically feasible and are compatible with the values of the decision-makers. Ideology is important in some policy areas but less so in others. The anticipation of future constraints also influences the chances of survival for an idea. There are two main sources of constraints, namely budget constraints and public acquiescence. Budgets can act as "promoters" that force items higher up on the agenda or "constraints" that hold them low or off the agenda. In times of budgetary constraints, less costly programmes or policies can come to the forefront; regulatory policies or policies that promise cost containment or reduction. However, budget constraints are often perceptual and subject to interpretation. Public acquiescence reflects the public opinion, whether a policy or a programme would be acceptable to the public. In the case of deinstitutionalisation these two were favourable; after the scandals of the 1960s and 1970s the public was generally supportive towards the idea of community-based care and the reprovision of institutions also promised to save money in some countries or be more cost-effective.

The politics stream consists of three elements: party ideology, national mood and organised forces. Changes in government have significant influence on agendas and bring certain issues to the agenda and push others aside. The national mood refers to public opinion; government officials can detect changes in the national mood and decide to promote certain problems on the agenda or abandon others.

Similarly, the support or opposition of organised forces to certain issues, such as interest group campaigns, can shape the agenda of politicians.

The three streams are by-and-large separate from each other and they have their own dynamics and processes (Zahariadis, 2007). The problems and politics stream shape more the agenda, while the policy stream affects the alternatives. Kingdon suggests that "the combination of national mood and elections is a more potent agenda setter than organized interests" (p. 199).

Policy entrepreneurs have a key role the Multiple Streams Framework. They are advocates for proposals or the prominence of an idea. They can be located anywhere in the policy community, in or outside the government. They are defined by their willingness to invest their resources – "time, energy, reputation and sometimes money" – in the hope of a future return which can be the adoption of a policy which they approve of, satisfaction from participation or personal gains such as job promotion. Policy entrepreneurs use a variety of strategies to 'soften up' the policy community or decision-makers.

When the three streams join a policy window opens: "an opportunity for advocates of proposals to push their pet solutions, or to push attention to their special problems" (Kingdon, 1995, p. 165). A window opens as a result of a change in the political stream which includes a political change, elections, shift in public opinion or a problem capturing the attention of politicians. Policy windows close for a variety of reasons: participants think they have done enough to address the problem; they get discouraged and give up; or stakeholders realise the financial and social costs of action. Policy windows generally do not stay open for long but present themselves from time to time. Without the prospect of an open window, participants are likely to get discouraged and give up.

If a policy proposal is successfully placed on the agenda and followed by governmental action, the actual policy outputs and outcomes are still unpredictable. Decision-makers are often unable to control subsequent stages of the policy process, including implementation. It is argued that "this unpredictability and inability to control events once they are set in motion creates a dilemma for the participants in the process [...] whether they risk setting in motion an unmanageable chain of events that might produce a result not to their liking" (pp. 177-178).

The introduction of new funding arrangements opened a policy window for the reprovision of institutions in the US in the 1970s and 1980s. Before 1970 residential services were funded by states (and private sources). The launch of the Intermediate Care Facility for the Mentally Retarded programme (ICF/MR) under Medicaid fundamentally changed this arrangement in 1971. This was the first-ever federal funding available for disability services and it was a long-term care benefit that allowed a federal contribution of 50-83% to the costs of services, a significant incentive for states seeking additional resources or reducing own spending. ICF/MR had a crucial role in shaping services (Anderson, Lakin, Mangan & Prouty, 1998). On the one hand services were eligible for funding if they met federal standards which often involved a reduction in the size of facilities and living units and the improvement of conditions. Moreover, the programme created incentives for states to move people with disabilities from psychiatric units to ICF/MR facilities. The new arrangements allowed advocates of community living at state level to push forward the idea of reprovision to decision makers already familiar with the problems in state institutions and facing federal budget constraints. But the ICF/MR had some unexpected policy outputs at state level. Anderson et al. (1998) wrote:

> The ICF/MR program may have had a dampening effect on the depopulation of state institutions by causing states to 'invest' hundreds of millions of dollars into state institutions' physical plants in the expectation of long-term federal reimbursements to meet these financial obligations and by establishing a federal contribution to the cost of ICF/MR-certified state institution services, making their steadily increasing per capita costs more affordable to states. (p. 432.)

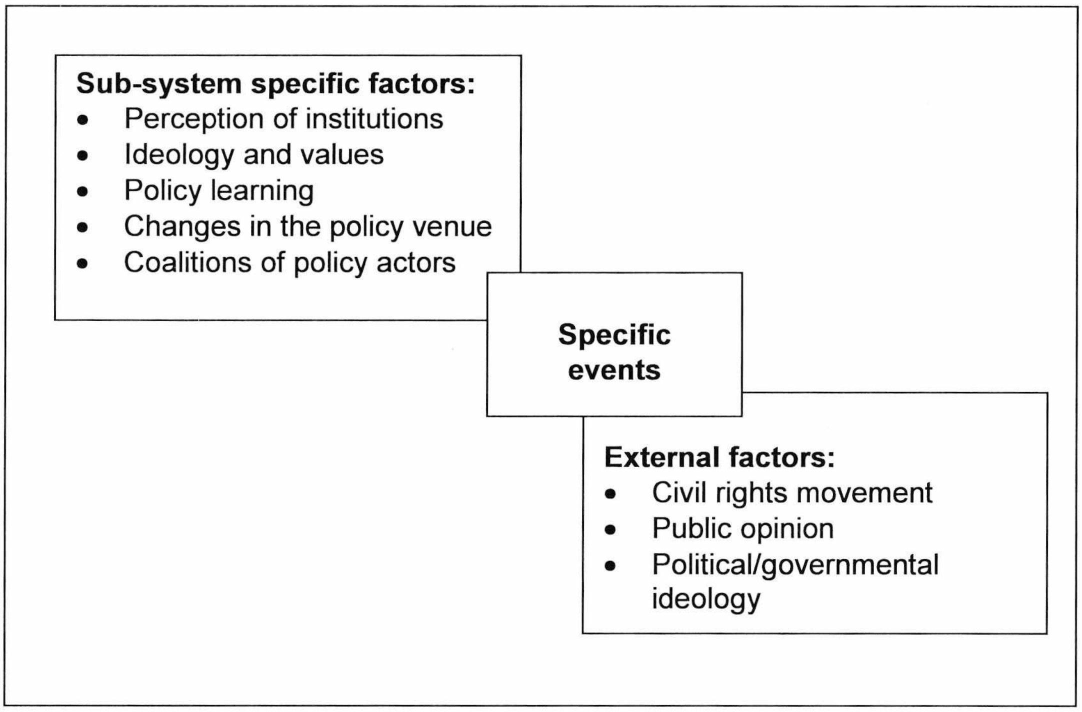
However, in less than a decade another policy window opened: the Medicaid Home and Community-Based Services (HCBS) Waiver Programme was created in 1981. This programme was launched to fund community alternatives to institutional care for people with intellectual disabilities at risk of a placement in an institution. The HCBS soon overtook ICF/MR both in terms of numbers of users and amount, and it brought about a rapid expansion of small-scale non-state provision (Prouty et al., 2006, p. 65).

In conclusion, the Multiple Streams Framework portrays policy change as a messy and rather unpredictable process where policy change happens when windows of opportunity open and policy entrepreneurs push their solutions to the agenda. In this framework deinstitutionalisation and community living is the result of a unique constellation of problems, political contexts and policy ideas. Although this explanation undermines the generalisability of experiences across countries, it still has the potential to offer useful insights for case studies of individual countries (Cairney, 2007).

2.5 Conclusion

Deinstitutionalisation was driven by multiple forces. This chapter aimed to explain the process using three theoretical lenses: Punctuated Equilibrium, Advocacy Coalitions and Multiple Streams. They seemed useful in identifying factors leading to change and bringing them together in an explanatory framework. The approaches offered three different but complementary interpretations of policy change, highlighting different aspects of the process. The picture that emerged is largely similar to the arguments put forward by Mansell and Ericsson (1996). Although the process of policy change differed from country to country there were some common themes and experiences. Figure 2.5 attempts to summarise these.

Figure 2.5 Driving factors of deinstitutionalisation and community living



Two main sets of driving forces can be distinguished: sub-system specific factors are directly related to residential provision; external factors include the broader socio-economic and political context as well as the influence of other sub-systems. The first includes changes in the perception of institutions that were indicated by the widespread scandals throughout the 1960s and 1970s. Scandalshad a special role in the policy process; they served as focusing events and put the institutions on the policy agenda, and also provided important resources to advocates of deinstitutionalisation. Scandalshelped to mobilise actors and consolidate advocacy coalitions.

The ideologies underpinning the provision of services moved away from the eugenic ideas of the pre-war period to normalisation and social role valorisation. Institutions could no longer meet the new expectations towards services. Policy learning was on the one hand facilitated by the shared cultural background and close ties between the English-speaking countries but also the tradition of social experimentationes. Pilot programmes demonstrated the feasibility of community living and also provided the know-how to implement deinstitutionalisation on a large scale.

There were also changes in the policy venue; the responsibility for the provision of residential supports shifted towards more local levels of government in many countries. Although the direction of change seems less relevant, the move itself helped to shift resources from the dominant institutional provision to community-based care. Finally, the analysis suggested that the presence of a strong coalition is important for policy change because it helps to take advantage of the opportunities that arise within or outside the sub-system. The composition of coalitions differed country by country (Mansell& Ericsson, 1996).

External factors included the public mood that was generally supportive of improving the living conditions of people with intellectual disabilities. The values of deinstitutionalisation and community-based care were broadly acceptable by the public. The civil rights movement had an important spill-over effect by raising awareness of human rights. Nevertheless one of the main drivers to replace institutions with community-based settings was induced by the social policy reforms of neo-conservative governments in the 1970s and 1980s aiming to cut back the public sector and welfare spending. The closure of institutions and community living were seen as a less costly alternative to improving the quality of institutions. A third set of factors includes both external and sub-system specific factors. These could be important drivers in one context while absent elsewhere, such as high real estate prices etc.

As to the relative importance of sub-system specific and external factors, there were no clear cut answers in the literature. The ACF has emphasised the role of external shocks as the main source of policy change, while the Punctuated Equilibrium model has highlighted the role of sub-system specific factors, such as the policy image and venue. It might be argued that reform itself was the result of external pressures on the sub-system, while the extent, direction and content of the reform, the decision to replace institutions with community-based care, was dictated by sub-system specific factors.

Chapter 3 Deinstitutionalisation and Community Living: A Systematic Review of Individual Outcomes in Different Residential Arrangements

Deinstitutionalisation was not simply the replacement of one set of buildings with another (Mansell & Beadle-Brown, 2010). Community-based services were different from the institutions they replaced in the material conditions, living environments, staff support and opportunities they offered to service users. The impact of deinstitutionalisation and different forms of residential supports on the quality of life of people with intellectual disabilities attracted considerable research attention. Emerson and Hatton (1994) reviewed 71 studies published in 1980-93 in the United Kingdom that looked at the effects of resettlement from long-stay hospitals in community-based settings on the lives of people with intellectual disabilities. They found that community-based services offered a better quality of life to people with intellectual disabilities than institutions including medium size hostels and 'community units'. In particular, smaller scale community-based settings provided:

- better material standards of living and less institutional environment;
- more opportunities to use existing skills and develop new ones;
- more choice over daily routines;
- more contact with people;
- better access and use of community facilities;
- and more engagement in meaningful activities.

But they also found a substantial variation among community-based services in terms of their quality: for some service users life in the community was little different from life in an institution. It was pointed out that people with intellectual disabilities supported in community-based settings:

- were relatively poor compared to the general population;
- developed few new skills once they had settled in the community-based setting;
- had few choices over important aspects of their lives, such as where and who to live with etc.
- had limited community presence;
- had few relationships with non-disabled people other than paid staff.

Emerson and Hatton concluded that "the quality of life offered in many community-based services falls short of the values and ideals which underlay their development and may also fall short of common notions of decency or acceptability when applied to non-disabled people" (p. 44).

Young, Sigafoos,Suttie, Ashman, and Grevell(1998) reviewed 13 Australian studies published between 1980 and 1998 focusing on the impact of relocation from institutions to the community by either comparing institutional and community-based settings or looking at the community adjustment of movers. The review found positive changes in community participation, contact with family and friends, and resident and parent satisfaction. Negative outcomes were reported regarding the social acceptance and health status of people resettling into the community. Findings concerning adaptive and challenging behaviours were more mixed, some studies reported positive changes or no change.

McConkey (2000), Heller (2002) and Beadle-Brown, Mansell and Kozma(2007) reviewed papers reporting on any aspects of deinstitutionalisation or community services for people with intellectual disabilities during periods of one year. Although outcomes were overwhelmingly positive, recent research suggests that people in the community might still experience institutional practices (Beadle-Brown et al., 2007).

A number of reviews focused on specific aspects of deinstitutionalisation. Kim (2001) reviewed the behavioural outcomes of deinstitutionalisation for people with intellectual disabilities in American studies published between 1980 and 1999. Felce (1998) reviewed British studies that explored engagement in activity and resident-staff interactions in services for people with intellectual disabilities. Myers, Ager,Kerr, and Myles (1998) reviewed UK research on the community integration of people with intellectual disabilities covering the key issues and debates after 1970. Walsh, Kastner,and Green(2003) reviewed selected US literature on cost comparison of community and institutional residential services. These reviews showed that the weight of research favoured community-based services in most domains considered, though there were exceptions and reviewers also frequently drew attention to the variability of results found in service models of the same type.

This chapter provides a systematic review of more recent research on outcomes in different residential settings for people with intellectual disabilities including both “deinstitutionalisation” and “post-deinstitutionalisation” studies. The review covers all the research published in English from whatever country since 1997. There are three main reasons that make a new review of literature worthwhile. First, to explore whether more recent experiences in different countries continue to provide evidence on the benefits of community living for people with intellectual disabilities. Second, it is very likely that the last decade included the move of more people with more severe disabilities to community services than earlier stages of the process, making more recent studies of interest for this reason. Third, the system of community-based services in some countries is now relatively well-established and also new forms of residential arrangements (e.g.

supported and independent living) are increasingly common that challenge and provide alternatives to more "traditional" models of community living. The outcomes of these arrangements are also worth reviewing.

3.1 Review method

Selection of studies

Studies for this review were identified using three methods: a) electronic search with a combination of key terms[8] on academic search engines (Web of Science, PsycINFO and Google Scholar); b) "hand" search of selected journals (Mental Retardation, American Journal on Mental Retardation, Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual Disability Research); c) following-up references of relevant papers and publications. One hundred and seven studies were identified as potentially relevant and screened more thoroughly using the following criteria: a) published either in print or electronically between 1997 and 2007; b) in a peer-reviewed English-language journal; c) based on original qualitative or quantitative research, and providing information on the participants and methodology; d) compared two or more residential arrangements for adults with an intellectual and/or developmental disability in terms of clearly defined user outcomes.

For the final review 68 studies were selected that met all the above criteria. These were also checked with a recent unpublished review (Noonan Walsh et al., 2007). Papers reporting on the Hissom Closure in Oklahoma (Conroy, Spreat, Yuskauskas, & Elks, 2003; Spreat & Conroy, 2002; Spreat, Conroy, & Fullerton, 2005) that met the inclusion criteria were excluded in the light of recent controversy and allegations of serious scientific errors(Walsh & Kastner, 2006).

Review Procedure

The 68 studies were reviewed and coded according to country, research design, instruments, number of participants, compared settings, outcome domains, and results.

Studies mainly came from English-speaking countries and only nine articles reported on experiences elsewhere (the Netherlands, Finland, Taiwan, and Norway). The majority of studies (49) evaluated the impact of deinstitutionalisation and compared institutions with a variety of community-based settings. "Post-deinstitutionalisation" studies (19)

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[8] Deinstitutionalisation/deinstitutionalization, learning/intellectual disabilities, mental retardation, living arrangements, community services, resettlement, transition to community care, relocation, hospital/institution closure, residential care institution.

(Stancliffe, Emerson Lakin 2004) compared outcomes of different community-based residential supports.

Definitions of institution and community-based services varied country by country. Common features of institutions typically included large size, atypical architectural design, segregation from the local community, and highly regulated restrictive environments. Community-based settings included a variety of arrangements such as dispersed or clustered, ordinary or purpose-built group homes, supported living etc. Studies reported the size (range) of settings but structural or functional characteristics were rarely discussed (Stancliffe, Emerson & Lakin 2004).

Twenty-seven studies had a cross-sectional design with matched samples, 23 studies had a longitudinal design. Eighteen studies combined both and either compared “movers” and “stayers” or people moving to different types of residential arrangements.

Studies used different methods to control for the impact of participant characteristics on the individual outcomes of residential arrangements. Longitudinal studies relied on pre-post designs with or without comparison groups. Cross-sectional studies used matched groups or statistical procedures.

The majority of studies (42 of 68) had a sample size of 100 or more participants, however 11 studies used a small sample with less than 50 participants. These studies might lack statistical power and therefore their results should be viewed with caution. Publications did not commonly report on sampling strategies. Convenience samples seem relatively widespread and a few, more recent studies (e.g. Emerson, 2004) used representative sampling techniques (Noonan Walsh et al., 2007).

Most studies (66 of 68) took a quantitative approach using a variety of instruments. People with intellectual disabilities had virtually no input into the design of studies. Only two papers (from the same study) reported some participation of people with intellectual disabilities (Emerson, 2004; Emerson & McVilly, 2004), although there are good examples in recent research (Miller, Cooper, Cook, & Petch, 2008).

The individual outcome domains reported by the studies were coded into ten categories by-and-large following the categories used by Emerson and Hatton (1994): 1) community presence and participation; 2) social networks and friendships; 3) family contact, 4) self-determination and choice; 5) quality of life; 6) adaptive behaviour, 7) challenging behaviour; 8) psychotropic medication; 9) health, risks and mortality; 10) user and family views and satisfaction. Twenty-nine studies reported on more than one domain.

The results of each study were briefly summarised, and the overall direction of change and magnitude of outcomes were indicated in the summary tables (e.g. “better”, “more”, “declined” etc.). In quantitative studies statistical significance, in qualitative studies the strength of opinion were used as an arbiter in reporting outcomes. Unless otherwise stated results reported in the summary tables are significant. Where results were non-significant or inconclusive this was noted. Internal variation of outcomes and factors associated with it were also highlighted.

The results are presented below by domain. Each section gives a brief summary of the general results and highlights the factors associated with variation. Summary tables of the studies for each domain are found at the end of the chapter.

3.2 Community presence and participation

The presence of people with intellectual disabilities in the community, their participation in community-based activities and use of community facilities are often seen as one of the core indicators of their social integration (Emerson & Hatton, 1994). Fourteen publications reported on some aspect of community integration, most often measured as the use of mainstream community facilities (services, leisure etc.) and participation in activities outside the home (Table 3.1).

Small-scale community arrangements were found to offer more community involvement to users than larger settings (Ager, Myers, Kerr, Myles, & Green, 2001; Chou, Lin, Pu, Lee, & Chang, 2007; Felce, Lowe, Beecham, & Hallam, 2000; Felce et al., 1998). Semi-independent or supported living arrangements were found to provide more community integration than traditional residential services (Emerson et al., 2001; Howe, Horner, & Newton, 1998; Stancliffe & Keane, 2000).

Community-based provision does not, however, guarantee better outcomes. Community participation was also found to be associated with adaptive behaviour (Baker, 2007), level and complexity of needs (McConkey, Walsh-Gallagher, & Sinclair, 2005), and the individual's social competence (McConkey, 2007). It was also found to be associated with service factors including the quality of supports.

Results also suggested that the community presence and participation of people with intellectual disabilities was very limited across all settings. People with more severe disabilities in particular are at risk of having limited community experiences (Baker, 2007).

3.3 Social networks and friendships

Meaningful friendships and social relationships are important determinants of emotional and physical well-being (Emerson & McVilly, 2004). Nine studies reported on some aspects of social networks and friendships (Table 3.2). Research typically focused on the size and density of networks and friendships.

Results show that friendships and social networks of people with intellectual disabilities were associated with living arrangements as well as personal characteristics. In terms of number of friends, people in small settings with low staff turnover had more friends. People in supported living arrangements had more friends outside the home, were more likely to be known by their neighbours and have visitors (Emerson & McVilly, 2004; Forrester-Jones et al., 2006; McConkey, 2007). Service characteristics, such as the implementation of active support (Stancliffe, Jones, Mansell, & Lowe, 2008) may moderate the effect of setting size and they are associated with larger social networks (Robertson et al., 2001). Friendship and social network were also associated with individual characteristics, such as adaptive skills and (lack of) severe challenging behaviour (Emerson & McVilly, 2004).

Although more able people in dispersed supported living were at relatively higher risk of being isolated (McConkey, 2007) there was no strong evidence of a relationship between loneliness and small setting size, including supported living. Loneliness was found to be associated with incompatibility between residents – which is more likely to happen in larger settings – and feeling unsafe in the local community (Stancliffe et al., 2007).

Friendship activities with other people with intellectual disabilities typically took place in the public domain. These relationships were characterised by high stability, reciprocity and were highly valued by people themselves (Emerson & McVilly, 2004; Forrester-Jones et al., 2006; Robertson et al., 2001).

3.4 Family contact

Family contact has been associated with social and psychological well-being and social inclusion of people with intellectual disabilities (Robertson et al., 2001; Stancliffe & Lakin, 2006). Eight studies in the current review reported on some aspect of family contact, most often frequency and form (Table 3.3).

Resettlement in the community was shown to be an opportunity to re-establish family contact, which tended to remain stable over time (Spreat, Conroy & Rice, 1998; Stancliffe & Lakin, 2006). Very large size was associated with less family contact (Chou, Lin, Pu, Lee, & Chang, 2007) but overall, form and frequency of family contact were not related to type and size of provision, rather than to distance to the family home and personal characteristics, such as ability and resident and parent age.

3.5 Self-determination and choice

Self-determination and choice are highly valued in Western cultures and are important criteria of independent adult life. The opportunity to make choices is also associated with personal development (Heller, Miller, & Factor, 1998, 1999; Heller, Miller, & Hsieh, 2002). Twenty-one studies examined the choice-making opportunities available to people in different residential arrangements (Table 3.4).

Results show that smaller, more personalised community-based services generally offered more choice and opportunities for self-determination than larger, congregate facilities (Emerson et al., 2000; Kearney, Bergan, & McKnight, 1998; Robertson et al., 2001; Saloviita & Aberg, 2000; Stancliffe, Abery, & Smith, 2000; Stancliffe & Abery, 1997; Stancliffe & Lakin, 1998; Wehmeyer & Bolding, 1999).

Community-based provision and small size however did not guarantee better outcomes: staff practices and empowerment were found to be crucial in promoting choice. Self-determination was also associated with structural and procedural aspects of the services, for example active support and home-like environment (Robertson et al., 2001). However, the availability of resources (costs, staffing levels) – within reasonable limits – was not associated with opportunities for choice-making (Robertson et al., 2001; Young, 2006). Individual characteristics, particularly adaptive skills and level of disability were associated with choice (Stancliffe & Abery, 1997).

Most people with intellectual disabilities have very limited choice-making opportunities that are restricted to relatively minor, everyday decisions. They had no control over the most important aspects of their lives such as where and with whom to live (Heller, Miller & Factor, 1999; Robertson et al. 2001; Stancliffe & Abery, 1997).

Young and Ashman (2004) highlighted that the increase in choice-making after resettlement in the community started to plateau after two years.

3.6 Quality of life

Quality of life is a composite and multi-dimensional concept that involves some of the domains that are also discussed separately here. The most frequently referenced quality of life domains are interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material wellbeing, emotional well-being, rights, environment (home/residence/living situation), family, recreation and leisure, and safety/security (Verdugo, Schalock, Keith, & Stancliffe, 2005). Eight studies used quality of life measures to evaluate residential provision (Table 3.5).

Relocation to the community was generally associated with better quality of life (Ager et al., 2001; Young, 2000, 2001, 2006; Young & Ashman, 2004), but there were considerable variations among people and settings in terms of gains associated with individual characteristics, staff practices and service procedures. (Young & Ashman, 2004).

3.7 Adaptive behaviour

Improving the adaptive skills, abilities and competence of people with intellectual disabilities were one of the most important rationales during the early stages of deinstitutionalisation (Emerson & Hatton, 1994). The level of adaptive behaviour is an important determinant of quality of life. Fifteen studies used adaptive behaviour as an outcome indicator using standardised measures (Table 3.6).

Some studies found no evidence of increases in adaptive behaviour upon relocation to community provision. Others found improvements in certain areas but not in other domains (Heller et al., 1998; Macleod, Morrison, Swanston, & Lindsay, 2002; Young, 2000, 2001). People who remained in institutions or other congregate settings were more likely to experience a decline, while "movers" maintained or improved their abilities. Some evidence also suggested that people with more severe and profound disabilities gained more in adaptive skills than people with mild/moderate intellectual disability as a result of resettlement (Young & Ashman, 2004).

Gains in adaptive skills were shown to be associated with environmental and service factors, including small size, attractiveness and stimulation of the physical environment, opportunities for choice making (Heller, Miller, & Factor, 1998; Spreat, Conroy, & Rice, 1998; Stancliffe, Hayden, Larson, & Lakin, 2002), teaching of skills and autonomy (Lerman, Apgar, & Jordan, 2005), and the implementation of active support (Young, 2006; Young & Ashman, 2004).

3.8 Challenging behaviour

Challenging behaviours are "culturally unusual or unacceptable behaviours such as self-injury or aggression which place the health or safety of the person or others in jeopardy or are likely to lead to the person being excluded or denied access to ordinary community settings" (Emerson & Hatton, 1994). Challenging behaviours are therefore an important determinant of quality of life. Thirteen studies looked at individual challenging behaviour and four studies compared responses to challenging behaviour in different residential arrangements (Table 3.7 and 3.8).

Most studies reported no significant changes in challenging behaviours upon resettlement to different forms of community provision (Heller et al., 1998; Hundert, Walton-Allen, Vasdev, Cope, & Summers, 2003; Spreat et al., 1998; Stancliffe et al, 2002; Young & Ashman, 2004b). Some studies however found a deterioration in certain behaviours, such as disruptive behaviour and passivity (Nøttestad & Linaker, 2002; Nøttestad & Linaker, 1999). Others noted that although the level of challenging behaviour as measured by standardised instruments remained the same, observation revealed changes in the nature of challenging behaviours and the reduction of certain problem behaviours after relocation (Young, 2006; Young & Ashman, 2004).

The eco-behavioural relationship between staff attention and challenging behaviour was found to be similar in institutions and in the community: problem behaviour was associated with lack of staff attention and staff tended to respond more to challenging behaviour than to appropriate behaviour across all setting-types (Hundert, et al. 2003).

Treatment and management of challenging behaviour were found to be associated with provision characteristics: institutions used more restrictive practices (Saloviita, 2002), and community-based services were more likely to use sedation (Emerson et al., 2000). People in community-based settings received more informal interventions, while people in institutions had more formal interventions and access to professional behavioural support (Stancliffe, Hayden, & Lakin, 1999).

3.9 Psychotropic medication

Psychotropic medication is widely used to manage and reduce challenging behaviours, although their efficacy is questionable (Matson et al., 2000). The use of psychotropic drugs in people with intellectual disabilities is receiving increased attention in recent literature; four studies addressed this issue (Table 3.9).

Some found a decrease in the medication of people with intellectual disabilities moving to community settings (Spreat, Conroy, & Rice, 1998), others reported non-significant changes in the number of people on medication, dosage and frequency (Nøttestad & Linaker, 2003).

One study showed a significant increase in psychotropic medication in Australian community settings in the 1990s; as a result a similar percentage of people were found to be receiving drugs in the community and in institutions in 2000 (McGillivray & McCabe, 2005).

However, poly-pharmacy was still more widespread in institutions (McGillivray & McCabe, 2005; Robertson et al., 2000).

3.10 Health, risk factors and mortality

Improving health and reducing lifestyle-related risks have been important in most countries. They are not only central to the well-being of the individual but poor health imposes significant costs on health and social services. Despite its relevance, relatively little is known about the health-related outcomes of different residential arrangements. Six studies surveyed health and lifestyle-related risk factors (Table 3.10).

Most studies found no evidence of "transfer trauma" or "transition shock", nor of an increase in mental health problems among people moving to community settings (Helleret al., 1998; Nøttestad & Linaker, 1999; Read, 2004), however some mortality studies (Strauss, Shavelle, Baumeister, & Anderson, 1998) claimed that the higher rate of mortality shortly after relocation could possibly be attributed to a "relocation syndrome".

The prevalence of certain health risk factors, particularly inactivity and obesity among people with intellectual disability was high. Less restrictive provision decreased the likelihood of inactivity, but increased the probability of smoking, poor diet and obesity, and there were significant differences between men and women (Bryan, Allan, & Russell, 2000; Robertson, Emerson, Gregory, Hatton, Turner et al., 2000).

A special aspect of community living is the exposure to crime and abuse that has received limited attention in the literature (see Table 3.11). Higher (perceived) exposure to crime and (verbal) abuse were thought to be associated with supported, semi-independent or independent living arrangements (Emerson et al., 2001). People living in intentional communities or other clustered provision were perceived to be at less risk (Emerson, Robertson, Gregory, Kessissoglou et al., 2000).

The issue of mortality in community settings has received considerable attention mainly in US literature. Ten studies are included in the review (see Table 3.12). Some studies found improvements (Conroy & Adler, 1998), others no difference (O'Brien & Zaharia, 1998) or higher risk of mortality in the community (Shavelle & Strauss, 1999; Shavelle, Strauss, & Day, 2005; Strauss, Anderson, Shavelle, Sheridan, & Trenkle, 1998; Strauss, Kastner, & Shavelle, 1998; Strauss, Shavelle, Anderson, & Baumeister, 1998; Strauss, Shavelle, Baumeister, & Anderson, 1998). Higher risk was hypothesised to be the outcome of inadequate access to health care. Some suggested that higher mortality was not related to relocation but rather to the presence of specific risk variables in people selected for moving out (Lerman, Apgar, & Jordan, 2003; Read, 2004).

3.11 User and family views and satisfaction

An important aspect of service provision is the satisfaction of its users. The use of subjective measures in evaluation has been contested (Hatton, 1998; Perry & Felce, 2005; Verdugo, Schalock, Keith, & Stancliffe, 2005) and it is not very widespread. Six studies surveyed the views of service users and their families using mainly quantitative techniques (Table 3.13).

Studies found high satisfaction with community-based arrangements among both service users and their families. Movers were critical about institutions and did not want to return – even if they missed certain things (people and some activities) (Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001).

Although a higher number of parents and family members had been more critical towards deinstitutionalisation and the prospect of resettlement initially, the majority were positive once it happened (McConkey, McConaghie, Mezza, & Wilson, 2003; Noonan Walsh et al., 2001; O'Brien, 2001) and satisfaction remained stable over a longer period of time (Tøssebro & Lundeby, 2006).

A limitation of these results should however be kept in mind: studies often use retrospective methods that are likely to distort opinion in favour of current arrangements. Most parents reported high satisfaction with institutions (Larson & Lakin, 1991).

3.12 Discussion

This review has presented the outcomes of deinstitutionalisation and a comparison of different residential arrangements for people with intellectual disabilities using studies published between 1997 and 2007. Studies predominantly report on mature service models from countries where deinstitutionalisation has been unfolding for decades and has made considerable progress. Five main conclusions emerge from this literature: 1) the overall picture is comparable to previous reviews, namely small-scale arrangements are superior to large, congregate options in most domains; 2) there is considerable variability in individual outcomes based on individual and service characteristics; 3) there are three areas where community-based services do not provide better outcomes; 4) experiences are similar in different countries; 5) despite significant improvements people with intellectual disabilities are still one of the most disadvantaged groups of society.

1) Similar outcomes to earlier studies

Evaluation literature has largely focused on objective components of quality of life measurements (Verdugoet al., 2005), using standardised instruments. Community participation, choice, adaptive and challenging behaviours are the most often used outcome measures, but new issues have also received attention, such as psychotropic drug use, risks, and lifestyle-related risk factors.

Results have confirmed the picture that had emerged from previous research: people in small-scale community-based provision or in semi-independent or supported living arrangements have a better objective quality of life than people in large, congregate settings. Particularly, they have more choice-making opportunities; have larger social networks and more friends; access more mainstream facilities and participate more in community life; have more chances to acquire new skills and develop or maintain existing skills; and are more satisfied with their living arrangements. A recent unpublished review found similar results (Noonan Walsh et al., 2007).

2) Variability of outcomes

Although people generally have a better life in the community, research continues to highlight disparities within the same type of provision. These are particularly salient in the domains of community participation, social networks and self-determination. There are two main patterns of variability: variations in the outcomes associated with the characteristics of service users, and variations associated with the characteristics of the services.

Positive outcomes are generally associated with better adaptive skills and abilities, and people with high or complex support needs, including challenging behaviours are at greater risk of experiencing poorer outcomes in community services. The provision of ordinary environments is not enough to achieve quality and positive outcomes in community services (Mansell, Felce, Jenkins, de Kock, & Toogood, 1987). Felce (1998) argued that three factors are necessary to create real opportunities for people with more severe disabilities in community settings: available activity, available personal support and effective assistance. Mansell,Beadle-Brown, Macdonald, and Ashman (2003) found that, among a range of organisational and staff variables, adaptive behaviour and care practices were the only factors predictive of engagement in meaningful activities in community settings.

The variability of outcomes in community services might threaten the consensus supporting deinstitutionalisation and community living policies by removing the evidence that community services are better for everyone (Mansell, 2006). Recent debates on the worth of clustered arrangements seem to be evidence of this (Bigby, 2004; Cummins & Lau, 2004; Emerson, 2004).

Countries that implemented deinstitutionalisation now face the challenge of strengthening the implementation of community living. This requires more than the adoption of certain residential arrangements (Bigby, 2004). Evaluation research in these countries can be used to identify factors associated with positive outcomes and good practices in community living.

3) Three domains where community services do not perform better

Results also show that there are three outcome domains where community services might not do better than institutions: challenging behaviour, psychotropic medication and mortality. Challenging behaviour has long been shown not to be directly linked to community living (Emerson & Hatton, 1994; Kim, 2001). Many challenging behaviours are a response to demands in the environment. While institutions often are a low-demand environment, community services provide more stimulation and demands. Certain challenging behaviours are a predictable response to these .There is a wealth of research on interventions for challenging behaviour, but now priority should be given to put this into practice in services (Emerson, 2001).

Psychotropic medication is closely related to challenging behaviours. The most common reason for the use of psychotropic drugs in people with intellectual disabilities is the management of challenging behaviours even though their effectiveness is questionable (Matson et al., 2000). It has been suggested that community services are not well equipped to deal with challenging behaviours which then leads to the overuse of medication. Research has also shown that medication can be substantially reduced if adequate clinical and environmental conditions are put in place in services (Ahmed et al., 2000).

Mortality is generally considered to be an objective, quantifiable and comparable measure of health status. Institutions had very high mortality rates (see e.g. Rothman & Rothman, 2005). In the late 1990s an extensive debate developed in the US as to whether community placement was associated with higher mortality. Evidence is inconclusive because a large number of studies focussed on one geographical area (California) and on the same period (1993-99). The issue has received less attention elsewhere and those studies found different results. It was also suggested that results might be confounded by participant characteristics and increased mortality is not, therefore, necessarily the outcome of the residential setting (Sutherland, Couch, & Iacono, 2002).

4) Similar experiences across countries

Similar results were reported from countries with different welfare arrangements, socio-economic context and service structures. This suggests that the model of community living for adults with intellectual disabilities is not bound to certain countries and it can successfully be implemented in different situations. But the fact that studies come from only a handful of countries suggests that there is a gap in our understanding of residential supports for people with intellectual disabilities in other geographical areas and socio-cultural, political and economic settings. Deinstitutionalisation and community living policies are advocated by international organisations (such as the United Nations and the European Union) therefore more and more countries are likely to embark upon some form of deinstitutionalisation. To understand and monitor the dynamic and the outcomes of these processes as well as their impact on the lives of people with intellectual disabilities there is a need to carry out similar research in different political and cultural contexts.

5) The importance of normative evaluations

Better outcomes found in community services in comparison to congregate settings are not necessarily "good enough". The evidence suggests that many people with intellectual disabilities have poorer life experiences compared with the general population. They have limited community experience, social networks and choice-making opportunities. This should encourage researchers to make comparisons with the general population, including gender differences and uncover the disadvantages and discrimination people with intellectual disabilities face in our societies.

The process of deinstitutionalisation is far from complete; institutions still exist in many countries and community-based alternatives face serious challenges of implementation in the context of societal and economic changes (Bigby, 2004; Emerson, 2004; Fujiura & Parish, 2007; Mansell, 2006). Continued evidence of the relative merits of small, local services is likely to continue to be important. However, this review also identifies how research is moving beyond simple structural characteristics of services and is turning to explore variations in outcomes, understanding the organisational determinants of quality services. As large institutions disappear, the policy problem will become one of sustaining good outcomes for everyone in the community; and this will require understanding of the relative contribution of different factors in different circumstances. A further trend is the shift from comparison with the past to comparison with the future – with the life experience of the general population, including the impact of recent trends in our societies upon the lives of people with intellectual disabilities. Increasingly, researchers will need to focus on issues and use methods which apply to the whole population, including people with intellectual disabilities.

Table 3.1 Community presence and participation

Study	Country	N	Design	Results
Ager et al. (2001)	UK	76	L (1.6), QN	People moving from hospital (95+ residents) to community homes (1-10 residents) increased community participation, however most outings took place in groups.
Baker (2007)	UK	60	L (1.5), CS, QN	People resettling into staffed group homes (6 residents) from a hospital increased community participation. People already in community provision experienced no change in the same period.
Chou et al. (2007)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) had more community involvement than those in larger homes (max. 50 places) and institutions (50+ places).
Emerson (2004)	UK	910	CS, QN	People in community houses experienced better community participation than people in cluster housing (3 or more houses grouped together).
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1-8 residents) and intentional communities (28-179 residents on site) had higher community involvement than people living on campus settings (94-144 residents on site).
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1-3 residents) arrangements participated in more community activities than people in small (1-3 residents) or larger homes (4-6 residents).
Felce et al. (1998, 2000)	UK	34	CS, QN	People with severe challenging behaviour in community settings (1-9 residents) had higher community participation than those in hospitals (10-188 residents).
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) had higher level of community inclusion and participation than non-movers.

Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	People who relocated to community settings (1-18 residents) and ICF/MR settings (20 or more residents) had higher level of community integration than people who stayed in nursing homes (91-417 residents).
Howe, Horner et al. (1998)	USA	34	CS, QN	People in supported living arrangements (1-3 residents) had higher community participation than people in larger homes (2-20 residents).
McConkey (2007)	Ireland, UK	620	CS, QN	People in small homes (max. 6 residents), and dispersed and clustered supported living used more community amenities than people in large homes (avg. 20 residents) or in campus settings (100+ residents on site).
Stancliffe, Keane (2000).	Australia	54	CS, QN	People in semi-independent living arrangements (1-4 people living together) used more community facilities than people who lived in group homes (3-7 residents).
Stancliffe & Lakin (1998)	USA	187	CS, QN	People in community settings (2-15 residents) enjoyed greater community participation than residents in institutions (16+ residents).

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative
The number in parentheses indicates the length of the study in years.

Table 3.2 Social networks and friendships

Study	Country	N	Design	Results
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1-8 residents) and intentional communities (28-179 residents on site) had larger social networks than people living on campus settings (94-144 residents on site).
Emerson et al. (2000c)	UK	40	CS, QN	People in community homes (1-8 residents) had larger social networks than people living on campus settings (94-144 residents on site).
Emerson, McVilly (2004)	UK	1,542	CS, QN	People in smaller community-based settings (1-4 residents) and supported living arrangements (1-3 people living together) participated in more friendship activities than people in larger settings. Other setting characteristics (type of provision, staffing) were also important predictors of friendship activities.
Forrester-Jones et al. (2006)	UK	213	CS, QN, QL	People in small community homes (2-5 places), supported and independent living arrangements and hostels (6+ residents, variable staff support) had more reciprocal relationships than people in residential and nursing homes (6+ places, continuous staff support). Supported living and hostel residents reported more reciprocal relationships.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) visited more friends and received more visits than non-movers.
McConkey (2007)	Ireland, UK	620	CS, QN	People in clustered and dispersed supported living (1-3 people living together) were more likely to have friends and visitors from outside the home than people in small homes (max. 6 places), large homes (avg. 20 residents) or in campus settings (100+ residents on site).

Robertson, Emerson et al. (2001a)	UK	500	CS, QN, QL	People living in smaller community-based settings (1-8 residents) and intentional communities (28-179 residents on site) had larger social networks than people living on campus settings (94-144 residents on site).
Stancliffe, Keane (2000).	Australia	54	CS, QN	No difference was found in the reported loneliness of people in semi-independent living arrangements (1-4 people living together) and people living in group homes (3-7 residents).
Stancliffe, Lakin et al. (2007)	USA	1,002	CS, QN	People in larger settings (7-15 residents) reported greatest loneliness. People living alone did not report more loneliness than those in small (2-3 residents) settings.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.3 Family contact

Study	Country	N	Design	Results
Chou et al. (2007)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) received more family visits than those in group homes (max. 50 residents) and institutions (50+ residents).
Emerson et al. (2000b)	UK	500	CS, QN	No significant difference was found in the level of family contact in community homes (1-8 residents), intentional communities (28-179 residents on site) and campus settings (94-144 residents on site).
Emerson et al. (2000c)	UK	40	CS, QN	No significant difference was found between the level of family in community homes (1-8 residents) and in campus settings (94-144 residents on site).
Heller, Factor et al. (1998)	USA	232	L (3), QN	No difference was found in the frequency and pattern of family contact between people who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) and those who stayed.
McConkey, Walsh-Gallagher et al. (2005)	Ireland	106	CS, QN	No direct and significant relationship was found between type of accommodation (campus with 55 residents on site and homes with 5 residents) and family contact.
Spreat et al. (1998)	USA	80	L (5), CS, QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living arrangements (2-3 people living together) had increased contact with their families. People who remained in nursing homes experienced no change.
Stancliffe & Lakin (1998)	USA	187	CS, QN	People in community settings (2-15 residents) had more contact with their families than residents in institutions (16+ residents).
Stancliffe & Lakin (2006)	USA	155	L (4), CS, QN	People who moved from institutions (16+ residents) to community settings (2-15 residents) increased family

	contact that remained stable. People remaining in institutions experienced greater loss of contact over time.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.4 Self-determination and choice

Study	Country	N	Design	Results
Chou et al. (2007)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) and community homes (max. 50 residents) had more opportunity to make choices than those who lived in institutions (50+ residents).
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1-8 residents) had greater choice than people in intentional communities (28-179 residents on site) and people in campus settings (94-144 residents on site).
Emerson et al. (2000c)	UK	40	CS, QN	People in community housing (1-8 residents) had greater choice than people in campus settings (94-144 residents on site).
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1-3 people living together) had greater overall choice and more choice over with whom and where they lived than people in small group homes (1-3 residents) and large group homes (4-6 residents).
Felce et al. (1998, 2000)	UK	34, 34	CS, QN	People with severe challenging behaviour in community settings (1-9 residents) had higher autonomy than people in hospitals (10-188 residents).
Heller, Miller et al (1999)	USA	58	L (3), QN	People who relocated from nursing homes (91-417 residents) to community-based settings (1-92 residents, mean size = 8) increased their autonomy and choice-making opportunities.
Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	People who moved to small and more attractive community settings (1-18 residents)had more opportunity for choice-making, than people who remained in nursing homes (91-417 residents) or larger, less attractive settings (ICF/MR homes with 20 or more residents).
Kearney et al. (1998)	USA	122 67	CS, L (1.25), QN	People who moved to small community-based facilities (6 or fewer residents) from large institutions (99-

				270 residents) experienced an increase in choice availability.
Robertson, Emerson et al. (2001b)	UK	281	CS, QN	People in smaller community-based homes or supported living arrangements (1-3 people living together) and with more home-like architectural design had more opportunities for self-determination than people living in larger community homes (4-8 residents).
Saloviita, Aberg (2000)	Finland	54	CS, QN	People in group homes (5-12 residents) had more self-determination than people in institutions (99 residents).
Stancliffe & Abery (1997)	USA	127	L (3), CS, QN	People who moved from an institution (16+ residents on site) to community settings (2-16 residents) had greater choice-making opportunities than those who stayed in the institutions.
Stancliffe & Keane (2000)	Australia	54	CS, QN	People in semi-independent living arrangements (1-4 people living together) had more choice than people who lived in group homes (3-7 residents).
Stancliffe & Lakin (1998)	USA	187	CS, QN	People in smaller community homes (2-4 and 5-6 residents) had more choice than residents in institutions (16+ residents) and larger community settings (7-15 residents).
Stancliffe, Abery et al (2000)	USA	74	CS, QN	People in semi-independent living arrangements (up to 3 people living together) had more personal control and self-determination than those in HCBS Waiver homes (2-6 people in one building) and ICF/MR settings (4-44 residents in one building).
Wehmeyer, Bolding (1999)	USA	273	CS, QN	People who lived in non-congregate (1-3 people living together) and congregate (4-6 residents) community settings had greater opportunities for self-determination than people in congregate non-community settings (12 or more residents).
Young (2000, 2001), Young,	Australia	32, 95, 104	L (1.5; 1.5; 2.5), QN	People had greater choice-making opportunities after relocation from an institution (160 residents) to community settings (2-4 residents).

Ashman (2004a)				
Young (2006)	Australia	60	L (2.5), QN	People had greater choice-making opportunities after relocation from an institution (160 residents) to community settings (2-4 residents). People who lived in dispersed settings had more choice making opportunities, than people in clustered group homes (up to 20-25 people on one purpose-built site).
Young, Ashman (2004b)	Australia	104	L (2.5), QN	People in all age groups had greater choice-making opportunities after relocation from an institution (160 residents) to community homes (2-4 residents).

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.5 Quality of life

Study	Country	N	Design	Results
Ager et al. (2001)	UK	76	L (1.6), QN	People experienced better quality of life after moving from a long-stay hospital (95+ residents) to community homes (1-10 residents).
Golding et al. (2005)	UK	12	L (1), CS, QN	People had better quality of life following relocation from a hospital to specialist challenging behaviour community settings (6 residents).
Janssen, Vreeke et al. (1999)	Holland	199	CS, QN	People living in dispersed community homes (1-18 residents, mean 9) and in group homes clustered on the site of the institution (1-18 residents, mean 9) had similar quality of life.
Young (2000, 2001)	Australia	32, 95	L (1.5; 1.5), QN	People had better life circumstances after relocation from an institution (160 residents) to community settings (2-4 residents).
Young (2006)	Australia	60	L (2.5), QN	People had better life circumstances after relocation from an institution (160 residents) to dispersed (2-4 residents) and clustered community settings (2-4 residents/setting, up to 20-25 people on one purpose-built site). People in dispersed settings had better quality of life than those in clustered settings.
Young, Ashman (2004a, 2004b)	Australia	104, 104	L (2.5; 2.5), QN	People had better life circumstances after relocation from an institution (160 residents) to community homes (2-4 residents) but there are considerable variations among individuals and settings.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.6 Adaptive behaviour

Study	**Country**	**N**	**Design**	**Results**
Golding et al. (2005)	UK	12	L (1), CS, QN	People who relocated from a hospital to specialist challenging behaviour community settings (6 residents) gained domestic skills. People already living in community homes (6 residents) also showed improvements in adaptive skills.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) improved adaptive behaviours, while non-movers declined.
Heller, Miller et al. (2002)	USA	186	L (8), CS QN	People who moved to community settings (1-18 residents) and ICF/MR settings (20 or more residents) maintained their adaptive skills, while people who stayed in nursing homes (91-417 residents) declined.
Heller, Miller et al. (1998)	USA	268	L (3), QN	People who relocated from nursing homes (82-485 residents, mean 285) to community-based settings (2-48 residents, mean 8) showed gains in adaptive skills, particularly those who moved to smaller homes.
Kearney, Bergan et al. (1998)	USA	67	L (1.25), QN	People who moved from a large institution (99-270 residents) to community-based homes (6 or fewer residents) experienced positive changes in adaptive skills.
Lerman, Apgar et al. (2005)	USA	220 (160)	L (7), QN	People who moved from an institution (1,190 residents) to community-based settings experienced an overall improvement in adaptive skills while stayers maintained or declined their adaptive behaviours.
Macleod, Morrison et al.	UK	4	L (3), QN	People who moved from a long-stay hospital to a community home showed an increase in communication behaviours and an improvement in daily living skills as measured by standardised instruments. However direct observation showed a decrease

				in adaptive behaviours.
Spreat, Conroy et al. (1998)	USA	80	L (5), QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living arrangements (2-3 people living together) showed no changes in adaptive skills, but those who stayed in nursing homes experienced a decline.
Stancliffe, Hayden et al. (2002)	USA	285, 148	L (3), QN	Study 1: People who moved to small homes (1-5 residents) and those who stayed in the institution (16+ residents) had no changes in adaptive behaviour. People who moved to large homes (6-14 residents) showed a decline in adaptive behaviours. Study 2: People who moved to small community settings (1-5 residents) with more favourable staffing ratio experienced greater gains in adaptive behaviours than people who move to large settings (6-14 residents).
Young (2000)	Australia	32	L (1.5), QN	Relocation from an institution (160 residents) to community-based settings (2-4 residents) had no impact on standardised adaptive behaviour scores. Direct observation showed an increase in adaptive behaviours.
Young (2001)	Australia	95	L (1.5), QN	People who relocated from an institution (160 residents) to community-based settings (2-4 residents) improved their adaptive skills, particularly in self-care, economic activity and domestic skills.
Young (2006)	Australia	60	L (2.5), QN	People who moved from an institution (160 residents) to dispersed community settings (2-4 residents) showed greater improvements in adaptive skills than people who moved to clustered community-based settings (2-4 residents/setting, up to 20-25 people on one purpose-built site).
Young, Ashman (2004)	Australia	104	L (2.5), QN	People who relocated from an institution (160 residents) to community settings (2-4 residents) showed improvements in certain adaptive skills.
Young,	Australia	104	L (5),	People with mild/moderate ID had few

Ashman (2004)	QN	and non-significant gains in adaptive skills, people with severe/profound ID from all age groups gained most in terms of adaptive behaviour after relocation from an institution (160 residents) to community homes (2-4 residents).

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative; the number in parentheses indicates the length of the study in years.

Table 3.7 Challenging behaviour

Study	Country	N	Design	Results
Golding et al. (2005)	UK	12	L (1), CS, QN	People who relocated from a hospital to specialist challenging behaviour community settings (6 residents) decreased observed challenging behaviours but no changes in standardised scores. People already living in community settings (6 residents) showed no changes.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) and those who remained there showed no changes in challenging behaviour.
Hundert, et al. (2003)	Canada	17	L (1.3), QN	People who relocated from an institution (70 residents) to dispersed community-based settings (5 residents) maintained challenging behaviour at similar levels.
Macleod, Morrison et al.	UK	4	L (3), QN	People who moved from a large hospital to a community home showed an increase in challenging behaviour along with improvement in adaptive and communication skills.
Nøttestad, Linaker (1999)	Norway	109	L (8), QN	People who relocated from an institution (128 residents) to community settings showed increased aggression towards others, disruptive behaviour and passivity, but no changes in self-injury and destruction of objects.
Nøttestad, Linaker (2001)	Norway	68	L (8), QN	Development of self-injury after resettlement from an institution (128 residents) to community-based settings was not associated with setting size and type.
Nøttestad, Linaker (2002)	Norway	64	L (8), CS, QN	Development of aggressive behaviour after relocation from an institution (128 residents) to community-based settings was not associated with setting size and type.
Spreat, Conroy et al. (1998)	USA	80	L (5), CS, QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living

				arrangements (2-3 people living together) and people who stayed in nursing homes showed no changes in challenging behaviours.
Stancliffe, Hayden et al. (2002)	USA	285, 148	L (3), CS, QN	Study 1: Initial deterioration in challenging behaviour after relocation from an institution (16+ residents) to community settings (1-14 residents). On the longer term no difference from institutional levels of problem behaviour. Study 2: Changes in challenging behaviour were not related to community setting type (ICF/MR or HCBS Waiver).
Young (2000, 2001)	Australia	32, 95	L (1.5; 1.5), QN	People who moved from an institution (160 residents) to community-based settings (2-4 residents) showed no improvement in challenging behaviour.
Young (2006)	Australia	60	L (2.5), CS, QN	People who moved from an institution (160 residents) to dispersed community settings (2-4 residents) showed greater reduction in observed problem behaviours than people who moved to clustered community-based settings (2-4 residents/setting, up to 20-25 people on one purpose-built site). Relocation had no impact on standardised challenging behaviour scores.
Young, Ashman (2004a)	Australia	104	L (2.5), QN	Relocation from an institution (160 residents) to community-based settings (2-4 residents) had no impact on standardised challenging behaviour scores, but changes were observed in the nature of behaviours.
Young, Ashman (2004b)	Australia	104	L (5), CS, QN	People who moved from an institution (160 residents) to community-based settings (2-4 residents) showed no improvement in challenging behaviour.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.8 Treatment of challenging behaviour

Study	Country	N	Design	Results
Emerson et al. (2000a)	UK	500	CS, QN	Community-based homes (1-8 residents) were more likely to use sedation, campus settings (94-144 residents on site) used more physical restraint.
Feldman et al. (2004)	Canada	625	CS, QN	Institutions (300-700 residents), group homes, and independent/semi-independent living arrangements are not different in terms of formality of interventions to manage challenging behaviours.
Saloviita (2002)	Finland	261	CS, QN	People who lived in institution (159 residents) were subjected to more restrictive and negative practices to manage challenging behaviour than those in clustered community homes (5 residents/setting, 3 settings clustered together in the community) and group homes (5-10 residents)..
Stancliffe, Hayden et al. (1999)	USA	151	L (3), QN	People who moved to community-based settings (2-15 residents, mean 6.6) had more informal interventions to manage challenging behaviours. Participants who stayed in institutions (16+ residents) were more likely to receive formal interventions and professional behaviour support services.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.9 Psychotropic medication

Study	Country	N	Design	Results
Spreat, Conroy et al. (1998)	USA	80	L (5), CS, QN	People received less medication after relocation from nursing homes (avg. 50 residents) to supported living arrangements (2-3 people living together) than those who stayed in nursing homes.
Nøttestad, Linaker (2003)	Norway	109	L (8), QN	Number of people receiving medication before and after relocation from an institution (128 residents) to community settings declined non-significantly.
McGillivray, McCabe (2005)	Australia	762, 873	L (8), CS, QN	No difference between proportion of people in community settings and institutions who receive medication to manage challenging behaviours. Initial differences in level of drug use between institutions and community settings were reduced.
Robertson, Emerson et al. (2000a)	UK	500	CS, QN	People who live on campus settings (94-144 residents on site) are more likely to receive psychotropic medication and more than one type of psychotropic medication than people in intentional communities (28-179 residents on site) and community settings (1-8 residents).

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.10 Health and risk factors

Study	Country	N	Design	Results
Bryan et al. (2000)	UK	118	L (1), QN	People resettling from a long-stay hospital into small community homes increased the likelihood of experiencing unintentional weight changes.
Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	Moving to community settings (1-18 residents) and ICF/MR settings (20 or more residents)from nursing homes (91-417 residents) was not associated with changes in health status.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) benefited from improved physical health and mobility. Stayers had no similar gains.
Heller, Miller et al. (1998)	USA	268	L (3), CS, QN	People who relocated from nursing homes (size range 82-485 residents, mean 285) to community settings (2-48 residents, mean 8) had better health than non-movers.
Nøttestad, Linaker (1999)	Norway	109	L (8), QN	People who moved from an institution (128 residents) to community settings had high prevalence of psychiatric health problems before and after relocation, no changes were associated with the move.
Robertson, Emerson et al. (2000b)	UK	500	CS, QN	People who lived in campus settings (94-144 residents on site) were more likely to be inactive. People in less restrictive community settings (1-8 residents) were more likely to be obese, smoke and have a poor diet, and less likely to access regular health checks.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative ; the number in parentheses indicates the length of the study in years.

Table 3.11 Risks in the community

Study	Country	N	Design	Results
Emerson et al. (2000b)	UK	500	CS, QN	People in intentional communities (28-179 residents on site) were relatively less exposed to crime and (verbal) abuse than people in community (1-8 residents) or campus settings (94-144 residents on site). Community settings were safer in terms of accidents.
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1-3 residents) arrangements were perceived to be at higher risk of abuse than people in small group homes (1-3 residents) or larger group homes (4-6 residents).
Stancliffe, Keane (2000).	Australia	54	CS, QN	No difference in the perceived safety of people in semi-independent living arrangements (1-4 people living together) and people living in group homes (3-7 residents).

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative.

Table 3.12 Mortality

Study	Country	N	Design	Results
Conroy & Adler (1998)	USA	1,154	L (8), QN	Decreased mortality was associated with the resettlement of the residents (1,154) of an institution (1,154 residents) in community settings.
Lerman, et al. (2003)	USA	300	L (7), QN	Resettlement from institutions to community settings was not associated with increased risk of mortality.
O'Brien & Zaharia (1998)	USA	6,810	L (5), CS, QN	Resettlement from institutions to community settings was not associated with increased risk of mortality. Mortality rates in community facilities were declining.
Read (2004)	UK	111	L (1.5), QN	Higher mortality after relocation from hospital to community settings was not associated with service factors.
Shavelle, Strauss (1999)	USA	1,812	L (1), CS, QN	Update of the 1998 study by Strauss, Shavelle et al. Again found greater risk of mortality for those moving to community settings from an institution than those staying.
Shavelle, Strauss, Day (2005)	USA	1,776	L (3), CS, QN	Greater risk of mortality was found in community settings than in institutions.
Strauss, Anderson et al. (1998)	USA	48	CS, QN	Similar causes of death among institutional and community residents.
Strauss, Kastner et al. (1998)	USA	22,576	L (10), CS, QN	Risk-factor adjusted mortality was found to be higher in community settings than in institutions.
Strauss, Shavelle et al. (1998b)	USA	1,878	L (3), CS, QN	Greater risk of mortality was associated with resettlement from institutions in community settings. The risk was higher shortly after the move..
Strauss, Shavelle et al. (1998a)	USA	520	L (14), CS, QN	Certain external causes of death are more common in community settings than in institutions and *vice versa*.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative; the number in parentheses indicates the length of the study in years.

Table 3.13 User and family satisfaction

Study	Country	N	Design	Results
Gregory et al. (2001)	UK	96	CS, QL	Service users expressed high overall satisfaction in community homes (1-8 residents), intentional communities (28-179 residents on site), and campus settings (94-144 residents on site). Residents of intentional communities were more satisfied with certain aspects of their lives.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) were more satisfied with their living arrangement and lifestyle than non-movers.
McConkey, McConaghie et al. (2003)	UK	39, 34	L (5), QL, QN	Service users and their families were more satisfied with community settings (2-36 residents) than with hospitals.
O'Brien (2001)	New Zealand	46 staff, 22 parents, 9 service users	L (9), QL	Service users, families and staff viewed relocation from an institution (61 residents) to community settings (5 residents) as clearly positive.
Tøssebro, Lundeby (2006)	Norway	222, 176	L (12), QN	Families expressed more satisfaction with community care than with institutions. Positive opinion remained stable longitudinally.
Walsh, Linehan et al. (2001)	UK, Ireland	291	CS, QN	Families were more satisfied with current living arrangements, community homes (1-8 residents), intentional communities (28-179 residents on site), and campus settings (94-144 residents on site), than with previous living arrangements, including hospital provision.

Note. CS=cross-sectional; L=longitudinal; QN=quantitative; QL=qualitative; the number in parentheses indicates the length of the study in years.

Chapter 4 Research Question and General Methods

The first part of the thesis reviewed the experiences of deinstitutionalisation from three perspectives: trends, policy change and individual outcomes.Information came from a small number of countries where the replacement of institutions with community-based services had advanced most.

Recent research revealed that approximately 1.2 million people live in residential settings for people with disabilities across Europe, many of them in large institutional facilities (Mansell et al. 2007). Estimated rates of institutionalisation are highest in countries of Central and Eastern Europe (ibid, p. 32) and these countries have been known to provide poor quality institutional care. There have been various reports by the media and human rights watchdogs revealing abuses in institutions in Bulgaria, Croatia, the Czech Repubic[9], Romania and Serbia (Ahern & Rosenthal, 2006, 2007; Freyhoff et al., 2004; Tavanier, 2010).Deinstitutionalisation is advocated by international organisations including the European Union, the Council of Europe and the United Nations and the reform of institutions has been on the policy agenda in many of Central and Eastern European countries for over a decade but progress seems very slow or non-existent (Vann and Siska, 2006; ECCL, 2010).

Research in countries where deinstitutionalisation and community living is well advancedshowed that policy change and implementation are complex processes and depend on local circumstances and conditions. Chapter 2 argued that deinstitutionalisation was driven by multiple forces and identified some common themes such as scandals, public support for deinstitutionalisaiton policies, ideologies, policy learning, and the influence of advocacy coalitions. There is limited information on residential care policies, policy change, structural characteristics of services and service user outcomes in other parts of the world and it is not well understood why despite international attention and support the deinstitutionalisation and community living policies seem to be weak in Central and Eastern Europe.

Therefore the purpose of this dissertation is to explore policy change, challenges and outcomes of deinstitutionalisation and community-based care using Hungary, a country in Central Europe as a case study. It is also hoped that the research will contribute to the general study of social care that is an increasingly popular subject in comparative and theoretical policy analysis, however it has been a largely neglected area in the analysis of policy change (Daly 2002).

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[9] Retrieved from: http://news.bbc.co.uk/1/hi/world/europe/7189556.stm (last accessed: 02/01/2012).

So far the analysis of social policy in Eastern and Central Europe generally concentrated on macro-level issues such as social expenditure or areas of 'decommodification' (e.g. pension systems, social benefits etc.) that constitute the traditional focus of welfare state models (Esping-Andersen, 1996). Welfare state models have been criticised for generalising about all forms of social policy provision based on cash benefits, even though welfare services – health care and social care – may account for greater differences between countries (Bambra 2005; Jensen 2008). Kasza (2002) for example questioned the utility of welfare regime typologies altogether, arguing that welfare programmes are a "contradictory and disjointed set of policies that are far from constituting a coherent whole of any sort" due to the inherent characteristics of policy making (p. 272-73). These include:

- Incrementalism and the cumulative nature of policy making;
- Diverse policy histories as a source of inconsistencies. Governments alter policies at different times and contexts or in other words policy change is idiosyncratic.
- Different actors in the policy process;
- Variations in the policy making process that may produce different policy outcomes in terms of ideology and values;
- Different levels and patterns of policy transfer in different areas.

Hungary is one of the post-socialist transition countries in Central Europe. In 1989 the governing Socialist Workers' Party and the democratic opposition negotiated a full political opening and electoral reform (Munck & Leff, 1997). The first competitive multi-party elections were held in more than 40 years in 1990. Political transition was rapidly followed by an economic crisis resulting from the collapse of former-Communist markets and production systems. Hungary experienced a dramatic drop in GDP, high inflation, and the growth of unemployment for a number of years. From 1995 the economy got on a path of recovery, the GDP started to grow again and in 1999 it reached its pre-1990 level (Ferge, 2002). Economic problems started to mount again from the early 2000s with high debt and budget deficit. The country joined the European Union on May 1, 2004. In 2008 the global financial crisis hit Hungary especially hard because of the weaknesses of its fiscal policy, and the country escaped bankruptcy with an IMF loan and austerity measures.

As regards social policies, the democratically elected government in 1990 inherited a welfare system that was characterised by the provision of cheap housing and transport, highly subsidised food prices, 'free' healthcare, education, and full employment. In Deacon's (2000) words this welfare system "was economically inefficient and insensitive to welfare and consumer needs" (p. 147) and it was no longer sustainable after the collapse of the socialist economic system. Social conditions started to deteriorate; poverty and unemployment were rising rapidly. This called for new policy responses to off-set the negative impact of transition and to facilitate the implementation of economic reforms. As put by Pestoff (1997), social policy was "being disentangled" from the policies and institutions it had been embedded during communism (p. 178). Deacon (2000) suggested that these policy responses were characterised by the following features and they were broadly similar in most Eastern and Central European countries:

- An ad hoc approach to the development of benefits, including assistance to the unemployed.
- A withdrawal of subsidies on goods and services, such as housing, energy prices, food etc. without mechanisms to offset the impact on the most vulnerable – the elderly, the long-term unemployed and large families.
- Privatisation of some health and social care provision without the development of consumer choice and competitive markets.
- The decentralisation of social provision including some benefit schemes to local governments without providing the adequate financial resources, and a strong element of discretion.
- Appeals to voluntary sector to fill in gaps in social services without the provision of adequate financial resources and legal framework.

Another characteristic of the social policy reforms was the influence of international organisations – the World Bank and the International Monetary Fund and from the mid-1990s the European Union – that exerted different levels of coercion and ideological influence on certain policy areas.

4.1 Research questions and methods

Deinstitutionalisation has been on the policy agenda in Hungary since 1998 when the Parliament adopted the Act on Equal Opportunities for People with Disabilities that set 2010 as the deadline for the "modernisation" of residential services and stipulated that "people who are capable to live more independently should be cared for in small-scale settings." Ten years on progress seems very slow: in 2000 there were a total of 15,322 long-stay residential places out of which 123 were group homes, in 2008 there were 1,378 group home places out of a total of 16,174 (CSO, 2009). According to the official narrative the Government is committed to deinstitutionalisation, they have been implementing it for over ten years but progress is slow due to the lack of financial resources. The alternative narrative is represented by advocacy organisations and even some civil servants who argue that there has been no policy change in residential care and the Government continues to support the segregation of people with intellectual disabilities in institutions. The gap between the Government's rhetoric of deinstitutionalisation and actual policies is revealed by the following statement:

> The National Program on Disability, as well as the Act on Equal Opportunties for People with Disabilities, set the target to abolish institutions step by step. The aim is that those who can live on their own or with only a certain type of supportive service could live in independent houses or in other forms of community based living. Besides deinstitutionalisation, modernisation of current institutions is also a priority.
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> . . . .
>
> Though the deadline of deinstitutionalisation is 2010, it is most likely that the programme will not be finished by then due to the lack of financial resources. (DHLG, 2009, p. 92)

The understanding of the dynamics of residential care policies for people with intellectual disabilities in Hungary is limited. What are the dynamics of policy change? Is there a transition from institutions to community-based care? What makes institutions so resistant to change? What are the characteristics of the alternative arrangements? Do community-based settings provide similar outcomes to service users as in other countries where deinstitutionalisation and community-based care is well advanced?

Based on the lessons drawn from the first part of the dissertation, the research looks at two areas for answers. Part 2 of the thesis concentrates on policies. Chapter 6 offers an account and interpretation of policy development using the theoretical models of policy change presented in Part 1. Chapter 7 provides a critical analysis of existing policies and examines their impact on institutions and community living. Part 3 discusses the findings of a field study that compares the characteristics and quality of life outcomes of different residential arrangements.

The research draws on a range of methods and sources. The analysis of government documents, statistics and the secondary analysis of published data form the basis of Chapters5, 6 and 7.Participant observation, informal and formal, semi-structured interviews were used in collecting data for Chapter 6. Seven policy makers at various levels and units of the Government and other participants of the policy process

– representatives of non-governmental organisations – were interviewed in 2008 using a semi-structured format (see Annex 1). The interviewees were selected on the basis of their role and potential contribution to deinstitutionalisation in Hungary based on prior knowledge of the field. An important source of quantitative data throughout the dissertation is a survey on the situation of people with intellectual disabilities and their families conducted in 2007. Part 3 of the dissertation is based on data collected in residential services in Hungary. Chapter 8 gives a detailed description of the methods and implementation of the field work.

The use of multiple methods and approaches was justified by the complexity of the area that was already demonstrated in Part 1 of the thesis. The use ofmultiplemethods – policy analysis and empirical field work – offers the advantage of identifying and explaining different aspects of the problem. The analysis of secondary sources of data is an effective way of complementing the data collected in the field work. With limited resources – time and knowledge of local languages – focusing on a single country, as opposed to a comparative study, allows a more in-depth analysis.

The methodological approach adopted by the thesisalso has some disadvantages that need to be acknowledged and addressed. First, it is difficult to control the quantity and quality of information from secondary sources. Thereforewhenever available, official data published by the Central Statistical Office was used. If no official statistics were available, data was cross-checked from other sources. Second, concentrating on a single country challenges the generalisibility of findings. Therefore, wherever possible comparisons were made with other countries, however this is limited due the availability of comparable data. Nevertheless it is hoped that the dissertation will offer some useful ideas and inspire further research in deinstitutionalisation in other countries.Finally, participant observation in the policy process might raise some ethical issues and questions about the position and values of the researcher.

The standpoint of this thesis is rooted in the human rights movement and the social model of disability most recently embraced by the UN Convention on the Rights of Persons with Disability in that it accepts that people with disabilities have equal right to live in the community with whatever assistance they need. The researcher has no claims of “objectivity” and “detachment” rather it aims to undertake “committed research” by being committed and an active participant of the deinstitutionalisation movement in Hungary (Stone and Priestly 1996).

One of the main sources of quantitative data throughout the dissertation has been the survey on the living conditions of people with intellectual disabilities in Hungary commissioned by the Government in

2007.This followed an earlier, smaller-scale study on the situation of families with children with profound and multiple intellectual disabilities (Bass 2004) that did not include individuals living in residential settings. I had access to the full data file in SPSS format because I was involved in the survey in two ways: I was asked to comment on the draftmethods and questionnaire and later to write a book chapter on the situation of people living in residential settings using the information from the survey.[10]This allowed some, although rather limited input into the design of the survey to make sure it was adequate to gather information on service users in residential care. As a result questions on relationships and the Index of Community Involvement (Raynes 1994) were added to the questionnaire (see Annex 2 for the translated survey questionnaire).

Data from this survey is used throughout Chapters 5-11 and it is referred to as *2007 Survey* or *survey on the living conditions of people with intellectual disabilities*. The survey (Bass 2008) explored:

- The demographic characteristics of people with intellectual disabilities, including their age, gender and regional distribution.
- The diagnosis and aetiology of intellectual disability, the health status and the level of unmet health needs of individuals, including discrimination faced in the health care system.
- The socio-economic situation of people with intellectual disabilities and their families, including education, income, employment status and housing situation.
- Access to and take-up of services, including education, support services, residential care etc.
- The social network and relationships of individuals with intellectual disabilities and their families.

It used a stratified sample based on age, severity of disability, gender and county of 750 individuals taken from the register of local governments. Selected participants were contacted to arrange a home visit. If the individual lived in a long-stay institution, researchers visited the facility. The purpose of the visit was to fill in a questionnaire with proxy respondents, parents or carers. The final sample had 721 participants, 39 individuals could not be contacted or refused participation.

The questionnaire had two parts; the first explored all of the above areas and it was designed for family respondents. The second part of the questionnaire consisted of 18 questions and was only administered for those in long-stay residential care, in addition to the first part. The questions in this section aimed to explore the reasons for

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[10] Published as Kozma, A. (2008).Az intézetben élő értelmi fogyatékos emberek helyzete. in. Bass, L. *Amit tudunk és amit nem az értelmi fogyatékos emberek helyzetéről Magyarországon*. Budapest, Kézenfogva Alapítvány. pp157-79.

institutionalisation and some important aspects of life in institutions – relationships, conflicts, services etc. It was expected that the first part of the questionnaire would provide relevant information on other domains such as challenging behaviour, health, daily routine, guardianship etc. for people living in residential care and would allow comparison of the two groups.

The survey had a number of limitations and methodological weaknesses that need to be acknowledged. Firstly, the sampling methods meant that the sample was younger than the general population with intellectual disabilities. Secondly, the validity of the survey might have been compromised by the lack of established measures and the heterogeneity of proxy respondents used. There was no information about the reliability of the data. Finally, there was a large amount of missing data as a result of inadequate training or confusing questionnaire layout. The limitations of the survey are discussed in more detail in Chapter 11.

Part 2
Policy and Practice in Hungary

Chapter 5 Definition, Diagnosis and Prevalence of Intellectual Disability and Earlier Research on Residential Provision in Hungary

The first part of this chapter presents the definition, diagnosis and prevalence of intellectual disabilities in Hungary and it is intended as a background to the subsequent chapters of the thesis. The second reviews existing research on deinstitutionalisation and residential provision for people with intellectual disabilities. The third part compares the characteristics and living conditions of people with intellectual disabilities who live with their families and those who live in a residential setting using data from the 2007 Survey.

5.1 Definition and prevalence of intellectual disability

The current terminology for intellectual disability in Hungary is *értelmi fogyatékosság* (people with intellectual disability are referred to as *értelmi fogyatékos emberek*). Other, less commonly used but equally accepted terminology includes *értelmi akadályozottság* or *értelmi sérülés* (intellectual impairment) and *intellektuális fogyatékosság* (intellectual disability). The law defines intellectual disability as a significant impairment of cognitive functioning and limited communication which have a long-term negative impact on social functioning (1998. évi XXVI. törvény). In addition, there is an age of onset criterion as well which is generally "the early age" or "developmental years".

The diagnosis of intellectual disability is usually established by a doctor or the Expert and Rehabilitation Committee of Learning Abilities (*Tanulási képességet vizsgáló szakértői és rehabilitációs bizottság*, ERC) which is a formal tribunal and part of local governments' Special Educational Service (*Pedagógiai szakszolgálat*). All children who show signs of a special educational need, including a cognitive delay/learning difficulty/intellectual disability are asssessed by these committees that also make referrals to specialist services (e.g. early development, behaviour support services etc.) and special education, and may also establish eligibility for admission to residential care (14/1994. MKM rendelet).

There are no single diagnostic criteria in Hungary and there is considerable inconsistency and disparity in diagnostic practices depending on the organisation that establishes the diagnosis and particularly in the diagnosis autism spectrum disorder or severe and multiple disabilities (Vekerdy-Nagy, 2008). While the medical diagnosis typically concentrates on the aetiology and symptoms of the impairment, rehabilitation committees usually focus on intellectual functioning as measured by standard IQ-tests (idid). ERCs use IQ-based criteria –

generally an IQ below 70 – in the diagnosis of intellectual disability without considering the impairment of social or adaptive functioning.

According to the 2007 Survey on the living conditions of people with intellectual disabilities 47% of individuals (n = 308) were diagnosed by doctors – a minority of them by general practicioners (3%) and the majority (44%) by specialists. In a further 11% of the cases (n = 72) the diagnosis of disability was already established at birth in the hospital, and 34% (n = 223) were diagnosed by an ERC. The average age for diagnosis was 3 years, 76.5% of children (n = 483) were diagnosed before statutory schooling age (6 years) and 97% (n = 612) received a diagnosis by the age of 10.

The literature makes a distinction between 'true' and 'administrative' or 'ascertained' prevalence of intellectual disability (Roeleveld, Zielhuis & Gabreëls, 1997; McConkey et al. 2006). The administrative prevalence is the number of people with intellectual disabilities recorded by authorities usually on the basis of access to services or benefits. The true prevalence is the total number of people with intellectual disabilities in a population whether or not they use services or receive payments. However, as McConkey et al. (2006) point out in countries with national coverage of services administrative and true prevalence of intellectual disability are probably very similar, particularly among adults or children of school age. To date there are no true prevalence studies in Hungary, most studies use administrative data sources or attempt to estimate true prevalence on the basis of administrative data.

The only epidemiological study of intellectual disabilities is the "Budapest study" from the early 1970s (Czeizel, Lányi-Engelmayer,& Rátai, 1978; Czeizel, Lányi-Engelmayer,Klujber, Métneki, & Tusnády, 1980). This was a comprehensive aetiological study of 1,364 children with intellectual disabilities aged 7-14 years in Budapest in 1971-72. The sample represented approximately 50% of all children in special schools and residential institutions in Budapest. The examination included genetic testing, full medical examination, and information on the physical and intellectual development, adaptive skills, speech development and psychometric tests (including the Stanford-Binet Intelligence Scale). In addition the team explored the socio-economic backgrounds of the families of children with intellectual disabilities and a matched group of 317 children.

Two broad categories of intellectual disability were defined on the basis of the aetiological characteristics: the "pathological" group included children with an intellectual disability clearly attributable to the presence of genetic, cerebral or somatic factors or a reliable medical history. The other group termed "familial-cultural intellectual disability" included those children who had no specific aetiological factors, no history of cerebral injuries, somatic or genetic disorders and at least two members of the immediate family attended either a special school or left school before completing the first four grades of primary education and their "IQ level was apparently much below the average according to the estimation of the interviewers". This method was shown to be reliable to estimate IQ levels.

Out of those children with a known aetiology (n = 1,104) 48.9% had "pathological" intellectual disability and 51.1% had "familial-cultural" intellectual disability. On the basis of the study Czeizel et al. estimated the true prevalence of intellectual disability among children aged 7-14 in Hungary at 3.3%; the prevalence of mild and moderate ID around 3% and the prevalence of severe and profound ID at 0.3%. It was also suggested that the prevalence of "familial-cultural" intellectual disability was approximately 2.1-2.6% in the children population. They found very high occurrence of intellectual disability among parents of these children; approximately 33.4% of mothers and 21.2% of fathers were thought to have ID in contrast to around 1% of the control group. It was argued that the relatively high prevalence of intellectual disability in these families was attributable to the following factors:

- The number of children in these families was more than twice the average which was just under two children/family. In contrast, the mean number of children in families where both parents had an intellectual disability was 6.35, where only the father had ID it was 6.44, where only the mother had ID it was 5.04.
- Higher rates of first cousin marriages or incestuous relationships.
- Low income and poor living conditions.

The authors also compared their findings to similar studies in the USA and the UK (Moser & Wolf 1971; Kushlick & Cox 1967; Kushlick & Blunden 1974 cited in Czeizel et al. 1980) and found that the prevalence of major epidemiological groups was largely comparable to those reported elsewhere, including the high prevalence of "familial-cultural" intellectual disabilities.

In another study Lányi-Engelmayer, Katona and Czeizel (1983) noted a 4.4-fold increase in the administrative prevalence of intellectual disabilities in Hungary between 1954 and 1975. This was partly attributed to changes in the definition and diagnosis of intellectual disability, and an improvement in data collection. But they also highlighted life-style factors contributing to increased prevalence, such as:

- High rate of low-birth weight and premature babies as a result of smoking during pregnancy and high numbers of induced abortions.
- Heavy alcohol consumption among pregnant women – it was suggested that seven percent of ID cases were attributable to this.

- A low birth rate and an increased risk of perinatal problems for first-borns.

Although these studies are a useful source of information, a few limitations need to be highlighted:

- They are not up to date and there might have been important changes as a result of the development of health-care, prenatal screening and maternity services (e.g. a decline in the pre- and perinatal causes of ID etc.).
- The sample was taken from school-age children receiving either educational or health (social) care services. It does not take into account infant mortality and those who were not receiving any services, most likely children with severe or multiple disabilities who were looked after at home. Also, some children with intellectual disabilities from Budapest would be placed in institutions elsewhere due to a shortage of places in the capital. Therefore the study might underestimate the prevalance of severe and "pathological" intellectual disability.
- On the other hand it might overestimate the prevalence of "familial-cultural" ID because some of these children (just like their parents) would lose the label of intellectual disability and would not need any specialist services in adulthood.

The current prevalence of intellectual disability in Hungary can be estimated using various data sources (Bass 2008). One of these is the 2001 Population Census (KSH, 2001) which asked whether the individual had a disability and if yes, what type. The reliability and validity of the data are however questionable, because response was voluntary and unclear categories were used.[11] For example there was no age of onset criterion for intellectual disability, therefore older people with dementia might have been included among those with an intellectual disability (as it is indeed suggested by the increase in the prevalence of ID in the oldest age group, see Table 5.1). The census might also

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[11] Questions 25.1-25.3 of the Census Questionnaire asked about disability. The Hungarian and the English questionnaires can be retrieved from http://www.nepszamlalas.hu (last accessed: 10/05/2010). An alternative translation is presented here which reflects better the original Hungarian terminology. Response was voluntary and the questions were as follows:
25.1 What type of disability do you have? (please indicate no more than 3 answers) 0, no disability; 1, impaired mobility; 2, missing limb; 3, other physical impairment; 4, intellectual disability; 5, hard of hearing; 6, deaf; 7, speech impairment; 8, mute; 9, deaf-mute; 10, partially sighted; 11, blind in one eye; 12, blind; 13, other; 99, prefer not to answer.
25.2. If you have more than one type of disability, please indicate which one is the most serious? 25.3. What caused your disability? If you have more than one disability, what caused your most serious disability? 1, congenital; 2, accident; 3, illness; 4, don't know.

underreport the prevalence of intellectual disability, particularly in younger age groups where there has been no diagnosis yet and among people with mild intellectual disabilities, although most of these people do not need special help or services.

Table 5.1 Prevalence of ID in the 2001 Population Census

Age groups	PWID	Total population	Prevalence (%)
0–4	986	488,456	0.2
5–9	3,543	581,985	0.61
10–14	6,021	624,495	0.96
15–19	5,505	668,609	0.82
20–24	5,309	809,302	0.66
25–29	5,126	786,991	0.65
30–34	4,455	700,857	0.64
35–39	3,691	608,734	0.61
40–44	3,881	708,584	0.55
45–49	3,958	824,725	0.48
50–54	3,128	704,742	0.44
55–59	2,531	609,276	0.42
60–64	2,257	535,309	0.42
65–69	1,920	490,297	0.39
70–74	1,630	437,347	0.37
75–79	1,501	338,823	0.44
80–84	706	154,224	0.46
85–X	815	125,559	0.65
Total	**56,963**	**10,198,315**	**0.56**

Note. Data from the 2001 Population Census (KSH, 2001)

The National Register of Congenital Disorders (*Veleszületett Rendellenességek Országos Nyilvántartása*) was established in 1970. It records all congenital disorders diagnosed either prenatally or within 1 year of birth. Therefore the scope of the register is on the one hand broader as it includes developmental disorders as well (e.g. tumours, cardiovascular, musculosceletal disorders etc.) that do not necessarily lead to intellectual disability. On the other hand it is narrower because it only includes those cases of intellectual disability that can be diagnosed at a very young age (mainly chromosomal disorders, cephalic disorders etc.). Most recent data from 2007 put the prevalence of congenital disorders at birth at 5.3% (Valek 2009). Other potentially useful administrative sources to estimate the prevalence of intellectual disability include the number of people using certain services (education and residential care) and the number of people claiming certain benefits. However these all have their limitations: in some cases they include people with all types of disability.

The most useful and reliable data source is probably the database of Expert and Rehabilitation Committee of Learning Abilities thathave been assessing all children with disabilities since the mid-1970s. However, these have some limitations too: children with severe and profound intellectual disabilities had not been assessed before 1993 because they were excluded from public education. Furthermore individuals aged over 40-45 years and very young children (under three years of age) are not represented or are underrepresented in the database. In 2008 there were 20.939 individuals in this database and the average number of new diagnosis of intellectual disability each year has been around 900 since 1993 (Bass, 2008).

Using the above sources and adjusting for increased mortality in certain groups, Bass (2008) estimated the prevalence of people with intellectual disability at approximately one percent of the total population, around 100,000 people. The prevalence of moderate and severe ID (an IQ of less than 50) was estimated to be 0.55-0.65% of the total population, which corresponds to 55-65,000 people. Within this approximately 11-13,000 people were thought to have severe and profound intellectual disabilities and 43-55,000 people moderate intellectual disability in Hungary.

It is difficult to make comparisons with prevalence rates reported in other countries due to methodological issues. The commonly reported prevalence rates for severe intellectual disabilities (approximately an IQ of less than 50) are between 0.3% and 0.4% of the population (McConkey, et al., 2006) The prevalence rates of moderate, severe and profound ID seem slightly higher in Hungary than those reported in some other European countries (IDRESNetwork, 2003). For example in England 0.47% of the adult population were known users of disability services, mainly people with moderate to profound ID (Emerson & Hatton 2008).

5.2 Earlier research on residential provision in Hungary

This chapter reviews earlier research on residential provision in Hungary. Unlike in other countries such as the UK where a considerable body of research exists on different aspects of residential provision for people with intellectual disability from care practices to individual quality of life outcomes, research in Hungary is very limited. This chapter reviews all research published in any format (book, book chapter, research report etc.) that could be identified; the only inclusion criteria was that the research provides information either on living conditions in residential settings or the quality of life of service users.

The first and to date the most comprehensive study of Hungarian institutions is from the early 1980s (Horváth, 1988). The study used stratified sampling to select a representative sample of 49 institutions of the total 254 facilities operational in 1982. The sample included 27 homes for the elderly (16% of the total provision), 22 institutions for people with mental health problems and intellectual disabilities (25% of total provision). Data collection took place in 1983 and 1984 and covered the physical conditions, staff characteristics, services, management and care practices in institutions. Horváth also selected a sub-sample of 16 institutions where she collected further data on staff and service users and conducted in-depth interviews and observations. The study revealed poor physical conditions and inadequate care practices particularly in intellectual disability and mental health institutions. Some of the main findings are summarised here.

Fifty-nine percent of service users (68% in mental health institutions) had four square metres or less personal space (approximately 43 square feet), 70% slept in bedrooms with four or more beds (76% in mental health institutions) and 15.6% of users shared the bedroom with six or more people (29.2% in mental health). Approximately a third of the homes had either twin beds or bunk beds. Horváth argued that overcrowding increased between 1960 and 1980 because the increase in the number of places was not accompanied by the development of the physical infrastructure. It was also noted that some bedrooms could only be accessed through other bedrooms (sometimes up to three) – a common feature in old mansions and palaces. Buildings were described as "bleak", "damp" and "dark". Researchers also noted unpleasent smells and cold temperatures indoors.

Seventy-eight percent of service users shared a toilet with at least ten others and researchers found many toilet facilities without partitions and doors. Thirty-eight percent used bathrooms shared by 31-40 people and 30% had to share with more than 50 people. Researchers also found wards without running water and toilet facilities. Intellectual disability institutions had less favourable qualified-staff-to-resident ratio compared to homes for the elderly and mental health institutions. The staff-to-resident ratio was less than one staff to ten residents in the majority of institutions. Staff presence at night was particularly low: 55% of people lived in institutions where there was one night staff for 50 or more residents including people with severe intellectual disabilities and complex needs. As regards daily life in institutions the study focused more on institutions for the elderly and highlighted the idleness, the lack of opportunities for meaningful day activities and the tensions and conflicts between staff and residents and among residents, many of which ended in aggression.

The Deinstitutionalisation Initiative of the Hungarian Soros Foundation supported some research in institutions in the late 1990s. Demeter (1998) and Bánfalvy (1998) surveyed living conditions and quality of life in long-stay institutions for people with intellectual disabilities. Demeter – who himself was the manager of an institution – surveyed 191 institutions providing care for people with intellectual disabilities using a postal questionnaire. His aim was to describe the characteristics of the settings, the services and the service users, with special attention to those who moved out to group homes. There were 14 institutions that had one or more group homes in 1996.

Out of the 191 institutions 105 returned the questionnaire, which was a response rate of 56%. Demeter put forward two main conclusions. First, institutions were typically far from cities, villages and communities in general, and the majority of buildings were inadequate for the purpose, particularly the old palaces and mansion houses that accommodated a large number of services. He also highlighted the constant conflict between the management of these institutions and the agency responsible for listed buildings. Services were often far from the original place of residence and families of people with intellectual disabilities which made it more difficult to maintain family contact. The location of institutions had a negative impact on the community participation and the employment prospects of the service users. It also had financial implications and meant extra expenses for organising transport for staff and residents in the absence of adequate public transport. The second main conclusion was that institutions lacked adequate staff. There were not enough therapists and specialist staff, some institutions had no specialist staff at all. There was a high percentage of staff with no qualifications.

Demeter noted that the first initiatives to move service users out of institutions to the community came from service users; people with mild intellectual disabilities who wanted to live an ordinary life.These ideas were then endorsed by a senior staff member or manager who also had good working relations with the county council and could secure additional funding. The commitment and capability of staff to implement these projects were a key factor.Institutions used a wide range of innovative funding solutions and the projects were largely driven by the needs of users.

Demeter reported a total of 232 service users who lived in group homes in 1997-98, out of them 186 people had intellectual disabilities and 46 people had physical disabilities. The 186 service users represented just over 2% of the total number of users with an intellectual disability in the institutions responding to the questionnaire (8,056). The majority (65%) of people who had moved out to group homes had mild intellectual disabilities,16% had moderate intellectual disability and for 19% the severity of their disability was not reported. In comparison, in the same institutions 35% of service users were reported to have a mild, 53% a moderate and 12% severe or profound intellectual disability. The group that moved out was also relatively young: 10% were aged 20 years or under, 30% were aged between 21-30 years and 60% were aged between 31-40 years. He also noted the relatively high number of Romani service users among those moving to group homes (although no numbers were reported).

Demeter concluded that the absence of any legal frameworks or requirements for community-based care seemed rather irrelevant from the point of view of organisations.[12] What mattered were the lack of any financial incentives and the presence of financial disincentives to deinstitutionalisation initiatives. It was also pointed out that better coordination was needed to promote deinstitutionalisation in Hungary. Although there was no opposition, there were many sceptics who questioned the possibility of community inclusion of people with intellectual disabilities or the financial feasibility of community living. Finally Demeter suggested that orthopedagogy should take "ownership" of deinstitutionalisation and promote it as a new trend.

Bánfalvy (1998) looked at the quality of life of 360 adults with an intellectual disability in institutions and compared them with people who lived with their families. There was no information regarding the sample and the methodology of the research and very limited quantitative results were reported. Bánfalvy concluded the following:

- People in institutions had no access to the necessary therapy services (e.g. physiotherapy, speech and language therapy) that were generally available for people living with their families.
- The health status of people with moderate and severe intellectual disabilities and complex needs living in institutions was poorer than that of people with similar disabilities living with their families.
- People in institutions had larger social networks than individuals living with their families.
- Although the life of people living in institutions was more structured, it lacked meaningful activity. Everyday activity was characterised by long periods of passivity or empty activities. Watching TV and listening to radio were the only regular activities commonly reported by the majority of service users (see Table 5.2).
- Educational attainment and the employment prospects of people living in institutions were worse than for people living with their families.

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[12] Group homes were not regulated by the law before 1996.

- People had very little privacy and personal space in institutions.
- Less than half of the people in institutions reported any plans for the future, most often starting an own family and finding a job.

Bánfalvy concluded that the institutional environment significantly limited the development of individuals and that the quality of life of people in institutions was worse and their needs were met at a lower quality compared to people who lived with their family. Nevertheless the conclusions of this study need to be treated with some caution because Bánfalvy did not use matched samples or control for the differences in terms of severity of disability between the two groups.

It was also argued that it was unlikely that families of people who lived in institutions would become strong advocates of the reprovision of institutions because of their socio-economic status and the weak contact with their relatives. Support was more likely to come from the institutions themselves. However, he pointed out, that institutions did not have the motivation to change because this would put an extra burden on staff and it would be seen as a threat to their existence, for example the loss of jobs etc. Overall he voiced a sceptical opinion about the prospects of deinstitutionalisation in Hungary which he saw as a "trendy topic" and an attempt to attract more funding to service provision, particularly using the success stories of early projects where the people moving out had mild intellectual disabilities (or no disability at all). He warned that the social trends of the 1990s in Hungary, namely increasing inequalities and social exclusion were undermining the fundamental principles of community living of people with intellectual disabilities.

A more recent and comprehensive study of the institutions is from the project *Included in Society*, an international comparative study (Mansell et al. 2004) that looked at institutions in four countries: France, Hungary, Poland and Romania. The total sample consisted of 25 institutions (seven in France, six in Hungary, Poland and Romania) and included institutions for disabled people and people with mental health problems. The average size of institutions was 164 in Hungary (range 120-400).

Table 5.2 Regular activities reported by service users in institutions (%)

	Type of disability		
	Mild	**Moderate**	**Severe**
Has regular activity	92	81	13
Has a social life	97	85	57
Has friends	77	67	7
Has a hobby	44	28	-
Doing housework	38	25	20
Reading	17	3	10
Going to cinema/theatre	24	14	-
Watching TV/listening to radio	96	98	100
Spending time with friends	21	14	-
Going for walks	44	35	-
Exercising	30	15	10
Playing music	1	1	-

Note. Adapted from Bánfalvy (1998), pp. 184-85.

Researchers visited institutions and interviewed directors, did observation and collected other data. Findings showed very poor conditions and low quality services in all countries with Hungary and Romania scoring worse on most domains. The study found that the average size of living units (care units) was highest in Hungary (50 persons). Living rooms were shared by 27-57 people, living units had on average 11 bedrooms and bedrooms were shared by two to seven service users. The mean size of sleeping areas was six square metres and the mean size of living area was one square metre per person. The average number of bathrooms and toilets per living unit were 3.15 and 6.4 respectively. Therefore on average between eight and 14 residents had to share these facilities. Facilities were rated in terms of homeliness on a scale of 0-5 (5 being most homelike). Hungarian institutions had an average score of 0.49, with a range of 0 to 3.

Forty-six percent of residents were reported to have high support needs and 23% had low support needs. Nineteen percent of service users had at least monthly contact with their families but a third had no contact. In terms of quality of care, researchers found rigid daily routines, depersonalisation – partly as a result of low staff to resident ratios – empty routines and a lack of meaningful activities, particularly in the case of people with more severe disabilities.

5.3 The Findings of the 2007 Survey on the Living Conditions of People with Intellectual Disabilities[13]

This section presents the main finding of the 2007 in three areas. First, it compares the characteristics of people with intellectual disabilities who live at home with their families and those who live in residential care. Second, it looks at the characteristics of residential settings, and third, it gives a snapshot of the life in residential care.

5.3.1 Characteristics of People with Intellectual Disabilities by place of residence

This section explores the differences between people with intellectual disabilities who live with their families or in residential settings in terms of age, gender, additional disabilities and support needs. In Hungary it is often thought that people in residential care are more disabled or have more complex needs than those who live with their families, although so far this has not been demonstrated.

Three statistical methods were used to test the differences between the groups:

- *Pearson's chi-square* (χ^2) to compare group differences along categorical variables.
- *Mann-Whitney U* test to compare ordinal variables or scale variables that do not meet parametric criteria (i.e. normal distribution and homogeneity of variance).
- *ANOVA* to compare scale variables that meet conditions for parametric tests.

Test results were reported as significant if they reached a significance level of 0.05. In the case of *Chi-square* tests, if more than 20% of the cells had an expected count less than five, the test has been reported as invalid and only descriptive statistics were presented.

There were no significant differences in the gender of individuals living in the family home or in a residential setting: in the first group 60.3% (n=328) were male, in the second group 58.2% (n=103). However, people in institutions were significantly older (mean age: 23; range=3-42).than people living with their families (mean age: 17.2; range=3-50; *Mann-Whitney U*=34,624.000; n=769; p<0.001)[14]. Forty-two percent of people living with their family were adults aged over 18, while in residential settings the same number was 71%. To put it differently, the

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[13] This section is based on Kozma, A. (2008). Az intézetben élő értelmi fogyatékos emberek helyzete. In L. Bass (Ed.), *Amit tudunk és amit nem az értelmi fogyatékos emberek helyzetéről magyarországon* (pp. 157-79). Budapest: Kézenfogva Alapítvány.

[14] Data did not meet parametric criteria because age did not have normal distribution.

rate of placement in a residential setting increased rapidly after the age of 18 when young people leave school.

For more accurate comparability of results adults (aged 18 or over) were selected for further analysis (n = 383; 65.9% living with their families).There was a significant difference between the two groups in terms of the severity of intellectual disability: 84.5% were reported to have moderate and 15.5% had severe or profound ID in families, while in residential settings 32.3% had severe or profound ID ($\chi^2 = 14.54$; df = 1; $p < 0.001$). However, there were only one or two significant differences in terms of additional impairments between the two groups (Table5.3and5.4).

Table 5.3 Additional impairments by place of residence,% (n)

	Family home	**Residential setting**	**Sig (test)**
Physical impairment	47.8 (121)	43.8 (57)	ns (χ^2)
Visual impairment	36.0 (82)	27.6 (34)	ns (χ^2)
Hearing impairment	14.7 (33)	15.0 (18)	ns (χ^2)
Speech impairment	76.2 (192)	71.3 (92)	ns (χ^2)
Autism	17.4 (38)	10.0 (10)	ns (χ^2)
Epilepsy	29.7 (74)	34.6 (45)	ns (χ^2)
Two or more impairments	88.1 (222)	82.0 (130)	ns (χ^2)

There were no differences in terms of the reported presence and severity of challenging behaviour in family and residential settings, however substantially more people in residential settings was receiving psychotropic medication.

Table 5.4 Reported level of challenging behaviour by place of residence, % (n)

	Family home	**Residential setting**	**Sig (test)**
No CB	43.0 (101)	45.2 (52)	ns (χ^2)
Mild CB	23.0 (54)	19.1 (22)	ns (χ^2)
Moderate CB	20.4 (48)	17.5 (20)	ns (χ^2)
Severe CB	13.6 (32)	17.4 (20)	ns (χ^2)

To explore the support needs of individuals respondents were asked to indicate if the individual: did not need any support; or could be left alone for a few hours; or needed constant supervision and support. These were then recoded into the categories of "independent", "intermittent support needs" and "pervasive support needs". A higher proportion of people living in residential settings were reported to have pervasive support needs, however the differences between the two groups were not significant. Table 5.5 gives an overview of the results.

Table 5.5 Reported levels of support needs by place of residence, % (n)

	Family home	Residential setting	Sig (test)
No support needed	29.0 (58)	18.8 (24)	ns (χ^2)
Intermittent support needs	36.4 (92)	33.6 (43)	ns (χ^2)
Pervasive support needs	40.5 (102)	47.7 (60)	ns (χ^2)

Respondents were also asked to indicate whether the individual needed assistance in six areas of everyday life. Table 5.6 gives an overview of the results.

The only significant differences between groups were in getting around in the home and in the community where significantly more people in residential settings were reported to need assistance. However, these might be influenced by the policies of residential settings that did not allow people to leave the setting without support.

Table 5.6 Reported level of adaptive behaviours by place of residence, % (n)

	Family home	**Res. setting**	**Sig (test)**
% (n) of people needing assistance in			
Eating	23.0 (60)	25.0 (32)	ns (χ^2)
Toilet use	32.4 (81)	37.8 (48)	ns (χ^2)
Getting dressed	42.9 (108)	43.0 (55)	ns (χ^2)
Bathing/showering	53.8 (155)	56.3 (71)	ns (χ^2)
Getting around in the home	10.4 (26)	25.0 (32)	χ^2 = 14.020, df = 1, p <0.001
Getting around in the community	57.9 (143)	72.8 (91)	χ^2 = 7.902, df = 1, p <0.01

These results suggests that the differences between the two groups, people with intellectual disabilities living at home or in a residential setting are limited to two main factors: age and level of intellectual disability. People living in institutions are significantly older and have more severe intellectual disabilities. The first is not surprising, given that the likelihood of institutionalisation increases with age. However other findings seem to contradict the second difference. Both groups had comparable levels of additional impairments, additional needs, adaptive and challenging behaviours.

There was only a limited range of variables that allowed the comparison of life experiences of people living with their families and in residential settings. The main findings were:

- People living in residential settings were significantly more likely to work than people living with their families (χ^2 = 45.127, df = 1, p <0.001, n = 365): in the first group 37.6% worked compared to 8.8% of those living with their families.
- People in residential settings were significantly more likely to be under guardianship than individuals who lived at home (χ^2 = 43.342, df = 1, p <0.001, n = 296): 52.1% in family as opposed to 89.9% in residential settings.
- People living in residential settings were taking significantly more medication and they were also at a higher risk of polypharmacy (see Table 5.7). There was no information on the health status of participants.

Table 5.7 Participants taking regular medication, % (n)

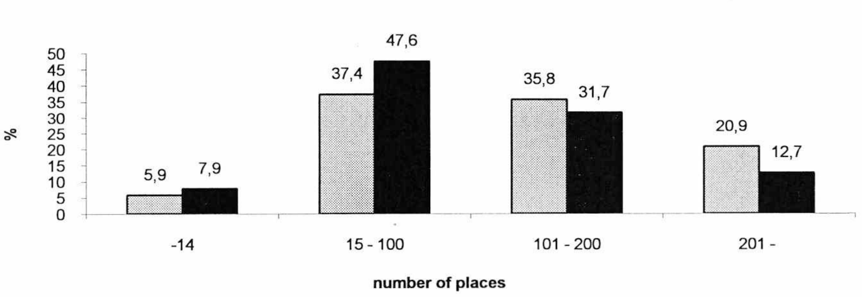
	Family home	Residential setting	Sig (test)
Regular medication	50.4 (126)	67.2 (80)	$\chi^2 = 9.257$; df = 1; p <0.01
Polypharmacy – two or more drugs	31.5 (79)	51.3 (61)	$\chi^2 = 13.437$; df = 1; p <0.001
Polypharmacy – four or more drugs	12.0 (30)	26.9 (32)	$\chi^2 = 12.788$; df = 1; p <0.001
Mean number of drugs	1.34	2.29	MW = 13,065; p <0.001

5.3.2 The living conditions of people in residential settings

In terms of the living conditions of people in residential settings the survey provided information on a sample of 177 individuals who lived in 65 different long-stay residential settings. The data allowed the use of descriptive statistical methods,however some caution is necessary considering the size and heterogeneity of the sample.

The majority of residential settings (80%) where participants lived were operated by the state (local governments), 11.5% were run by religious organisations and 8.5% by independent, voluntary providers. Just under 6% of the participants lived in group homes that comprised 13% of the facilities (n = 9). The distribution of places and service users by size of settings is shown in Figure 5.1.

Figure 5.1 Distribution of places and service users by size of the residential setting (%)

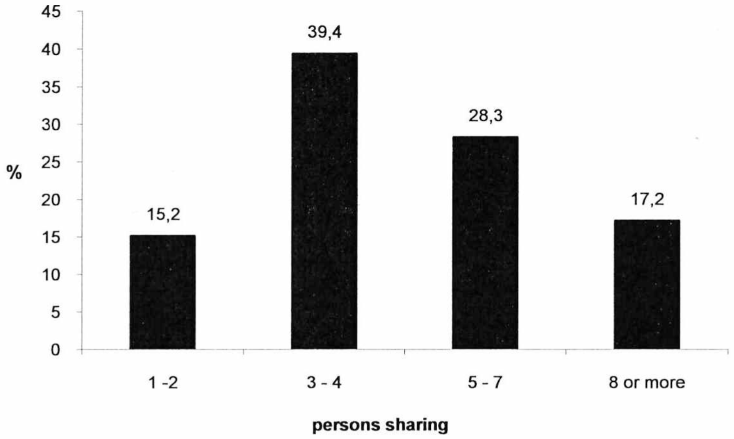


The average length of current placement was ten years, with a range of one to twenty-six years. The majority of service users (90%) had a permanent place and could stay for an indefinite period. The average

age at admission was 12.5 years. Around half of the people came from their families (52.5%) and the remainder from other residential settings (47.5%).

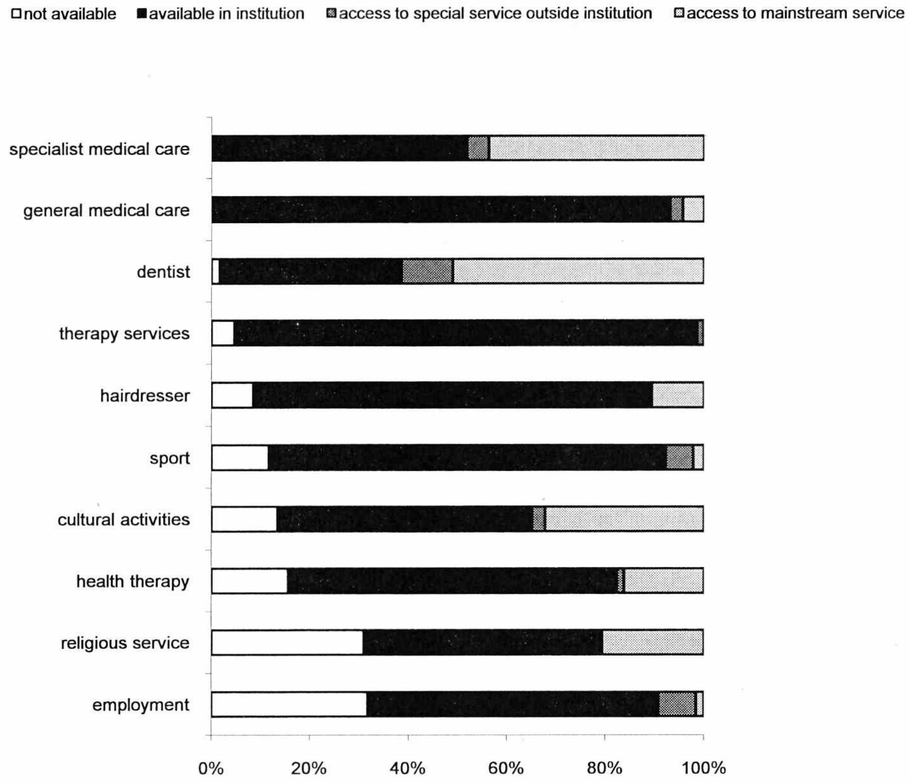
The average number of beds in bedrooms was 5, but a sizeable group of service users (17.2%) had to share with 7 or more others (see Figure 5.2).

Figure 5.2Distribution of service users according to the size of the bedroom (%)



Most residential settings were found to provide access to a wide range of services, including general medical care, employment etc. Most of these activities were available in the institution, even in the case of services that would be (more) easily available in the community such as a church, hairdresser or cultural activities (see Figure 5.3).

Figure 5.3 Access to different services in residential settings (%)



5.3.3 Life in residential settings

The questionnaire explored three areas of everyday life: interpersonal relationships, personal possessions and autonomy. Questions on interpersonal relationships included information on family contacts, friendships, relationships and intimacy, and conflicts with staff or other service users. The questions on autonomy aimed to find out whether service users had any choice or say in daily routines and basic life-style choices. Personal possessions included three categories: furniture, material goods such as CD players etc. and personal items such as clothes, toys etc.

Overall 62% of service users were reported to have family contacts. Children (under 18) were somewhat less likely to have family contact (52.3%) than adults (65.9%), however the difference was not significant. Family contacts were most often parents and siblings in the case of adult service users (see Table 5.8).

Table 5.8 Family contacts of service users, % (n)

with	Children	Adults	Sig (test)
Parent(s)	50.0 (22)	55.0 (71)	ns (χ^2)
Sibling(s)	25.0 (11)	42.2 (54)	$\chi^2 = 4.115$; df = 1; $p < 0.05$
Other relative(s)	13.6 (6)	26.6 (34)	ns (χ^2)

As regards the frequency of contact, there were no differences between children and adults. Less than half of the service users had at least monthly contact with their parents and less frequent contact with other relatives or siblings (see Table 5.9).

Table 5.9 Service users who have at least monthly contact with family, % (n)

	Children	Adults	Sig (test)
Parent(s)	38.6 (17)	41.9 (54)	ns (χ^2)
Sibling(s)	13.6 (6)	25.8 (33)	ns (χ^2)
Other relative(s)	9.1 (4)	12.5 (16)	ns (χ^2)

Just over 68% of people were reported to have friends in the residential setting. This number was somewhat higher among adults (72.4%, n = 92) than among children (56.8%, n = 25), but the difference was not significant. These numbers were considerably higher than those reported for people living at home where only 42% were thought to have friends and only 43% had the possibility to spend time in a peer group. Sixteen percent of adults (n = 21) in residential settings were in a relationship.

Living conditions in institutions, particularly the large number of people living together, overcrowding in bedrooms and enclosed lifestyle might lead to conflicts with staff and other service users. Only four percent of service users (n = 7) were reported to have regular and serious conflicts with other service users, somewhat higher among children (10.9%, n = 5) than adults (1.5%, n = 2), however the difference was not significant. Nearly 61% (n = 107) had no conflicts at all. The patterns were similar with respect to relationship with staff: respondents said that most service users had good relationships and only a small minority (4.7%, n = 8) had serious issues; again somewhat more common among children (11.4%, n = 5) than adults (2.4%, n = 3).

Nearly 90% of adults (n = 108) in residential settings was under guardianship. In approximately half of the cases the guardian was a family member (a parent or a sibling) and in the other half a professional guardian was appointed. Most service users had very limited choice in daily routine decisions, such as what to wear and how to decorate their room. For example even though 43% of people did not need assistance in getting dressed, only 22% (n = 39) could decide what to wear and a further 24% (n = 43) could have a say, but in 15% (n = 26) of the cases the answer was that there was no possibility to make decision in this issue – somewhat higher for children (26.7%, n = 12) than adults (10.7%, n = 14).

No children had the possibility to handle money (even with assistance) while among adults this was 11% (n = 14). The rest of the service users could not handle money, including their own income (e.g. social benefits etc.). Just over half of service users could go out to the shops independently or with staff assistance – considerably less among children (20.9%, n = 9) than adults (63.5%, n = 80). The others were "not able" to leave the facility or were not allowed by the house rules.

These findings reveal some important characteristics of residential care in Hungary. First, at least one out of four people with moderate and severe intellectual disabilities is affected by residential placement at one point during their life. Institutionalisation among children is still relatively common and it increases with age. The "de-population" of institutions in Hungary is an unlikely trend. Second, a large number of people in institutions seem to have mild and moderate disabilities and low support needs. They are largely comparable to those who live at home with their family. Finally, external contacts and social networks of people in institutions are very limited; they mainly consist of occasional contact with parents. Children in particular seem to be at high risk of loss of family contacts. However, some caution is necessary when interpreting the results due to the limitations of the data. The size of the sample was rather small and there was no possibility to create matched samples of participants in residential and family settings. The small sample size did not allow the use of parametric statistics and regression. Finally, heterogeneity of the sub-sample in residential care – the 177 participants came from 65 different settings – might have influenced the results.

Chapter 6 The development of residential care policies – policy change and stability

This chapter aims to critically analyse policy change and stability in the provision of residential care for people with intellectual disabilities in Hungary after 1990 and explain events using the theoretical frameworks presented in Chapter 2. The chapter is divided into three sections: the first section presents the origins of the current provision and describes the development of residential services for people with disabilities in Hungary from the late nineteenth century until 1990, the year of political transition. Its aim is to help explain the characteristics and weaknesses of the current system arising from constraints and legacies of past policies. The second part gives an overview of the institutional framework and actors of the policy process. The third section presents the main stages in the development of deinstitutionalisation and community living and offers three interpretations based on the theoretical frameworks of Punctuated Equilibrium, Multiple Streams and Advocacy Coalitions.

6.1 The origins of the current provision for people with intellectual disabilities in Hungary

In Hungary until the Second World War the family and the local community (municipality) were the main providers of care to people with intellectual disabilities. This meant that people who were not supported by their families were either issued a begging licence by the local municipality or those who were too disabled to beg were looked after in almshouses. The Population Census in 1880 found 16,690 "idiot individuals" in Hungary and Transylvania[15], 75% of them were paupers who lived on charity and in "extreme and shocking poverty". These individuals were often targets of bullying and harassment all over the country rather than being "educated and supported" to become useful members of the community (Kemény, 1888).

The first institution and residential school for children with intellectual disabilities opened in Budapest in 1875. Initially it had only nine pupils but in 1888 the service moved to a new building – the first purpose built institution for people with intellectual disabilities in the country (idid). This was followed by the opening of several special classes and "orthopedagogic institutions" mostly for children. The

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[15] Before 1919 the territory of Hungary (the Kingdom of Hungary) included the Western part of Romania (Transylvania), the Southern part of Slovakia and the Northern part of Serbia (Vojvodina). In the Trianon Peace Treaty after the First World War Hungary lost these regions that made up nearly two thirds of its original territory and one third of its ethnic Hungarian population.

founder of the first institution, Frim (1884) suggested that "asylums" should be established for adults with intellectual disabilities with the aim of helping them maintain and develop the skills acquired in residential schools and provide "good quality care". He described the situation of people with intellectual disabilities as follows: "Often families keep them hidden in the house or sometimes they are abandoned by the family or placed with families or charitable hospitals at the lowest possible cost." (ibid, p. 81) He also argued that the treatment of people with intellectual disabilities in Hungary is comparable to countries "we do not like to be compared with" and the country is lagging far behind "modern Western countries"(ibid, p. 94).[16]

There were no changes in the situation during the first half of the twentieth century: municipalities were still responsible for looking after people with intellectual disabilities whose families lacked the financial resources or the willingness to support them. Municipal provision could mean a place in a charitable hospital but more often no provision at all. Begging was prohibited from 1936 and municipalities were called to strengthen provision for vulnerable groups however this did not happen. The authorities and the community failed to acknowledge the importance of adequate provision for people with disabilities (Schuler, 1937). In poor, rural communities the selective killing of people with disabilities within the family remained a common practice up to the Second World War (Horváth, 1988). The first charitable association to support people with intellectual disabilities[17] was established in 1930 and one of its aims was to create a network of residential institutions across the country. The association itself operated a campus for 50 adults with intellectual disabilities in Budapest. Another home opened in Dunakeszi, outside Budapest in the 1930s. However, developments were disrupted by the Second World War after 1939 that left the country devastated.

The first half of the twentieth century saw the rise of eugenic ideas about the need to control children and adults with intellectual disabilities, and eugenics become the dominant ideology in disability policy in many Western countries, including the UK, the USA and Germany (Mitchell & Snyder, 2003, pp. 18-20; Welshman 2006). In the words of Mitchell and Snyder (2003) "as one of the first truly trans-Atlantic scientific movements, Eugenics bound much of Europe, the United States and Canada in a concerted movement to rid disabilities from their own national spaces (p. 856). The history of eugenics movements in Central and Eastern Europe remains largely unexplored,

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[16] The period after the Austro-Hungarian Compromise in 1867 was characterised by a rapid industrialisation, economic and cultural development of the country.

[17] Szellemileg Elmaradottakat Gyámolító Emberbarátok Országos Egyesülete

particularly theirimpact on disability policies.[18]However, there was less concern about the control and containment of people with intellectual disabilities: the eugenic sterilisation of people with intellectual disabilities was debated in the 1930s by the legislaturebut it was rejected (Turda & Weidling 2006, p. 8).

After the war, the new democratically elected government planned to introduce a social-democratic welfare model. Social policy became government responsibility (as opposed to municipal responsibility before the War) and the Ministry of Social Welfare was established. However the communist turn in the late 1940s disrupted the reform process and the development of social policy took a new direction. Szalai and Orosz (1992) described this as follows:

> In the period of building the socialist planned economy the new system abolished social policy in general. All of its traditiotnal institutions were cast away as the requisites of overthrown capitalism. At the same time – and it was the essence of its self-contradiction – the 'socialist' planned economy was regardced as the main trustee of social rationality and the social good. It followed that each and every segment of economy and society, of private and public life, became imbued with 'social' considerations as the central intention. It this sense we can say that the elimination of social policy was accompanied by 'injecting social policy' into the entire system. (p. 149)

The communist "welfare state" was organised around the principle of full employment. Everybody – men and women – were required to work except those who were considered too ill or too disabled to work. High social value was attached to manual and physical labour. Those who did not want to work were labelled as "workshy" which was also a criminal category and could mean imprisonment or institutionalisation. People with disabilities did not fit in this model and they were seen as a burden on their families and on society. On the other hand, however looking after them in institutions were seen as an employment opportunity for large numbers of unskilled (female) labour in rural areas. Families had two options: either to institutitonalise their disabled child or look after

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[18] The agendas of eugenics movements in Central Europe were somewhat different from their counterparts in Western Europe in that their main goal was "the strengthening of their newly created national states" and eugenics was appropriated by racial nationalism (Turda & Weindling, 2006, p. 7). They pursued agendas that arose from local conditions and realities (ibid, p. 8). In Hungary this was the racial question and the protection of racial characters mainly against the Jews as demonstrated by the so-called "Jew laws" that restrictred access to higher education, prohibited marriage with non-Jews and excluded Jewish people from certain professions.

them at home with no support from the state. The latter was strongly disapproved by professionals (e.g. paediatricians) and the general public.Institutions were regarded as the only adequate option for both people with disabilities and their families. It was common practice – until recently – toencourage women to abandon their newborn baby with disabilities in maternity wards (Bass 2004; Kálmán 2004). Children with severe and profound disabilities were excluded from public education until 1993.

Social care was the responsibility of the Ministry of Health from 1950, however social care institutions were not formally part of the health care system, most importantly they were not financed as hospitals and the system was chronically underfunded. The provision did not change much in the 1940-50s. Care continued to be provided in institutions resembling old charitable hospitals accommodating people who were unable or unwilling to work, including people with disabilities, elderly people, people with mental health problems, those with substance abuse problems, severe anti-social behaviour or certain long-term health conditions, most commonly tuberculosis.

A wide range of nationalised buildings – mostly mansion houses but also empty warehouses, barracks and even brothels – were used to create new facilities on the outskirts of towns or in rural areas (Horváth 1988). These institutions were simply warehousing people and they were increasingly considered inadequate. There were early attempts in the mid-1950s to create separate provision for people with intellectual disabilities with the creation of work-based institutions (*foglalkoztató intézet*) for young adults with mild and moderate intellectual disabilities. These were typically located close to large collective farms and provided residents with seasonal agricultural and light industrial work.

It was around this time when two ideas shaping future provision emerged: the idea of "rehabilitation" of people with intellectual disabilities and the idea of the institution as a "mini society" (Galambos, Papp, Verdes. 2003). It was thought that people with mild and moderate intellectual disabilities can be rehabilitated and move on to live without support in the community. Rehabilitation became the official aim of work-based institutions (later renamed as rehabilitation institutions), and full independence became the standard against which the individual's ability to live in the community was judged: if this was not possible, the individual was deemed "unfit for community living". The idea of "the mini society" saw the institution as a commune of people and attempted to create an alternative community rather than promoting the community inclusion of people (Bajáczi in Galambos et al. 2003). This was also termed as a "golden cage" (for an ethnographic study of an instituton organised on the basis of these principles see Benedek, 1957).

Large scale changes in the provision of residential care for people with intellectual disabilities started in the 1970s with the "profile-cleaning" of institutions. This meant the reallocation of residents between settings on the basis of their disability and needs. The concept of a single framework of residential provision for people with intellectual disabilities was created in the late 1970s. It distinguished two types of insititutions: work-based institutions and social care homes. The plan envisaged that 10% of the total population with mild intellectual disabilities and 70% of people with moderate intellectual disabilities would be looked after in a work-based institutions and all people with severe and profound intellectual disabilities should live in social care homes (Hermányi, 1985). Stollár (1999) wrote about the guiding principles of the reform:

- Creating separate provision for elderly people, people with mental health problems and people with intellectual disabilities.
- Creating separate provision for people with intellectual disabilities according to support needs,
- Service users should be able to move between provision types if their support needs change.

Profile-cleaning also had a significant impact on the daily life of people living in institutions. It meant that thousands of people were moved to new settings often without any consultation or preparation. Horváth (1988) described the process as follows:

> Profile-cleaning in practice meant moving people between settings. Elderly people were offered the possibility to stay in their current place in the new type of provision. And some of them indeed decided to stay and continued to live among people with intellectual disabilities or people with substance abuse. It is impossible to know how many people had to move as a result of profile cleaning and thus how many people lost their social contacts or moved to a new environment. (p. 58)

It is important to note that these moves did not result in improved physical conditions or better care for users they simply meant a reshuffling of individuals between settings.There has been a substantial expansion of capacities since the 1970s (see Table 6.1 and 6.2). Between 1970 and 1985 the total number of residential care capacities (including for example nursing homes for elderly persons) increased by nearly 50%, with a greater relative increase in residential services for disabled people, which then levelled out in the 1990s. In 1980 around 10% of capacities served people with disabilities, in 1990 this figure reached 26% (NM, 1990). Some of these were new, purpose-built settings (such as service 304), but the majority of newly established disability institutions moved into existing buildings (such as services 103 and 305). In the 2000s most of the increase of capacities was seen in the provision for the elderly that made up nearly two thirds of the places in 2009.

Table 6.1 Number of social care institutions and places,1970 – 2009

	Number of		Places per 10,000
	institutions	**places**	**population**
1970	241	27,364	26.6
1975	257	30,565	28.9
1980	267	33,737	31.5
1985	283	37,706	35.4
1990	304	40,857	39.4
1995*	-	56,527	54.7
2000*	-	65,863	64.4
2005*	-	73,783	73.1
2008*	-	76,622	76.3
2009*	-	78,537	78.3

Note. Includes all types of provision.Data from NM 1990 p. 90 and Stadat On-line database of the Central Statistical Office.

*Figureswere adjusted to remove the number of places in long-stay institutions and shelters for homeless people that did not exist before 1990.[19]

Table 6.2 Distribution of places by type of provision (%), 1980-2009

	Elderly people	Disability	Mental Health	Other*
1980	66.1	9.6	24.3	-
1987	55.2	25.7	19.1	-
1990	55.5	26.5	18.0	-
1995	57.4	25.4	13.2	3.4
2000	60.5	23.3	12.3	3.9
2005	64.1	22.1	10.9	2.9
2008	65.1	21.4	10.8	2.7
2009	65.4	20.9	11.0	2.7

Note. Data from NM 1990 p. 96 and Stadat On-line database of the Central Statistical Office.[20]

*Includes residential provision for people with substance abuse.

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[19] Retrieved from: http://www.ksh.hu (last accessed: 02/01/2012)

[20] Retrieved from: http://www.ksh.hu (last accessed: 02/01/2012)

The first non-residential, community-based services for people with intellectual disabilities were created in the late 1970s: these included sheltered workshops and day care centres (Galamboset al., 2003). By this time there were also a range of maternity benefits available for women to stay at home with their children, including children with disabilities. This offered an alternative to institutionalisation for many families.[21]

In conclusion, institutions for people with intellectual disabilities are a relatively new provision in Hungary. Elements of control centred on the idea of productive employment appeared in the 1950s, however until the 1970s the dominant model was a custodial provision for mixed groups of people with diverse needs and abilities, largely inherited from the charitable hospitals of the pre-1945 era. This left a number of legacies on the current system:

- Social care was a neglected policy area. People with disabilities had little value in the society which resulted in a lack of interest in residential policies among policy makers and the public.
- A shortage of funding in the sector, including investment in the infrastructure and provision of support.
- "One model fits all" approach to residential services to different groups. Despite the differentiation of provision, this still remains a dominant idea. It is still assumed that different user groups such as elderly people, people with intellectual disabilities and mental health problems have similar needs, and thus the same generic model of institutional care is adequate for everybody.
- Inadequate support practices and a lack of a professional ideology. The lack of professional and qualified staff and the diversity of service users – elderly people, people with mental health problems, people with intellectual disabilities and alcoholics were often looked after in the same setting – resulting in a focus on meeting the basic needs of residents. Besides employment, therapies or support were rarely offered to people. This started to change after differentiation, however – as it will be shown in Chapter 9 – the number of staff with specialist knowledge remains low.

The ideas of de-institutionalisation appeared in the mid-1980s among professionals and parents of people with intellectual disabilities who visited or heard about Austrian, Canadian and US services (Lányi-Engelmayer 1982). The first group homes opened in the late 1980s,

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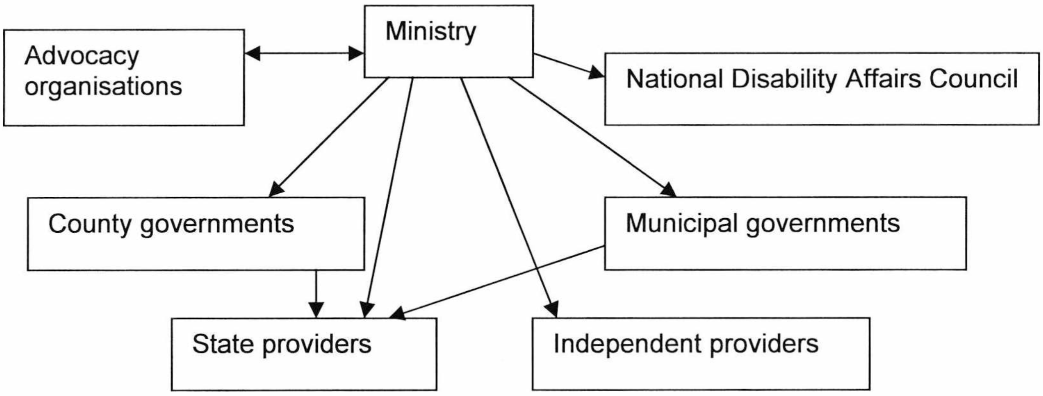
[21] The introduction of the Child Care Benefit in 1966 provided women the right to 3 years paid maternity leave. This was on the one hand part of a pro-natalist fertility policy in response to the sharply declining birth rate but also aimed to address tensions in the labour market, namely difficulties in maintaining full employment (Gábos, & Tóth-István, 2000).

shortly before the political transition. By this time the erosion of the Communist regime reached a point where private initiatives were no longer prohibited. This period was also characterised by an intense search of new approaches and openness to new ideas. Grass-roots parents groups more and more openly voiced concerns over conditions and human rights abuses of service users in institutions and demanded alternative, community-based services based on Western models. There were also reform attempts in institutions initatied by staff and service users with mild intellectual disabilities seeking more independent lifestyles. These included group homes, "half-way houses" and even supported living-type arrangments. There seemed to be a real prospect of policy change. The next section will explore these developments in the 1990s and 2000s and try to explain the dynamics of policy change and stability.

6.2 State structures and actors in residential provision

This section briefly describes the institutional context of the policy process and highlights the constraints and limitations of the actors. The institutional framework of residential care is characterised by the involvement of multiple levels of government and actors (see Figure 6.1).

Figure 6.1 Policy actors in residential care



6.2.1 The Ministry

The Ministry responsible for social affairs defines the strategic priorities in social care, the legislative framework of service provision, and in cooperation with the Ministry of Finance sets the level of funding for services.

The Ministry is also responsible for coordinating the activities of the National Council of Disability Affairs established by the 1998 Act on

Equal Opportunities of Persons with Disabilities (1998. évi XXVI. törvény, Article 24).

6.2.2 National Council on Disability Affairs (Országos Fogyatékosügyi Tanács)

The Council is a consultative-advisory body to the Government on issues affecting people with disabilities. Their main task is the elaboration of the National Disability Programme, a national strategy revised every four years. They can also initiate new policies and provide feedback on existing policies (i.e. request information from relevant bodies, commission research etc). It also acts as the national focal point of the implementation of the Convention on the Rights of Persons with Disabilities. The Council is presided by the minister responsible for social affairs and a representative of the non-governmental side – this post has been filled by the president of the National Federation of Disabled Persons' Associations, the largest advocacy organisation for people with physical disabilities.[22]

The Council's membership consists of:

- The representatives of ministries and relevant government bodies;
- One person representing local governments;
- The representatives of the five main, state-funded advocacy organisations including the Hungarian Association for Persons with Intellectual Disabilities and the Hungarian Autistic Society.;
- Four representatives of independent organisations of disabled people;
- Two persons representing sheltered employers;
- One person representing the Hungarian Sport Federation of People with Disabilities.

6.2.3 Local governments

There are two levels of local government in Hungary: county governments and municipal governments. The total number of county governments is 20 – 19 counties and Budapest – and the number of directly elected municipal governments was 3,168 in 2005; the average number of inhabitants per municipality was 3,100 (KSH, 2005a). Social care responsibilities are shared between the two levels as follows:

- County governments are responsible for the provision of residential care, child protection and secondary education. They may provide services themselves or purchase them from independent (or quasi-independent) providers, but this is uncommon.

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[22] Retrieved from http://www.meosz.hu/index_23.php (last accessed: 02/01/2012).

- Municipal governments are responsible for the provision of pre-school and primary education, and non-residential social services, such as day care, meals-on-wheels etc. depending on the number of inhabitants. Only municipal governments with more than 10,000 inhabitants are required to provide day care for people with intellectual disabilities.

6.2.4 Service providers

The service provision sector is dominated by state providers. In 2008 out of the 281 residential settings for people with disabilities 60% were operated by state providers and 23% by independent non-profit providers. In terms of the distribution of places, 80% were in state provision, churches and religious organisations provided 8%, independent non-profit organisations provided 6% and 'public interest companies' – state-owned non-profit companies – had 6% of places (KSH, 2009).

State providers are supervised by local governments or state authorities. Planning and financial decisions are made jointly, however authorities can impose decisions on providers. State providers are linked by various informal and formal networks, including special sports and art associations. The Association of Social Care Institutions represents the interests of state providers in the policy process. The Association established a disability sub-section in 2009 that brings together state providers for adults with learning disabilities and currently has 30 member organisations.[23] Independent non-profit providers are organised in two main networks with somewhat different profiles: ÉTA ('Hungarian Federation of Associations and Foundations serving people with Mental Handicap')[24] and Céhalozat[25]. ÉTA was set up in 1997 and now has over 70 member organisations. Its main activity is the provision of information, particularly about funding opportunities and projects. Céhalozat was set up in 2006 and has 31 members, all of them residential providers. Their aim is to represent the interests of independent service providers in the policy process, particularly in decisions affecting their financial situation: they monitor legislative proposals, issue position papers and represent members at consultative and partnership forums.

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[23] Retrieved from http://www.sziosz.hu (last accessed: 02/01/2012).

[24] Retrieved from http://www.eta-szov.hu/ (last accessed: 02/01/2012).

[25] Retrieved from http://www.kezenfogva.hu/cehalozat/ (last accessed: 02/01/2012).

6.2.5 Advocacy organisations

The term 'advocacy organisations' is used here to describe organisations that aim to achieve policy or attitudinal change and positive imagery of people with intellectual disabilities whether or not their voices are directly represented within the organisation (Walmsley, 2001). Advocacy is not necessarily the main or only activity of these organisations nonetheless they are actively present in the deinstitutionalisation and community living policy arena in Hungary.

Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ)[26]

The Association was set up in 1981 by parents and currently it is the largest advocacy organisation representing people with intellectual disabilities and their families in Hungary. It has around 22,000 individual members and 25 local branches. In addition to advocacy, in recent years ÉFOÉSZ has also become a service provider: it has nine residential and non-residential community-based services. ÉFOESZ is subsidised by the state, each year it receives a lump-sum contribution towards its operation, although this has decreased in recent years and a larger share of its budget comes from programme-based financing.

The objectives of ÉFOÉSZ is "to represent the interests of the people living with intellectual disability and their families in national level and also in international organizations such as the European Disability Forum, Inclusion Europe, Inclusion International" and "support persons with intellectual disability in the field of having equal rights, equal opportunities and leading a life without having to rely on others, while actively participating in social life as visible citizens". The Association is member of the National Disability Affairs Council. Recent activities focus on mental capacity and guardianship reform, promoting self-advocacy among people with intellectual disabilities.

Despite recents efforts to include people with intellectual disabilities in advocay activities, ÉFOÉSZ remains an organisation dominated by parents and parental agenda.

Hungarian Autistic Society (Autisták Országos Szövetsége, AOSZ)[27]

AOSZ was established in 1988 by parents of persons with autism and currently has 53 affiliated organisations, mainly community-based service providers, and over 1,300 individual members – mainly parents.

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[26] Retrieved from http://www.efoesz.hu/index.php?m = en (last accessed: 02/01/2012).

[27] Retrieved from http://esoember.hu(last accessed: 02/01/2012).

The organisation focuses on two main activities: the provision of information and support to parents and policy advocacy. AOSZ is member of the National Disability Affairs Council and Autism Europe. Similarly to ÉFOÉSZ, AOSZ is also subsidised by the state.

Hand in Hand Foundation (Kézenfogva Alapítvány)[28]

The Foundation was established in 1993 by the wife of the (then) President of Hungary, Mrs Zsuzsa Göncz. The organisation's aim is to improve the situation of persons with intellectual and multiple disabilities, their families and organisation supporting them. It is a professionally-led organisation that focuses on four activities: service development and facilitating the adaptation of new methods; research; awareness raising and lobbying; and international cooperation. Kézenfogva is member of the European Association of Service Providers, an umbrella organisation representing disability service providers at the European level.[29]

Hungarian Civil Liberties Union (Társaság a Szabadságjogokért, TASZ)

TASZ is the most recent actor in deinstitutionalisation; the organisation was established in 1994 and it is a human rights watchdog active in a broad range of areas from disability policy to data protection and freedom of speech. TASZ became active in the field of deinstitutionalisation and community living in 2009. [30] TASZ is independent from the state, it does not take any state funding.

6.3 The development of deinstitutionalisation and community living

It has been shown that community-based settings for people with intellectual disabilities already existed in Hungary before 1990 and there was also an increasing discontent with the existing system of provision among parents and professionals. It has also been suggested that the post-transition welfare reforms of the early 1990s were characterised by decentralisation of social provision, both services and benefits to local governments incorporating a strong element of discretion and failing to provide adequate financial resources. And, appeals to voluntary sector to fill in gaps in social services without the provision of adequate financial resources and legal framework (Deacon, 2000). A new law on social care came into force in 1993that represented a major a departure

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[28] Retrieved from http://www.kezenfogva.hu/english/ (last accessed: 02/01/2012).

[29] Retrieved from http://www.easpd.eu/(last accessed: 02/01/2012).

[30] Retrieved from http://tasz.hu/en/patients-rights/help-reform-policies-intellectually-disabled-plan-us (last accessed: 14/03/2011).

from the welfare policies of the previous regime in many areas by introducing new provisions to tackle the challenges of transition such as long-term unemployment and poverty however social care services were left unchanged (1993. évi III. törvény). The Act preserved the institutional system developed in the 1970-1980 with institutions as the only form of residential service provision for individuals with an intellectual disability and it failed to take account of already existing community-based services and deinstitutionalisation initiatives.

Responding to anonymous complaints the Ombudsman carried out an inquiry in three residential institutions for adults and children with intellectual disabilities in 1996. The report[31] concluded that there were no adequate controls and safeguards to protect the human rights of people living in institutions. The inquiry found that:

> In two of the institutions medical care was inadequate, in one institution residents did not get their prescribed medication and in the other institutions there were serious problems with personal care. Service users had no access to any developmental services or education. There was no regular monitoring and assessment of their condition. Children had inadequate or no access at all to education and developmental activities. Leisure activities or personalised care were extremely limited.
>
> None of the buildings were adequate for human accommodation; they were crowded, dirty and in a poor state. In one of the institutions the provision of clothing was inadequate. Two institutions used professionally unjustified restraint measures (such as cage beds or tying individuals to their bed) that were a violation of human dignity. Some institutions did not provide residents with the minimum spending money required by the law. None of the institutions created the conditions of possessing and using personal objects and property for all residents. (no page number)

The Ombudsman called for changes in the law to modernise social care and the enforcement of constitutional rights in the provision of services. The report received considerable publicity and generated public and policy debate that contributed to some of the non-governmental initiatives and changes in legislation.

In 1998 the Hungarian Parliament adopted a law on the rights and

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[31] Retrieved from: www.obh.hu/allam/jelentes/199602255.rtf (last accessed: 02/01/2012).

equal opportunities of people with disabilities (1998. évi XXVI. törvény). The Act aimed at aligning national legislation with international recommendations, most importantly those of the United Nations and Council of Europe. The act stipulates the principle of equal rights of people with disabilities and sets out actions in seven target areas of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities: health care, education and training, employment, transport, housing, social services, culture and sports.

The Act was based on the social model of disability and stipulated that it was the State's responsibility, within its means, to provide adequate support to ensure equal opportunities for people with disabilities. With respect to residential services, the Act declared that "residential institutions for people with disabilities should gradually, but latest by January 1, 2010 be transformed in a way that allows those who are capable of independent living with adequate personal support to live in small-scale group homes, and for those people with severe disabilities who need more intensive support provide humanised and modernised institutional care" (Article 29:5). Group homes at that time were not yet regulated by the law and the Act defined them as "a small-scale residential setting that supports independent living of individuals with disabilities" (ibid, Article 4/e).

The Act established the National Council on Disability Affairs, which adopted the first National Disability Affairs Programme in 1999. This programme already forecasted the rhetoric shift from deinstitutionalisation to what was termed the "modernisation of institutions". Chapter 8.2 declared that "the humanisation and modernisation of residential institutions must be carried out in accordance with the Act on Equal Opportunities". In more practical terms the Programme set out the following actions:

- Creating the regulatory framework of group home provision including eligibility and content of provision in 1999.
- The adoption of a modernisation strategy for residential institutions. This strategy should be drawn up with the involvement of county governments and it should address the improvement of the physical infrastructure, the modernisation of care, and better staff provision by September 2001.
- An assessment of the condition and needs of all service users in institutions to decide who was capable of independent living and who needed institutional care in 2001.

In 1999 the act on social care was amended and group homes were incorporated as a new form of residential support. The new rules created a very narrow and rigid definition of group homes: eight to fourteen places, for people with low or moderate support needs who have their own income and are aged between 16 years and the retirement age (55-60 years then). These restrictions affected a number of already existing services that supported people with severe disabilities or complex needs or were smaller than eight places.

In 2001 the Ministry amended the social care act again and replaced the definition of group homes with two new categories that mirrored the existing categories of institutions: care group homes and rehabilitation group homes. As a result people with severe disabilities and complex support needs were allowed to live in group homes. At the same time the emphasis shifted from legislation to supporting the development of infrastructure in the communication of "modernisation".

In 2006 the 'New' National Disability Affairs Programme for 2007-2013 was published. This still regarded group homes as "the new" type of provision and outlined the main directions of a future reform to "reprovide and transform" institutions:

> The number of places in group homes should be increased and it should be explored whether this form of provision can be extended to other groups with disabilities as well. The regulation of group homes should be reviewed with special attention to eligibility and standards. This new form of provision should be disseminated across the country.
>
> Taking into account the written and unwritten norms of the European Union and the position of European organisations of people with intellectual disabilities and their families (such as Inclusion Europe, European Disability Forum) and in line with the reform implemented in the child protection system in 1997, the feasibility of limiting the maximum size of residential institutions at 40 places should be examined from a legal, professional, infrastructural and financial point of view. A strategy should be drawn up to the reprovision and transformation of long-stay institutions, including alternative living arrangements in consultation with county governments, national advocacy organisations and independent service providers for people with disabilities. The strategy should also consider the re-utilisation of existing buildings (for example as centres for complex rehabilitation), any investment in infrastructure and the modernisation of care. (pp. 12-13)

Hungary ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol in 2007. Article 19 (Living independently and being included in the community) makes the unjustified segregation of people with disabilities in congregate settings a violation of human rights and calls on states to take "effective and appropriate measures" to facilitate full enjoyment of this right, the full inclusion and participation of people with disabilities in the community (ECCL, 2010). In the ratification process no consideration was given to its implications for government policies and implementation (interviews with civil servants). The Ministry considered this as "an outstanding achievement of Hungarian disability policy that we have been the first country in the world that ratified both the Convention and the Optional Protocol".[32] However, as Rozman (2009) points out "true motives for signing and ratifying was self-promotion rather than awareness" and the desire to appear "progressive" (p. 11).

In the meantime the deadline to resettle service users in group homes and "modernise" institutions was approaching but progress was very limited: in 2008 60% of residential services for people with intellectual disabilities were institutions where 85% of service users lived (KSH, 2009). Only 15% of service users lived in some form of group home provision, many of these clustered on the site of institutions. The Government decided to amend the Disability Act in 2009 to prevent any legal action for failure to fulfil obligations at the Constitutional Court. The amended act stated that the Ministry would prepare a reprovision strategy by the end of 2010 and allocate Structural Funds resources to reprovide at least 1,500 institutional places in the community by 2013. A new provision was also inserted into the Act on Social Care that stipulated that as of January 2011 new residential places could be created in group home settings only; however the law did not say whether these must be dispersed in the community, therefore they can be clustered on the grounds of institutions.

The Government presented a draft deinstitutionalisation strategy to the representatives of the European Commission who attended a one day workshop on the "deinstitutionalisation of social institutions in Hungary" organised by the National Development Agency in December 2010. This document was only available in English to the participants of the event and never released for public consultation. The strategy reinforced the earlier position of the Ministry that it "is necessary to keep institutions providing a higher level of nursing and care with broader content for other small groups of at most 50 persons" (*DI Strategy*, p. 7) and suggested that approximately 50% of the current population of institutions would fall into this category (ibid. p.8). In addition people could also "choose" to stay in institutions that would be "adapted to the requirements of the current age by changing professional rules and devising new objective and staffing conditions" (ibid. p. 12). On the basis of the strategy the Ministry issued a press release[33] in March 2011 that

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[32] Retrieved from: http://www.szmm.gov.hu (last accessed: 14/03/2011).

[33] Retrieved from: http://www.fidesz.hu (last accessed: 14/03/2011).

announced the “reprovision of large institutions”. Institutions would be replaced by three types of residential arrangements: independent flats for three to six people with low support needs, group homes for six to twelve people and “residential centres of up to 50 places providing intensive support”. The communication highlighted that the proposal was in line with the requirements of the UN and the European Union and it also enjoyed the approval of “professionals” who argued that “it would be a sin to break down institutions into smaller units as it would lead to the loss of expertise”. [34] The next section will critically analyse the development of residential policy and try to explain policy change and stability using the theoretical frameworks set out in Chapter 2.

6.3.1 Punctuated Equilibrium

The Punctuated Equilibrium model explains why long periods of policy stability are interrupted by short but intense periods of policy change. The main source of policy change is “the interaction of beliefs and values concerning a particular policy, which we term the policy image, with the existing set of political institutions – the venues of policy action” (Jones = Baumgartner 1991, p. 1045). Actors involved in policy change aim to manipulate the prevailing policy image and try to find the most favourable policy venue for their issues. Policy systems where decision and transaction costs are low tend to be more responsive to a wider range of signals and weaker signals. However, if institutions create too much friction then many signals are ignored. This leads to longer periods of stability, ignored signals tend to accumulate and result in punctuations, bursts of policy change.

This model highlights two main sources of inertia in the Hungarian system that act against policy change. It has been argued in Chapter 3 that Punctuated Equilibrium explains deinstitutionalisation in terms of changes in the image of institutions and the venue of policy action, shifting responsibility for the provision of residential supports from the state to more local levels of government. Neither of these changed significantly in Hungary for most of the 1990s and 2000s. Institutions are still generally regarded as a necessary form of provision for people with intellectual disabilities both in the policy documents of the Ministry and by the majority of professionals.

Scandals had a crucial role in driving change towards deinstitutionalisation and community care in other countries. They were not seen as isolated incidents in certain facilities but they came to symbolise the weakness of institutional care and signalled the changes

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[34] Retrieved from: http://www.fidesz.hu/index.php?Cikk = 159949 (last accessed: 14/03/2011)

that were taking place in the policy subsystem. Hungary on the other hand has been characterised by the absence of scandals. Although the media reported on a number of serious incidents in institutions[35], no official response or independent investigations followed these – exceptfor criminal trials. Authorities, including the Ministry were keen to protect the image of institutions and demonstrate that these cases were either false accusations or simply isolated events.

The most recent case provides an example of this: In February 2010 one of the television channels reported that three staff allegedly physically assaulted, sexually abused and submitted to humiliating treatment residents with severe mental health problems and autism in an institution for elderly people, people with mental health problems and intellectual disabilities. The claim was made by two nurses who had lost their job in the institution. The case was investigated by the Ministry, the county authorities and an "independent organisation", and because of the severity of the claims the prosecutor's office.[36] None of these inquiries were public and the first three found no evidence of abuse and rejected the allegations arguing that the institution "provided a good quality care" and implied that the two nurses made false claims because they had been made redundant.[37] The Ministry also invited the representatives of and independent user-led organisations, institutions and the HCLU for a meeting where they highlighted the importance of reporting the positive side of life in institutions and suggested that a coordination mechanism and consensus was necessary before commenting on negative events to avoid generalisations that put institutions in a negative light.[38] However, the prosecutor found evidence of the allegations and also discovered fraud by the management. Charges were pressed against the three staff who were detained but

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[35] To identify incidents, cases of neglect or abuse in institutions a web-based search was used on one of Hungary's main news sites (http://www.index.hu) with the combination of the following search terms: institution, disabled, tragedy, violence (in Hungarian: intézet, fogyatékos, tragédia, erőszak). The search identified seven cases of severe incidents: regular beating of students in a special residential school and some years later the use of seclusion rooms for extended periods of time in the same setting; the death of a woman with severe intellectual disabilities in an institution after she was tied to the radiator with her own t-shirt by night staff to prevent her disturbing others; the death of a young man with severe autism left unsupervised and drowned in the Danube in one of the institutions; the rape of a young woman by two male service users in a special residential school; and the sexual and financial exploitation of male service users by male staff in an institution for adults with mental health problems or intellectual disability.

[36] Retrieved from http://hirszerzo.hu/belfold/148205_tovabb_gordul_a_pszichiatriai_botrany_ujabb (last accessed 07/02/2011).

[37] Retrieved from: http://www.nol.hu/belfold/20100130-borzalmak_a_zart_osztalyon (last accessed 07/02/2011)

[38] Retrieved from: http://www.pef.hu/dokument/cezura%20a%20cenzura%20urugyen.pdf (last accessed 07/02/2011)

released on bail shortly after that and were still working in the institutions when their criminal trial started. The Ministry or the county authorities have not commented publicly on the events since then.

The most important difference between the landmark scandals of the 1960s and 1970s in Western countries and the stories of cruelty, neglect and abuse in institutions is the absence of a public inquiry and any form of policy response. It also suggests that signals for policy change are not strong enough and are routinely ignored by policy makers.

The stability of the policy venues where relevant policy decisions are made has also been working against major policy change because existing arrangements favour institutions. The Ministry has been characterised by multiple, often conflicting interests and values. Services for people with disabilities fall under the competence of two departments: the Department for Social Services is responsible for the regulation of services and the Department of Disability Affairs is responsible for disability policy making. The former is known to be pro-institution while the latter is more reform-minded, favours small-scale, community-based provision however has a marginal role in terms of legislation and deciding about financial allocations and budgets that is under the control of the Ministry of Finance. Most funding for capital investment in the infrastructure of services was channelled through the Ministry of Home Affairs and allocated directly to local governments without any consideration of reprovision (Interviews with civil servants, 2008). Although technically nothing prevents deinstitutionalisation, counties that are responsible for the provision of residential care are interested in maintaining the status quo for various reasons. First, they lack the resources, expertise and money, to close institutions and set up community-based supports. Second, institutions are a politically sensitive issue and they are important factors in many local economies (see for example the profile of services in Annex 4). The decision to resettle people with intellectual disabilities in local communities is seen as politically risky decision that directly elected council governments are unlikely to take.

In summary, the Punctuated Equilibrium framework highlights two important sources of policy stability in the current system of residential care. These are the image of institutions that is still largely positive in Hungary and the venues of policy action that carry a bias toward maintaining institutional care.

6.3.2 The Advocacy Coalition Framework

The ACF aggregates actors into advocacy coalitions that are distinguished by a shared belief systems and coordinated activity over time. Coalitions include interest group leaders, policy-makers from various levels of government, civil servants, professionals and researchers. Belief systems comprise of deep core beliefs, policy core beliefs and secondary aspects. Deep core beliefs are external to the policy subsystem and very resistant to change. Policy core beliefs are general assumptions regarding the policy subsystem. They are more likely to change in the longer term. Secondary aspects of belief systems hold a large set of more specific assumptions regarding the problem and its possible solutions. These are readily altered in light of new evidence, experience, or even out of strategic considerations.

The model identifies four paths to policy change: policy learning, external subsystem events, internal subsystem events and negotiated agreements between coalitions (Weible et al., 2009). Policy-oriented learning results from experience or new information from within the policy subsystem or outside the immediate policy context; this is also termed policy transfer. Policy learning is generally limited to minor or technical aspects and takes place over a longer period of time. Policy-oriented learning is more likely when there is a forum which is dominated by professional norms and prestigious enough to compel participants from different coalitions take part.

It is sometimes argued that the ACF explains stability better than change (Cairney, 2007). It has two specific hypotheses on policy change:

> The policy core attributes of a governmental programme in a specific jurisdiction will not be significantly revised as long as the subsystem advocacy coalition that instituted the programme remains in power with that jurisdiction – except when the change is imposed by a hierarchically superior jurisdiction.
>
> Significant perturbations external to the subsystem (e.g. changes in socio-economic conditions, public opinion, system-wide governing coalitions, or policy outputs from other subsystems) are a *necessary, but not sufficient,* cause of change in the *policy core* attributes of a governmental programme. (Sabatier 1998, p. 106)

Residential policy for people with intellectual disabilities has been dominated by a single pro-institution coalition in Hungary during the 1990s and 2000s. This coalition consists of some civil servants of the Ministry and county governments, and directors of institutions. Actors supporting community living were not organised into a coalition before 2009 when they were mobilised as a response to Government proposals to refurbish institutions using European Unionfunding. Although the membership of the deinstitutionalisation coalition is more limited than that of the institutional coalition, it is characterised by a higher degree of coordinated action; members meet regularly and network with each other on an informal basis as well. In addition, there is also a "fuzzy periphery" consisting of large organisations with a diverse membership and no clear commitment to community living (Weible et al., p. 130). For example some senior figures in the management of ÉFOÉSZ support deinstitutionalisation and community living, some parents at lower levels of the organisation are generally not in favour.

Table 6.3 The belief systems of advocacy coalitions

	Institutional coalition	**Community living coalition**
Policy core	Institutions are necessary to provide services for people with more severe ID. Not all people with ID can be supported in small scale CB settings. Institutions can be 'modernised' and 'humanised'.	Institutions cannot be modernised. Institutions should close and people should be supported to live in the community. Everyone can live in the community regardless of the severity of their disability.
Secondary policy aspects	"Small institutions" up to 50 places should be retained/created for people with intensive support needs. Eight to fourteen places are an adequate size for group homes. Smaller settings are more expensive and less cost-effective. Campus style reprovision of institutions should be supported as it is a cost-efficient alternative to dispersed provision.	Institutional facilities should be kept for the provision of employment and day care. Institutions should be depopulated gradually. Institutions should be closed and residents resettled in the community. Institutions should be replaced by group homes of eight to fourteen places. Facilities of up to 20 places should be permitted. Institutions should be replaced by supported living and community-based settings of up to eight places.

Table 6.3 presents the belief system of the two coalitions as outlined in their strategic documents: the DI strategy of the Government and the joint policy response by the advocacy organisations. While the DI coalition shares the same policy core beliefs, there is a relatively high level of internal division in secondary aspects which might be the result

of the recent formation of the coalition, however might also forecast the emergence of sub coalitions in the future (ibid.).

Chapter 2 argued that external shocks were a major driving force in deinstitutionalisation in liberal welfare states by drastically changing funding arrangements and making resources available for community-based services. In Hungary regime change had no impact on residential policy in the absence of an advocacy coalition. The main source of policy change has been policy learning and policy transfer facilitated by policy brokers; particularly two initiatives were important.

In 1996 the Hungarian Soros Foundation [39] launched a programme entitled 'Kitagolas' (Outplacement) that aimed to bring out people from institutions to live in small-scale settings in the community, set up according to the principles of normalisation (Soros Alapítvány, 1996). The programme provided financial assistance to community-based settings for adults and children; and it also promoted policy transfer and learning by supporting study visits to Austria, the dissemination of experiences and existing models as well as the translation and adaptation of international literature and measures including Wolfensberger's PASS and Schwarte and Oberste-Ufer's LEWO[40] (Kedl, 2002). There were yearly conferences between 1997 and 2001 that brought together policy makers from various levels of government as well as service providers from the state and voluntary sectors. The perception of the Foundation as an organisation with no vested interest in service provision and its moderate stance in deinstitutionalisation also facilitated communication and the acceptance of new ideas. The programme played a large part in the decision to incorporate group homes in social care legislation.

The other policy initiative came from the Dutch Government and supported independent non-profit organisations to set up community-based settings for adults with intellectual disabilities between 1997 and 2002. The Fészek (Nest) Programme was managed by Kézenfogva and had various components that served the creation and consolidation of a network of independent community-based services. It provided funding for the purchase or building of community-based settings and created the "knowledge-base of community living" by sponsoring study visits and staff exchange with Dutch organisations. It also developed a training

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[39] The Soros Foundation was the largest international non-governmental donor in Hungary. It is the private foundation of the Hungarian-born financier George Soros. The Hungarian office opened in 1984 and supported over 40,000 projects with a total of 30 billion forints in education, health and social care, culture. The Foundation closed the Hungarian office in 2007 following Hungary's accession to the European Union in 2004 (Retrieved from: www.soros.hu).

[40] LEWO: LEbensqualität in WOhnstätten für erwachsene Menschen mit geistiger Behinderung – Quality of Life in Residential Settings for People with Intellectual Disabilities

programme for managers and support workers in community-based settings that later was extended to involve support staff from institutions. The publicity of the programme and the success of the projects helped to demonstrate the feasibility of community living to policy makers and secured some funding for capital investment from the Ministry of Social Affairs.

These programmes had important limitations as well. Although they made community-based group homes an accepted part of service provision for adults with mild and moderate intellectual disabilities, they did not challenge the policy core aspects of institutional provision. Also by introducing and disseminating the ideas of normalisation and independent living, these were incorporated into the rhetoric of reform and modernisation while preserving institutional care and practices. For example the modernisation pilot programme funded by the Ministry in 2001-2002 (Stollár, 2004) largely consisted of re-labelling existing practices in institutions.

There were some attempts to lesson drawing from various countries throughout the 1990s; particularly Hungarians living in Canada had a major influence on parent-led community based services by introducing the ideas of normalisation and community living in Hungary. Also Kitagolás and Fészek draw on practices in other countries, particularly Austria, Germany and the Netherlands and aimed to disseminate models of provision (see Lányi-Engelmayer, 1998). But these countries have retained their institutional provision to a differing extent therefore they accepted and supported the modernisation of institutions in Hungary. The experiences of other countries where considerable progress had been made with the reprovision of institutions, such as the United States and the UK, were described as "alien" to the Hungarian context (Stollár 2004, p. 15).

The success of policy transfer has been constrained by various factors in Hungary. Although there is an emerging consensus on deinstitutionalisation and community living within the European Commission as indicated by the reports of the Ad Hoc expert group, this is non-coercive and cannot be used as a "political weapon" to legitimise proposed changes. Member States of the European Union have very different residential support systems for people with intellectual disabilities and institutional care is still common in some of the "old" Member States such as Germany and France (Mansell et al. 2007) that to some extent legitimises institutions in Central and Eastern Europe as well. Secondly, there is limited access to information on community living by policy makers and providers due to language barriers and insufficient resources (interviews with civil servants). And finally, administrative structures (i.e. policy venue) also hinder successful transfer of community living policies as suggested in the previous section.

In summary, the Advocacy Coalition Framework highlights minor change – the introduction of group homes – resulting from policy learning within the dominant institutional coalition. Policy learning was limited to technical aspects and left the policy core unchanged.

6.3.3 The Multiple Streams Framework

According to the Multiple Streams Framework policy change can happen when the problem, the policy and the political streams join and a window of opportunity opens. This is a unique constellation of events and it usually opens as a result of political changes. Windows of opportunity do not stay open for long, but they present themselves from time to time. In the policy stream ideas, alternatives and proposals are floating around. For a proposal to survive it needs to be technically feasible and compatible with the values of the decision-makers. The anticipation of future constraints, particularly budgets and public opinion, also influences the chances of survival for an idea.

The explanation using the MSF looks for windows of opportunity in deinstitutionalisation and community living and attempts to understand their dynamics. It might be argued that there were two periods when the constellation of streams was favourable for policy change. The adoption of the Disability Act in 1998 opened the first window of opportunity. Living conditions in institutions had been recognised as a problem, although it was largely framed in terms of poor infrastructure and the need for capital investment. A report of the National Audit Commission(Állami Számvevőszék) in 1997 pointed out that "adequate resources were necessary to be able to **update and enlarge** the existing institutions" (*DI Strategy* p. 1). Nevertheless, the ideas of deinstitutionalisation and community living were being discussed in the policy community for a number of years (Lányi-Engelmayer, 1998). The way the Act was adopted allowed these factors to combine and move residential care on the policy agenda. One civil servant remembers this process as follows:

> Ministry of Welfare was responsible for this piece of legislation in 1997-1998. We tried to involve individuals with disabilities and their organizations into the process of legislation. In February of 1997, NGO-s, professionals, many persons living with a disability, service-providing non-profit organizations *of* people with disabilities, and organizations *for* people with disabilities were asked to write studies about what *they wanted to seein the law* and what they *did not want to see in the law.* Hundred and fifty requests have been sent out for studies and received

> about 90 responses, their length varying between two and fifteen pages. (Konczei, 2005, p. 126)

The provisions of the Act on the "modernisation and humanisation" of institutions were rather vague and open to different interpretations. The Ministry's response was in line with their values and therefore was rather conservative and focused on the modernisation of institutions rather than in their replacement with community-based settings. In the absence of policy entrepreneurs pushing alternative proposals the Government amended the Social Care Act and added group homes to the list of residential arrangements. According to the initial plans of the Ministry, group homes were not to become the dominant form of service provision; it was envisaged that 2,700 people, less than one fifth of the population of institutions could move to group homes mostly clustered on the site of institutions (Kisgyörgyné,2003). This plan was to be implemented in the framework of a ten-year programme together with the "modernisation" of institutional care. In 2001-02 the Ministry carried out an assessment of the condition and needs of service users in institutions for people with disabilities with a view to estimating the need for group home provision. The assessment found that 13% of all service users were not placed in the adequate type of provision, but only a small number of these individuals were considered 'suitable' for living in a group home (ibid.). And according to the DI strategy "the emphasis was therefore placed on efforts to humanise and modernise larger institutions" *(DI Strategy)*.

In 2004 Hungary joined the European Union and became eligible to receive money from the Structural Funds.[41] This meant that an unprecedented sum of money became available for human development, but the requirement of 25% national co-financing tied down Hungary's limited own resources. Therefore policy agendas were influenced by what was required, allowed, or prioritised by the European Union. The objective of the first National Development Plan for 2004-2006[42] was to reduce to income gap relative to the EU and one of its main priorities was to increase employment. The development of social services was eligible for funding only so far as it could be linked to economic activity. This pushed residential care off the governmental agenda and shifted the emphasis towards the development of employment services and

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[41] The Structural Funds are financial instruments of European Union regional policy, that aim to narrow the development disparities among Member States and regions. There are two Structural Funds: the European Regional Development Fund and the European Social Fund. Retrieved from: http://europa.eu/legislation_summaries/glossary/structural_cohesion_fund_en.htm (last accessed: 02/01/2012).

[42] Retrieved from: http://www.nfu.hu/development_programmes(last accessed: 02/01/2012)

non-residential day care for people with disabilities.[43]

In 2006 when the EU reviewed the regulation of the Structural Funds for the period between 2007-2013 and permitted the use of the European Regional Development Fund (ERDF) for investments in "social infrastructure which contribute to regional and local development and increasing the quality of life" in the new Member States (EC, 2006, Article 4.11). This time, the stakes were even higher than in the previous programming period; Hungary was projected to receive 22.4 billion Euros for development between 2007 and 2013. The general perception among stakeholders was that issues that did not make it into one of the 15 operational programmes would be left out of the agenda for many years to come. Residential care was again put on the policy agenda. Priority Axis 3 of the Social Infrastructure Operational Programme (TIOP, 2006) supports the "modernisation of residential institutions" in order to "enhance their (i.e. service users') activity and to create worthy living conditions for them". This would be achieved by:

> Continuing the replacement of large residential institutions – which was started on the basis of national financial resources – by establishing small-scale home-like services and housing solutions. . . .At the same time, the development activities will constitute a milestone in rolling back large residential institutions, because it will be group homes and other modern forms of housing implemented through the development, to which we will adapt the services that are provided, concerning a given target group, near or within the home of the indigent. (p. 122)

Some sentences later however it is stated that "the development activity is aimed at the modernisation of institutions, the reconstruction, construction and furnishing of buildings" (ibid.).

SIOP allocated ten billion forints to reprovision and three billion forints to renovation of residential facilities for 2009 and 2010 and envisaged that 12 to 20 institutions would be reprovided in the community and another 30 facilities would be refurbished. In 2008 the Government published the first call for proposals. The draft was published for public consultation on the website of the National Development Agency (NDA) and received very limited attention and feedback from advocacy organisations. There were a total of 21 comments submitted on the website, out of which 19 suggested technical changes in eligibility or financing. Only two comments that pointed out that the refurbishment of large institutions was contrary to

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[43] It was argued that day care would help family members looking after people with disabilities to return to work and day centres could prepare service users to find a job.

Hungary's commitments: Kézenfogva Alapítvány argued that the refurbishment of institutions for people with disabilities was contrary to Article 19 of the CRDP and should not be supported; instead the money should be used to support the replacement of institutions with community-based services. This comment was rejected and the Ministry suggested that reprovision would be financed from another programme. The other comment was by the Mental Disability Advocacy Centre and it pointed out that the programme was contrary to the National Disability Affairs Programme and suggested to limit support to the refurbishment of 'small' institutions of up to 50 places for people with intellectual disabilities. This proposal was accepted and the size of institutions qualifying for support was lowered to 50.

Another window of opportunity opened in 2009 when the second programme was released for public consultation. This proposal permitted the construction of new institutions with up to 150 places if they were located in an integrated setting with access to public transport. This time response from advocacy organisations was coordinated and organised by the Civil Liberties Union. Hungarian and international advocacy and disability organisations, university departments and community-based service providers addressed an open letter[44] to the Prime Minister, relevant ministers and the European Commission to protest against the use of Structural Funds to build institutions and urged the Government to commit the available funding to the replacement of institutions with community-based services. The Government withdrew the proposal and agreed to re-write the programme together with advocacy organisations and publish a deinstitutionalisation strategy. The new proposal reflected a compromise and supported the reprovision of "large" institutions with more than 50 places in group homes of eight to twelve places and "small" institutions of up to 20 places (see also ECCL, 2010) In May 2010 national elections were held and the launch of the programme was delayed indefinitely, however the Ministry prepared a Deinstitutionalisation Strategy – without the involvement of advocacy organisations – which has not been released for public consultation at the time of writing this Chapter.[45]

The Multiple Streams Framework also highlights the importance of changes and stability in personnel. Since 1998 the Ministry has been characterised by a high level of organisational instability and frequent changes in the portfolio and strategic priorities, as well as the top personnel, ministers and high level civil servants. Since 1998 there

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[44] Retrieved from: http://tasz.hu/files/tasz/imce/nyiltlevel_intezetek_TIOP.pdf (In Hungarian, last accessed: 14/03/2011)

[45] The Strategy was released for public consultation in May and it was basically identical to the draft DI strategy presented to the European Commission and discussed in Chapter 6.3.

werefive different configurations with nine ministers and changes in governing coalitions interrupted policy developments both in 1998 and 2010.

In conclusion, two windows of opportunity have been identified that had the potential to trigger deinstitutionalisation. Nevertheless due to structural factors, particularly the lack of knowledge and understanding of decision makers resulted in policy outputs that favoured the modernisation of institutions.

6.4 Conclusion

This chapter analysed policy change and stability in Hungary applying the three theoretical frameworks that were used to explain the development of deinstitutionalisation and community-based care in Chapter 2. Figure 2.5 summarised the driving forces of policy change in countries where deinstitutionalisation is well advanced. The three interpretations highlighted important differences between these countries and Hungary that help to understand policy stability.

First, the perception of institutions is very different from the first wave of countries that implemented deinstitutionalisation. The scandals focused on the quality of care and quality of life of people living in institutions; the physical infrastructure of provision was just one aspect of that. In Hungary the problem is framed in terms of buildings and physical infrastructure: institutions need to be made smaller and more modern. Their perception is still positive, institutions are viewed as centres of expertise and it is implied that deinstitutionalisation would erode quality and it would lead to high levels of unemployment in disadvantaged rural areas.

Normalisation and Social Role Valorisation were radical new ideas that were developed in response to the issues of residential provision in the socio-economic context of Scandinavian and liberal welfare states and provided powerful guiding principles to the transformation and provision of services. Although the ideas of normalisation were translated and disseminated in Hungary they did not make an impact on the provision of services because they were incorporated into the vocabulary of current provision, particularly institutions. The proposed policy changes lack ideological guidance and clear direction.

Another important difference is that while the replacement of institutions with community-based services followed the human rights and emancipation movements of the 1960s and 1970s, in Hungary human and political rights have come under increasing pressure from poverty, social exclusion and inequalities and the rise of traditional values (Inglehart& Baker, 2000) after the collapse of the Communist regime. There was also an increase in discriminationagainst minority groups, particularly the Roma who are the largest ethnic minority group in Central and Eastern Europe (Brearley, 2001).

There are also important differences in policy learning that was shown to be an important driving force of deinstitutionalisation in the first wave. Although policy learning had an important role in disseminating group home provision in Hungary, it had no impact on deinstitutionalisation. Various models of residential provision co-exist within the Member States of the European Union that can serve to legitimise investment in institutions.

It has also beenargued in Chapter 2 that one of the main drivers to replace institutions with community-based settings came from the social policy reforms of neo-conservative governments in the 1970s and 1980s aiming to cut back the public sector and welfare spending in the UK and the US. In Hungary the political transition and large scale social policy reforms of the early 1990s did not have similar effects due to the absence of a strong advocacy coalition or policy entrepreneurs supporting deinstitutionalisation or the improvement of living conditions in institutions that could potentially drive the Government towards their reprovision. Policy advocacy for deinstitutionalisation and community-based care is relatively recent and weak; advocacy organisations and community-based service providers are dependent on state funding and therefore reluctant to voice concerns or protest against Government proposals. The next chapter will consider policy stability from a different perspective and critically analyse the policies that help to sustain institutions and hinder the transition to community-based care.

Chapter 7 Why are institutions strong? A critical perspective on residential care policies

Institutions do not exist in a vacuum, they are at the intersection of different policy areas. As Korman and Glennerster (1989) put it "just as the history of institutions is an interplay between the medical profession, public morality and hard political-economy, so too is the story of deinstitutionalization." (p. 11). This chapter takes a broad perspective on institutions and goes beyond the boundaries of social policy to include other policy areas. To understand the persistence of institutions, it is important to consider their broader societal context and explore the roles they fill in a particular society. This chapter is a critical policy analysis of institutionalisation in Hungary. Its aim is to explore the impact of public policies and show how they help to maintain the dominance of institutional provision and prevent the development of community living. The analysis looks at the implications of education, employment, child protection and social inclusion policies for community living and it will try to uncover the dynamics of the policy system; how other policies help to perpetuate institutions and hinder the development of community based alternatives. The analysis builds on a variety of data sources: mainly data collected in the 2007 Survey on the living conditions of people with intellectual disabilities (see Chapter 4), and statistics published by the relevant ministries and the Central Statistical Office of Hungary. Where the data allowed appropriate (non-parametric) statistical tests were used. Results were reported as significant if they reach a confidence interval of $p < 0.05$.

7.1 Resources and alternatives in the community

The family has historically played a key role in the care of persons with intellectual disabilities. Families are the largest provider of care however there is little research directed to explore the balance of care and the interaction between family care and out-of-home placement (Lewis & Johnson, 2005). The decision of families to institutionalise their offspring with disabilities is influenced by a number of factors. Sherman and Cocozza (1984) in a review of factors affecting the decision of families to seek out-of-home placements identified the availability of community services and social supports as one of the related factors. They found that these resources mediate the impact of stress on families. The forms of social support that influence the placement decision of parents include respite care, schooling and advice from professionals (Blacher & Bromley, 1990). Deinstitutionalisation in the United States accelerated when families no longer had to place their children with disabilities in institutions because they could access non-residential services in the community. In Chapter 2 the expansion of schooling to children with severe intellectual disabilities was shown to be a key factor in the depopulation of institutions in the United States (Anderson et al. 1998).

Chapter 5 showed that the majority of people with intellectual disabilities live with their families and around one in four people live in some form of residential care in Hungary. Out-of-home placement is lower among children and higher among adults. The 2007 Survey found a rate of out-of-home placement of 12% among children aged under 14 years, while nearly 40% of those aged over 26 years lived in residential care.

The rate of residential care per 100,000 population was estimated to be at least 242 and the rate of institutional care was 224 in 2007, which placed Hungary in the mid-field of international comparison (Mansell et al. 2007). Individuals with intellectual disabilities are typically placed in residential care at a relatively young age. The average age at institutionalisation was 13.7 years in the 2007 Survey. Children and young people often end up in residential care because their families cannot cope with the situation at home for various reasons and they are likely to remain in the system for the rest of their lives. Bass (2004) found that 15.6% of families with children with severe and multiple disabilities were planning out-of-home placement and 14.2% of families had already placed their children in some form of residential provision. He also reported a relationship between the condition of the child and the demographic and socio-economic status of families. Families that were younger and better off financially were less likely to consider residential placement than older and poorer families.

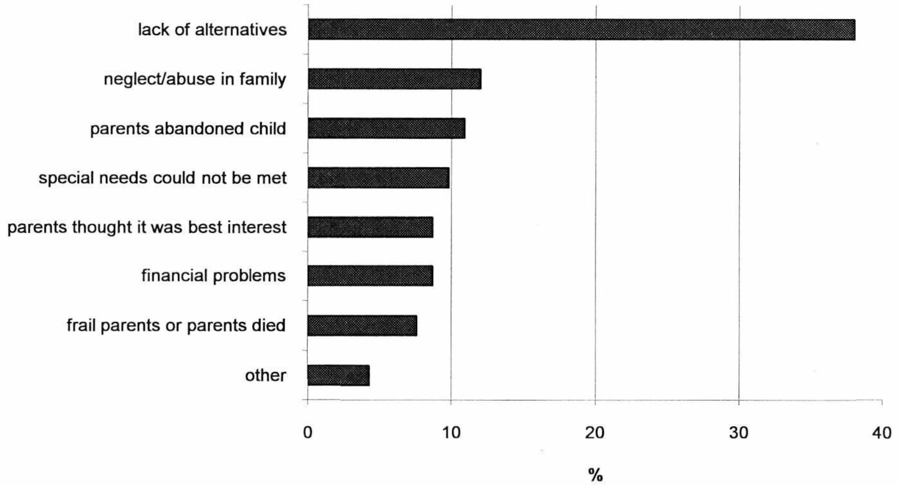
According to a report by the Open Society Institute:

> Most families do not want to put their children in residential institutions, but they often feel obliged to do so in the absence of appropriate information and support services. Parents who do choose to institutionalise their child tend to do so when the child is age three or four, after they become aware of the dearth of services. (EUMAP, 2005, p 45)

In the 2007 Survey (n = 721) 24.5% of people with intellectual disabilities lived in residential care and 13.8% of families were planning out-of-home placement, however the majority of families (61.7%) was not considering this option. The severity of disability was associated with the likelihood of out-of-home placement among families supporting individuals with an intellectual disability at home ($\chi^2 = 19.42$, df = 1, $p < 0.001$, n = 544). There was also a positive relationship between the age of the individual and plans for out-of-home placement ($\chi^2 = 11.07$, df = 2, $p < 0.01$, n = 541). More families of schooling age children (6-19 years) considered out-of-home placement, and this further increased in families of young adults (aged 20 years or over).

Figure 7.1 shows the known reasons for out-home-placement for individuals already in residential care (N = 104). This was asked as an open question and answers were coded into 8 categories. Most people (nearly 40%) were institutionalised because their families did not have enough support or alternatives in the community. For example the mother had to return to work and day care was not available, or the person left education but there were no day services in the area. Twelve percent of individuals were removed from their families under child protection arrangements because of neglect or abuse, and 11% were abandoned by their parents because of their disability – usually at a very young age and often upon the advice of professionals (Bass, 2004; Kálmán, 2004). In 10% of the cases the respondent said that the special needs of the individuals could not be met at home (e.g. adaptations, equipment etc.) and this is why their families decided to place them in an institution. Eight percent indicated financial difficulties, and a relatively small but still sizeable group (7%) of parents thought that institutionalisation was in the best interest of the individual. It was only a small group of people who had to leave home because the parents got too frail to look after them or died.

Figure 7.1 Reasons for out-of-home-placement



Note. Data from the 2007 Survey.

This suggests that institutional placement is still the only option for many families in the absence of adequate non-residential supports (EUMAP, 2005). It might be argued that at least half of individuals are placed in residential care because their families lack even the most basic supports to look after them. Institutions are thus a "functional" part of the policy system and filling in the gaps of other policies. The rest of this chapter will explore these policy gaps. There is very limited or no research in these areas, even national statistics are rather scarce. Therefore some of the arguments and conclusions put forward here are rather tentative and would need further quantitative investigation.

7.2 Education

The education of children with intellectual disabilities in Hungary remains highly segregated; access to inclusive education is very limited (EUMAP, 2005). There is a two-tier system of special education where access to different types of schools depends on the level of disability. Children with mild and moderate intellectual disabilities, who are considered "educable", attend mainstream or special schools. Special schools follow the National Core Curriculum and provide at least 20 hours per week of curricular and additional extra-curricular activities. Children with severe or multiple disabilities are considered "trainable" and currently can only receive up to 3-5 hours/week of individual or group treatment. This system is changing in 2010 with the establishment of developmental schools. Table 7.1 gives an overview of educational options for children with intellectual disabilities.

Four issues are worth highlighting with respect to schooling of children with intellectual disabilities that help to sustain the need for institutions: First, children with severe, profound or multiple disabilities are practically excluded from education. Until 1993 children with severe and multiple disabilities were considered "ineducable" and completely excluded from public education (Radványi, 2008). In 1993 a new Education Act (1993. évi LXXIX. törvény) came into force that abolished this category but instead of integrating these children in the system of public education either in special or mainstream schools, it created the concept of "trainability" and the "right to training" that gave children access to up to three hours of individual development or five hours in a group each week. Individual development is not part of the National Core Curriculum, thus its content and quality is not regulated (EUMAP, 2005). Children with severe and multiple disabilities continued to be excluded from education. Bass (2004) found that 9.2% of children of schooling age (7-18 years) did not have access to any development, 33.8% received therapy at home by a visiting professional (teacher or teaching assistant) and 56.9% accessed therapy outside their home. However, this included children placed in an institution and receiving treatment there.

Table 7.1 Educational options for children with intellectual disabilities

	Mild ID	Moderate ID	Severe or profound ID
Early intervention	Specialist services in the community, mainstream nurseries or kindergartens, visiting professionals, residential settings		
Kindergarten	Mainstream or special kindergartens		Mainstream or special kindergartens, residential settings
Primary education	Mainstream or special schools	Special schools	Up to 3-5 hours per week "training" at home by visiting professionals or in a residential setting or in a specialist day service. Developmental schools from 2010.
Secondary education	Mainstream or special vocational schools	Special vocational schools or vocational skills development in special training schools	None

Note. Updated version of EUMAP Report (2005) p. 53.

After years of lobbying by non-governmental organisations to end discrimination against children with severe and multiple disabilities in education the Government amended the Education Act and created the category of "developmental schools" in 2006. Developmental schools are part of the education system - they are required to have a curriculum, they have teaching requirements and qualified teachers etc. These schools are required to provide 20 hours of curricular activities and optional extra-curricular activities to pupils. The law requires local governments responsible for education to set up developmental schools by 2010. However, the Act has a major shortcoming: it allows existing residential institutions to establish developmental schools on their premises – despite the opposition of advocacy groups. This is an opportunity most institutions with at least some children population would or have already taken advantage of to strengthen their status and secure additional funding. The impact of the new legislation on the institutionalisation of children with severe and multiple disabilities remains to be seen.

Second, the segregation of children with mild and moderate intellectual disabilities in special boarding schools far from their families disrupts family contacts and fails to prepare them for community living.Access to special schools or inclusive education outside major cities is rather limited. There are one or two special schools in each county therefore children as young as three years of age are placed in boarding schools if there are no mainstream/inclusive alternatives in the community or parents cannot organise their transport to school on a daily basis. Furthermore, special boarding schools fail to prepare children for community living and they also have a negative impact on the family contact of children. There is no research on the life trajectories of young people leaving special boarding schools in Hungary, but anecdotal evidence, personal life stories of people with intellectual disabilities suggest that they face difficulties in returning to their families and are often placed in a residential setting shortly after leaving school.

Third, the lack of transition planning puts many young people on a pathway to institutionalisation.Transition from youth to adulthood for young people with intellectual disability is a complex process characterised by discontinuity and often confusion and frustration (Hudson, 2006). Research in the UK identified four key factors for successful transitions. These are the capacities of the individual, the support given to the family, the content and quality of local support systems, and the range of local opportunities (Heslop & Abbott, 2007). Transition is often problematic even when support services are available, and young people are often left without meaningful choice and poor outcomes (Heslop & Abbott, 2009; Hudson, 2006; Winn & Hay, 2009). Research also showed that people placed away from home experience additional barriers (Abbott & Heslop, 2009).

In Hungary there are no formal transition services in place and the range of local opportunities is extremely limited. According to the EUMAP Report (2005)

> As children reach adolescence or leave school, many services come to an end. Students and their parents are left on their own, and often do not know where to turn for assistance. After leaving school, it is rare for people with intellectual disabilities to find employment. The opportunities for supported or sheltered employment are limited, and there are few accessible day centres. Most, therefore, end up back at

> home or, in the worst cases, in residential institutions. Children leaving residential institutions, and those finishing primary and secondary level special schools, are especially disadvantaged, as they have almost no access to employment services. Due to the lack of opportunities and/or follow-up services, many people with intellectual disabilities simply disappear from the system. They either end up on the street or isolated at home, with no services. (p. 93)

The implications of this is that many young people, particularly those in state care (see also Chapter 7.5) move to a long-stay institution when they leave school. Depending on their resources, families cope differently with transition from education to adult services. Some find or set up alternatives in the community, others decide to institutionalise their offspring or support them at home.

Families lack any support to plan towards the future. The 2007 Survey asked families regarding their plans for when they would no longer be able to care for their disabled child. Twenty-seven percent responded that they had no plans, 35.4% expected siblings and 21.3% other relatives to take over and only 13.3% indicated residential care as an option. However, experiences suggest that other family members are less likely to continue caring for adults with intellectual disabilities and they seek out-of-home placement.

Lastly, vocational schools fail to equip young people with intellectual disabilities with skills and qualifications that are useful on the labour market and thus reduce their chances of living independently or with their families in the community. Over 60% of young people with intellectual disabilities continue their education at secondary level, the majority of them in special vocational schools or in schools providing vocational skills development (EUMAP, 2005). Although special vocational schools provide individuals with qualifications registered in the National Vocational Qualifications Register, they offer a limited range of qualifications that are often not sought after on the labour market. Pupils with moderate intellectual disabilities in vocational skills development are taught simple self-care and vocational skills (cleaning, kitchen assistance, pottery etc.) in segregated settings. This offers hardly any prospects on the open jobs market in contrast to the relatively high levels of employment and work opportunities for people living in residential settings. Recently there have been some innovative initiatives supported by the Ministry of Labour and Social Affairs; these are discussed in more detail in the section on Employment.

7.3 Shortage of non-residential supports in the community and the concentration of services in residential provision

Services for adults with intellectual disabilities are still very much concentrated in institutions that are the main form of service provision and community-based alternatives – employment and day services – aimed at people who live with their families are in short supply.

7.3.1 Day care

Despite considerable improvement in recent years the number of places in day care is still about one third of those in residential provision. In 1995 there were nearly ten times less places in day services than in residential care, but their number more than tripled from 1,320 to 4,287 between 1995 and 2007. The number of settings has also increased at a similar rate from 56 to 160 improving access outside Budapest and major cities. The expansion of places accelerated after 2004 as a result of EU co-funded development project. Despite these improvements, the geographical distribution of settings remains patchy, with no day care options in some counties and towns with less than 20 thousand inhabitants (KSH, 2008).

State funding for day care nearly doubled in 2008 (2007. évi CLXIX törvény) to encourage provision by local authorities because day care is now regarded by the Government as a cheaper alternative to residential provision. Although this might not be true, and many families would still seek out-of-home placement at some point, at least it would give them the option to delay this decision or consider other alternatives. The impact of this measure on the availability of day centres remains to be seen.

7.3.2 Employment

According to Mansell (2008) employment "addresses so many issues relevant to personal development – money versus poverty, social contact instead of isolation, goals instead of purposelessness". Employment includes both traditional, facility-based approaches such as sheltered workshops and integrated approaches including supported employment and access to mainstream employment services. Integrated employment has many advantages: it provides better financial outcomes, the opportunity for personal growth in work, the social inclusion of people with intellectual disabilities and high reported satisfaction. However, there are some concerns regarding integrated employment, for example the risk of discontinuity of jobs, particularly at times of economic downturn, the difficulties of access and transportation to the workplace, and the social relationships and potential isolation of individuals with an intellectual disability (Migliore, Mank, Grossi, & Rogan, 2007).

Employment has been receiving increasing attention in post-deinstitutionalisation countries as well. Despite evidence on the benefits of integrated employment and governments' efforts to promote the labour market participation of people with intellectual disabilities, their employment remains low. Although there are supported employment initiatives in countries with different social, economic and political situation but they only reach a minority of people with disabilities and there are still more segregated employment facilities (Jenaro et al. 2002). This is also true for countries that have made significant progress in deinstitutionalisation and community living. For example in the US out of adults with an intellectual disability in work 24% were in integrated employment and 76% were served in facility-based programmes. Instead of a shift to more integrated employment programmes, policy efforts resulted in a dual system where integrated options are offered along traditional facility-based services (Migliore et al. 2007).

The employment of people with disabilities has been at the top of disability policy agenda in Hungary since 2004, the country's accession to the EU. Before that[46] the main form of employment for people with intellectual disabilities was either in sheltered workshops or institution-based employment. From the late 1990s there were also community-based initiatives, including the adaptation of supported employment, and after 2002 the piloting of a work experience and placement scheme for students in special vocational colleges.[47] From 2004 more funding for integrated employment programmes became available from the European Social Fund. Supported employment and the work experience programmes were rolled out nationally and new pilot initiatives started with support of the EQUAL Community Initiative in Hungary.[48] Although these programmes reach less people than the sheltered workshops, they are being promoted and receive the continued support of the Government and they are seen by many as a better alternative to sheltered employment.

The regulation of employment for service usersin residential care took a completely different direction and it used the rhetoric of integrated

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[46] The situation was different before the economic and political transformation. The state-socialist regime was characterised by "full employment" and people had the obligation to work. Those who were found "avoiding work" could end up in prison. The number of workers was kept very high and unemployment was hidden within the companies in the form of low productivity and unnecessary positions. The employment rate of people with mild and moderate intellectual disabilities was relatively high, including integrated employment. These jobs were among the first to disappear in the early 1990s when unemployment soared. Most people with intellectual disabilities lost their job and employment retracted to sheltered workshops.

[47] By the Salva Vita Foundation.

[48] http://equal.nfu.hu/main.php?folderID = 1028 (last accessed 02/01/2011)

programmes to strengthen institution-based employment. The current rules for employment in residential services were introduced in 2006 as part of the reform of vocational rehabilitation and sheltered employment in Hungary. The new legislation was made necessary by Hungary's accession to the EU and transposition of state aid legislation. It aimed to create a fairer, more transparent and efficient system of employment aid for disadvantaged groups, including people with disabilities. Although the new regulations were labelled as a "reform of facility-based employment" in reality they preserved the existing structure after companies were no longer eligible to claim subsidies for employing people in institutions.

The stated aim of the new regulation was to support people with disabilities in residential care or using day centres to have a job where they can develop their skills and move on to more independent forms of work or ordinary jobs on the open job market. The law distinguishes two forms of employment, largely based on earlier practice. Vocational rehabilitation is organised by the service provider, it is open to all service users, including people under full guardianship. It typically involves jobs in and around the service such as cleaning, maintenance, gardening etc, however it can also include art and craft-type activities. People in vocational rehabilitation are not employed and thus they do not get a salary, they are not entitled to annual leave and sick leave. The remuneration they get for their work is up to 30% of the national minimum wage (although the institution can decide to pay the national minimum wage).

The other form of employment is the developmental-preparatory employment. As the name suggests this is intended to prepare people to move on to the open labour market by developing their vocational skills. It usually includes manufacturing jobs and services (e.g. gardening etc.). Most often it is jointly organised by a sheltered company and the service provider. This form of employment is open for people who have full or partial legal capacity (i.e. those under full guardianship are excluded) because it requires signing a work contract. The wage normally equals to the national minimum wage (pro-rata) with paid annual leave, sick leave, old-age pension entitlements etc.

The regulation also introduced vocational assessments and individual vocational plans for all service users in both types of employment. The plan should be prepared together with the service user and identify skill areas that need development and possible "career paths". In addition, services are required to have a business plan but they do not have to make income from the activities because they receive funding to cover all costs of employment.

The implementation of new rules was regarded a "great success" by officials in the Ministry and some service providers. However, the new rules are problematic for a number of reasons: Firstly, it is unclear how facility-based employment would promote transition into the open labour market. Service providers have no incentives to help their users to move on to ordinary jobs because then they would loose funding. Funding is not related to performance, service providers receive state funding regardless the marketability of their products or service. In 2008 the Public Foundation for the Equal Opportunities of Persons with Disabilities started an initiative to pilot supported employment in institutions, but they encountered a complete lack of interest. Only two institutions volunteered to take part in the programme.[49] Secondly, linking employment status to residential service user status in institutions prevents people to move on to live independently in the community. Thirdly, even though sheltered employment is different from integrated employment, it excludes people under full guardianship. This is discriminatory and there is no justification why certain people should be excluded from employment and only allowed to work in "vocational rehabilitation".

A study (Kézenfogva & Savaria, 2008) evaluated the initial experiences of facility-based employment in 2008 and found that most institutions continued the old patterns of employment. The research did not investigate whether the number of service users in work changed as a result of the new legislation. However the number of people with disabilities who work in institutions at the end of 2006 suggests that there was no significant increase. Over a third (34%) of the 9,185 users of the services which had responded to the questionnaire was reported to work. Forty-seven percent of them were in vocational rehabilitation and 53% in developmental-preparatory employment. They also found that 15% of services did not market their products or services and 24% produced for internal use only (ibid).

To understand the role of residential services in providing access to employment, it is necessary to consider the broader picture. According to the Population Census in 2001 only nine percent of people with intellectual disabilities were in work, compared to 56.2% of the general population (Eurostat). The 2007 Survey found that among people with intellectual disabilities aged over 18 years (n = 336) 20.2% were in employment and a further 7.7% had had a job before but were not employed at the time of the survey. The absolute majority, 72% have never had a job.[50] There was a significant difference in people's employment situation according to residential status. Those who lived with their families were significantly less likely to be in work than those

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[49] Personal communication with Ms Csilla Szauer, managing director of the Foundation July, 2009.

[50] In the Hungarian system people claiming disability-related benefits can take up work (full-time or part-time) without losing eligibility for the assistance, therefore their impact is expected to be minimal on people's decision to work.

living in residential settings. In the first group 9.7% were in employment and 10.6% had had a job before, in the residential group the same figures were 39.2% and 2.5% ($\chi^2 = 44.525$; df = 2; $p < 0.001$; *Cramér's* V=0.364; $p < 0.001$).

In countries where deinstitutionalisation and community living is well advanced, there has been a trend towards the separation of accommodation and individual supports. In Hungary there is an opposite trend of residential supports becoming more closely integrated with other services, particularly education and employment. Residential services have become major providers of employment services for people with intellectual disabilities and they also might become providers of special education as well. The concentration of services strengthens the position of institutions and makes institutions more acceptable for families who continue to face a lack or a shortage of services in the community.

7.4 Poverty and social exclusion

According to Emerson (2007) there is a known association between poverty and intellectual disability in the "world's richer countries". This reflects two different processes. First, poverty has been linked to intellectual disability through a number of mediating factors such as exposure to a range of environmental and psychosocial risks. Second, families supporting an individual with intellectual disabilities are at increased risk of poverty due to the direct and indirect costs of caring and the exclusion of people with intellectual disabilities from the labour market (Blackburn, Spencer & Read 2010). Although only eight percent of respondents in the 2007 Survey said that they institutionalised their children because of financial difficulties, indirectly the lack of financial resources might have influenced the decision of more families. The relationship between poverty and institutionalisation has not been explored before.

Poverty, particularly child poverty is a major problem and public policy challenge in Hungary and poverty affects a large number of children. During the 1990s child poverty[51] soared by 13 percentage points from seven percent to over 20% (Chen & Corak, 2005). A number of studies reported on the prevalence of child poverty. Gábos and Szivós (2004) found that 45% of children aged 0-18 years were in the lowest three income deciles in 2002-3. Darvas and Tausz (2007) reported that 32% of 0-15 year-olds and 22.3% of 16-24 year-olds lived in poverty as defined by 60% of the median individual equivalent income, in comparison to 17% of the total population in 2005.

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[51] This study uses 50 per cent of median individual equivalent income as poverty threshold.

The risk of poverty is highest in families with young children under the age of five, three or more children or single-parent households. Poverty is considerably higher among Romani people[52]. According to a household-panel survey in 2003 87% of Roma households were in the lowest three income deciles. Romani families were seven times more likely to be poor than the non-Roma. Other factors associated with poverty included long-term unemployment, exclusion from the labour market and low education (Gábos & Szivós, 2004).

Families with disabled children are known to be among the most vulnerable groups. Bass (2004) found high rates of poverty among families with children with severe and multiple disabilities and an association between the age of the individual and the incidence of poverty. He argued that poverty is the direct consequence of caring and financial assistance was ineffective in compensating the direct and indirect costs of disability in the family.

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[52] Roma or Romani people are the largest ethnic group in Hungary. However, the definition of who is Roma has been a highly debated topic since the early 1990s (Babusik, 2004). According to law in Hungary self-identification is the only legal ground for defining ethnicity. In the 2001 Population Census 190,000 people identified themselves as Roma in Hungary. (Kemény, Janky, & Lengyel, 2005). However it is also widely acknowledged that self-reporting in national statistics hugely under-reports the actual number of minorities for various political, historical and personal reasons. There are two sociological approaches to defining who is considered Roma. (Babusik, idem) One of them is represented by the work of Kemény, Janky and Lengyel who argue that Roma are all those persons who are considered to be Roma by the surrounding non-Roma community. According to them the Roma are distinguished on the basis of a darker complexion and ancestry. The other approach is represented by Iván Szelényi and Ladányi (2001) who claim that ethnic groups are "social constructions" and they argue that "classificatory acts take place in highly contested social terrains where some, occasionally a great deal of ethnic prejudice and discrimination can be detected". Therefore classification is "highly consequential for the person thus classified" (p. 80). They point out that expert or community definition often confounds Roma ethnicity and poverty. Csepeli and Simon (2003) showed that the population defined as Roma varies according to the nature of the encounter. While both approaches are valid and equally useful for policy thinking, the advantage of Kemény et al. is that they actually attempted to describe the size and characteristics of the Romani population in Hungary at 3 time points: 1971, 1993 an 2003 using representative surveys. In 2003 the size of the Roma population was thought to be around 600,000, by-and-large 6% of Hungary's total population. The number of Romani people has doubled since 1971 due to a declining but still substantially higher birth rate than that in the non-Roma population. Approximately 15% of new babies born in Hungary are Roma. The number of children in Romani households is considerably higher than in non-Roma families and the share of children under 15 years is more than double of that in the general population (37% and 17% respectively). However, life expectancy and mortality is much higher among the Roma – due to poverty, lifestyle and access to health care – and only 4% of the Roma population was aged over 60 years, in comparison to over 20% of the general population. Kemény et al. also mapped the composition of the Roma community which is far from being homogenous. It is made up of three main linguistic groups. The majority are "Hungarian Roma" (also referred to as Romungro) whose native language is Hungarian. They represented 86.0% of the Roma community in 2003. The "Vlach Roma" whose first language is Romani (Lovari or Kalderash dialects) represented 7.7%; and the Romanian-speaking "Beás" (or sometimes referred to as "Boyash" people made up 4.4% of the Roma population.

Individuals with disabilities and their carers can receive a range of financial supports (see Table 7.2):

- Parents of children with disabilities are entitled to parental leave and benefit until the age of ten. Parents claiming this benefit are allowed to work and the benefit might be claimed by grandparents.
- Family members caring for children or adults with disabilities can claim Carer's Allowance. This is a two-tier fixed-sum benefit: the basic rate is paid for carers of individuals with at least some self-care skills and a higher rate is paid for carers of people who need complete care. People claiming Carer's Allowance are required to pay national insurance contributions therefore the allowance also creates entitlement to pension. Claimants are also allowed to work up to 4 hours a day. Under certain conditions the Allowance can be combined with old-age or disability pension, or parental benefit if the child has severe and multiple disabilities and needs complete care. In these cases however, it is paid as a top-up that brings the other assistance to the level of Carer's Allowance.
- The Family Allowance is a universal benefit paid to all families with children. Its rate depends on the number of children in the family; children with disabilities and in single-parent families also get a higher rate. People with disabilities aged over 18 years can continue to claim this allowance, however it cannot be paid in conjunction with the Disability Support.
- Disability Support is paid for persons with disabilities to compensate for the additional costs of disability. It is paid in two rates, a higher rate is paid for those with high support needs.
- Disability Allowance is paid for those adults (aged 18 years or over) who have lost at least 80% of their capacity to work before the age of 25, including people with congenital impairments. People claiming Disability Allowance are allowed to work part-time and receive other benefits such as the Disability Support or the Family Allowance for adults with intellectual disabilities.

Other, means-tested benefits that are not aimed at people with disabilities or their carers but might be claimed by them include:

- The Child Protection Benefit (*gyermekvédelmi támogatás*) is a means-tested assistance to contribute towards the costs associated with education in low income families. It covers the cost of school meals, school books and a lump-sum payment twice during the school year. However, children with severe and multiple disabilities who are not in school are excluded from this benefit.
- Social welfare benefit (*rendszeres szociális segély*) is a means-tested benefit for those who have no other source of income and the income per capita in their household is below a certain level. However if the individual and their family claim at least two of other

benefits they would no longer be eligible for this benefit due to the low income-threshold.

- The Housing Benefit (*lakhatási támogatás*) is a means-tested benefit that contributes towards the costs of housing. Its sum is based on the income per capita in the household and the size of the dwelling.

People with disabilities are also eligible for a range of benefits in kind, including free public transport and free prescriptions.

Table 7.2 Cash transfers for people with disabilities and their carers, 2009

Type of assistance	Monthly amount (HUF)
Parental benefit (*GYES*)	28,500
Carer's Allowance (*ápolási díj*)	28,500 (net: 25,792)
Higher rate	37,050 (net: 33,530)
Family Allowance (*családi pótlék*)	Per child
Two parents, two children	13,300
Single parent, two children	14,800
Two parents, three or more children	16,000
Single parent, three or more children	17,000
Children in long-term care (paid to the child's account)	14,800
Two parents, children with disabilities	23,300
Single parent, children with disabilities	25,900
Adult with intellectual disabilities	20,300
Disability Support (*fogyatékossági támogatás*)	18,525
Higher rate	22,800
Disability Allowance (*rokkantsági járadék*)	33,330
Housing Benefit (*lakhatási támogatás*)	2,500-10,000

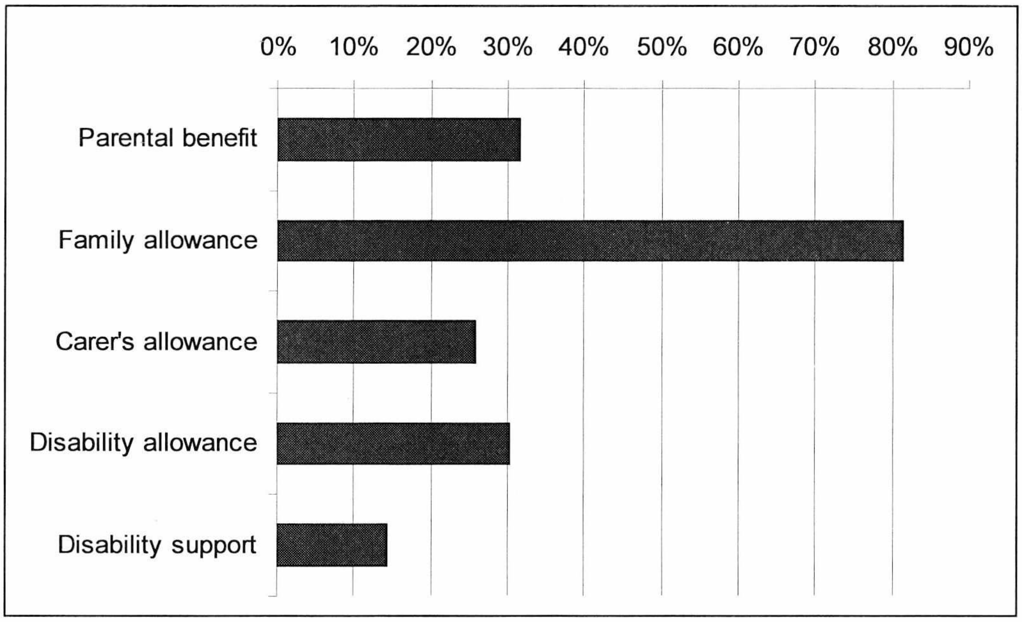
Note. Data retrieved from the website of the Ministry of Social Affairs and Labour: http://www.szmm.gov.hu

Families supporting a child with disabilities can receive between 23,300 and 59,340 forints per month depending on the size of the household and employment status of the parents. The first sum would be for a two-parent family where both parents work full time. The higher sum would be for a single parent who is caring full-time for a child with severe and multiple disabilities. An adult with intellectual disabilities could claim 20,300 forints as family allowance and 33,300 forints as disability allowance. If they need to be looked after by a close relative (parents or siblings) the family could also claim the Carer's Allowance.

This way they would receive between 80 and 88 thousand forints each month depending on the support needs of the individual.

Figure 7.2 gives an overview of the share of families claiming certain types of cash supports based on data from the 2007 Survey.

Figure 7.2 Uptake of disability-related assistance by families, % (n)



Note. Data from the 2007 Survey

To put these sums into perspective, the "subsistence level", a monthly income necessary to have access to a basket of basic goods and services was 71,740 forints per month for a single-person household in 2008.[53] For two adults living together it was 125,540 forints and for one adult and one child 118,365 forints (KSH, 2009).

There are other measures of poverty that are used for statistical and administrative purposes. One draws the threshold of poverty at the national minimum pension, namely 28,500 forints per capita in the household – less than half of what is the "minimum subsistence" level. This is used to establish eligibility for most means-tested benefits and therefore the most stringent measure. Families where the per capita income is under the national minimum pension typically live in deep poverty. Another threshold is the 50 or 60 percent of median individual equivalent income – after social transfers. This is used in most

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[53] The subsistence minimum for families is calculated using consumption units. The first adult is 1.00, the second adult is 0.75 consumption unit, the first child (0-14 years) is 0.65, the second child is 0.5 and the thirds and subsequent children represent 0.4 consumption units. Older adults (over 62 years) represent 0.9 and 0.65 consumption units. These weights do not take into account disability or any other special needs.

international comparisons (e.g. Laeken indicators of the European Union), however its use has disadvantages in countries like Hungary where there is a large "grey economy" and the underreporting of income is widespread.

The 2007 Survey found that between 22.5 and 86% of families of people with intellectual disabilities were below the poverty threshold according to any of the above definitions. It has been argued that the risk factors for poverty include the number of children in the family, single parent, joblessness and Romani background. Families of people with intellectual disabilities are particularly vulnerable because they tend to have more children and parents are more likely to be out of work. Twenty-five percent of families in the survey had 3 or more children in comparison to only 16% of the total households with children (Darvas & Tausz, 2007). Poverty was found to be associated with the number of children and the presence of a child with intellectual disability seemed to increase the risk of poverty in certain categories (See Table 7.3).

The share of single-parent households was similar to the general population, 27 and 25% respectively. Thirty-eight percent of households were jobless (60% of single parent and 26.6% of two-parent households), 44% had one economically active member (32 and 50% respectively) and only 16% were dual-earner families (20.8% of households with two parents). This confirms that one member of the family usually gives up work to look after the individual with intellectual disability. It might be also associated with the higher number of children in these families.

The following statistical analyses of data from the 2007 Survey use the poverty threshold of 60% equivalent median income that is accepted by the European Union and the OECD (Trinczek, 2007). Its sum is also close to the administrative threshold of old age minimum pension in Hungary. There was no significant association between poverty and the number of parents ($\chi^2 = 2.302$, df = 2, $p \leq 0.316$; n = 551). However this might be the result of high levels of joblessness in these families (i.e. at least one of the parents usually has to give up paid work) given that the relationship between the number of earners and poverty was significant ($\chi^2 = 52.827$, df = 2, $p < 0.001$; n = 490). Jobless families were twice as likely to have a per capita income under the poverty level.

Table 7.3 Poverty rates of families with children (%)

	60% of median income		**Minimum subsistence level**	
	Families with		Families with	
	non-disabled	disabled	non-disabled	disabled
	children		children	
Households with children	19.0	22.5	41.0	86.0
1 child	11.0	15.1	29.0	75.0
2 children	19.0	21.6	34.0	89.1
3 or more children	36.0	34.4	60.0	97.0

Note. Data from Darvas and Tausz (2007) and the 2007 Survey

Poverty was also associated with the type of settlement: it was significantly higher in villages than in cities or towns ($\chi^2 = 16.466$, df = 2, $p < 0.001$; n = 498). This is particularly concerning given that 43% of the families in the survey lived in villages as opposed to only 31% of Hungary's total population[54]. Romani people (n = 55; 10.1%) were also at much higher risk of poverty than non-Roma families ($\chi^2 = 69.012$, df = 1, $p < 0.001$; n = 489). Over two thirds of Roma families were under the poverty level.

Poverty was not associated with the severity of disability of the individual but there was a link between poverty and age: poverty was least prevalent among families with young children aged under five – it was similar or lower than in the general population. Poverty increased dramatically in families with children with disabilities of school age (29% of these families had less than 60% of the median income) and decreased again in families with adults with ID (23.2% respectively), probably as a result of increased cash benefits to adults with intellectual disabilities ($\chi^2 = 19.378$, df = 2, $p < 0.001$; N = 502).

As for the subjective feeling of poverty, the Household Monitor Survey found that 46% of the general population expressed a subjective feeling of poverty in 2005 (Darvas & Tausz, 2007). The 2007 Survey asked respondents about the financial situation of their families now and before the birth of the individual with learning disabilities. Nearly 85% of families expressed subjective feelings of poverty: 24.1% considered themselves very poor and 59.4% thought that they were poor in some respects.

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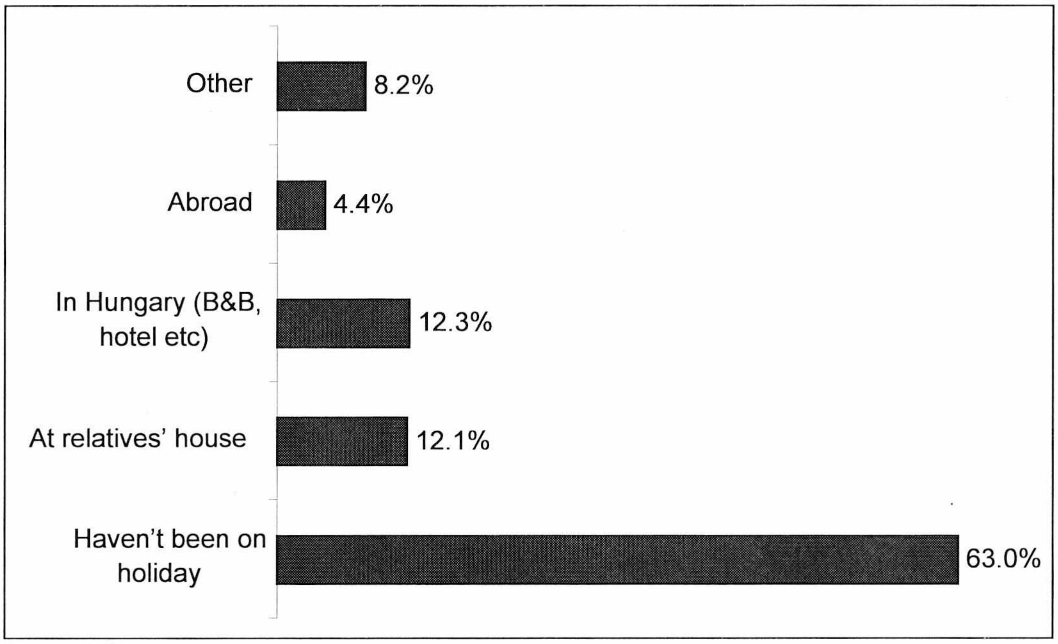
[54] Retrieved from: http://portal.ksh.hu (last accessed: 02/01/2011).

In terms of material and social deprivation, many families were struggling to make ends meet: 7% said that their income was not enough to buy food, 18% said that they did not have enough money to provide for the needs of the individual with disabilities, 22% lacked money to buy clothes and 63.4% said they could not afford to spend money on leisure. Figure 7.3 and Table 7.4 also illustrate this.

Figure 7.3 Where have families spent their holidays in the previous 24 months?



Note. Data from the 2007 Survey

Table 7.4 Community participation:percentage of families that have visited the following facilities

	Cinema	Theatre	Eating out	Visiting friends/family
Past 4 weeks	4.8	5.6	10.5	44.9
Past 12 months	9.4	16.8	17.4	25.7
Longer	85.2	76.9	71.2	29.1
Never	0.6	0.8	1.0	0.2

Note. Data from the 2007 Survey

The housing situation of families was similar to that of the general population. The majority of the families were home-owners (92%), 4.4% were in council housing and 3% were renting privately. Thirteen percent of homes were sub-standard, without a bathroom. The socially/culturally accepted standard for overcrowding is different in Hungary than in some other countries in Europe (for example the UK). It is generally accepted for siblings to share a bedroom, however for adults – not couples – it is generally regarded as a sign of deprivation. Only half of the people with intellectual disabilities who lived with their families had their own bedroom. Although having an own room was significantly associated with age ($\chi^2 = 32.643$, df = 2, $p < 0.001$; n = 534), even among those aged 20 years or over only two thirds (65%) had an own room. The relationship between severity of disability and having an own bedroom was not significant. There is no data on whether these people were sharing a bedroom with another family member (e.g. siblings) or they slept in rooms used for other purposes (e.g. kitchen and dining room, living room).

It has been shown that families supporting individuals with intellectual disabilities are exposed to high levels of poverty due to the financial and social impact of caring. But does financial hardship increase the likelihood of out-of-home placement? The results of the survey suggest this is not the case. There was no significant association between poverty and intention of out-of-home placement. The likelihood of institutionalisation was associated with the severity of disability and the age of the disabled individual and the parents. Financial reasons do not seem to play a key role in the decision of families to seek institutionalisation. Families that are committed to support their disabled children at home will probably do so despite financial difficulties and institutionalisation is regarded by many as a last resort.

In summary, families of individuals with intellectual disabilities were at increased risk of poverty and social exclusion in Hungary and some of them experienced high levels of financial and material deprivation. The patterns of poverty were similar to those in the general population, but these families were exposed to higher risk due to their demographic and labour market status. Poverty was strongly associated with economic inactivity as generally one or both of the parents had to give up their jobs to look after the individual with disability in the family in the absence of accessible day and support services. The data also revealed two other dimensions of poverty in families of people with intellectual disabilities: an ethnic and a geographical dimension. Cash transfers to families could not offset the financial impact of supporting an individual with intellectual disabilities at home. Nevertheless, poverty was not associated with the likelihood of out-of-home placement.

The other dimension of poverty is its association with the prevalence of less severe intellectual disability (Emerson, 2007). This is a politically sensitive issue in Hungary – and in most post-socialist transition countries of East-Central Europe – due to the legacy of state socialism when children in underprivileged families, particularly Romani children were routinely taken into child protection, often also labelled as "intellectually disabled" and sent to special schools.

Hungary ranks unfavourably on a number of health and social indicators, including low birth rate, infant mortality and harmful lifestyle behaviours (i.e. smoking, alcohol consumption and unhealthy diet). Low birth weight is an important indicator of child health and socio-economic development. Infants with low birth weight are more likely to develop significant disabilities (OECD, 2009a). In Hungary the proportion of infants with low birth weight was 8.5%, somewhat higher than the OECD average (6.4%) and the EU average (6.6%) in 2005 (OECD, 2009b). Low birth weight was 2.5 times more common among the babies of mothers with the lowest education, at 21% (Darvas & Tausz, 2007). The share of infants with very low weight (less than 1,500 grams) was consistently around 1.4%. Premature birth and low birth weight were shown to be associated with low education of mothers, poor living conditions, unhealthy lifestyle (diet, smoking and poor personal and sexual hygiene) and previous abortions (Czeizel et al. 1978; OGYEI, 2005; Puporka & Zadori, 1999).

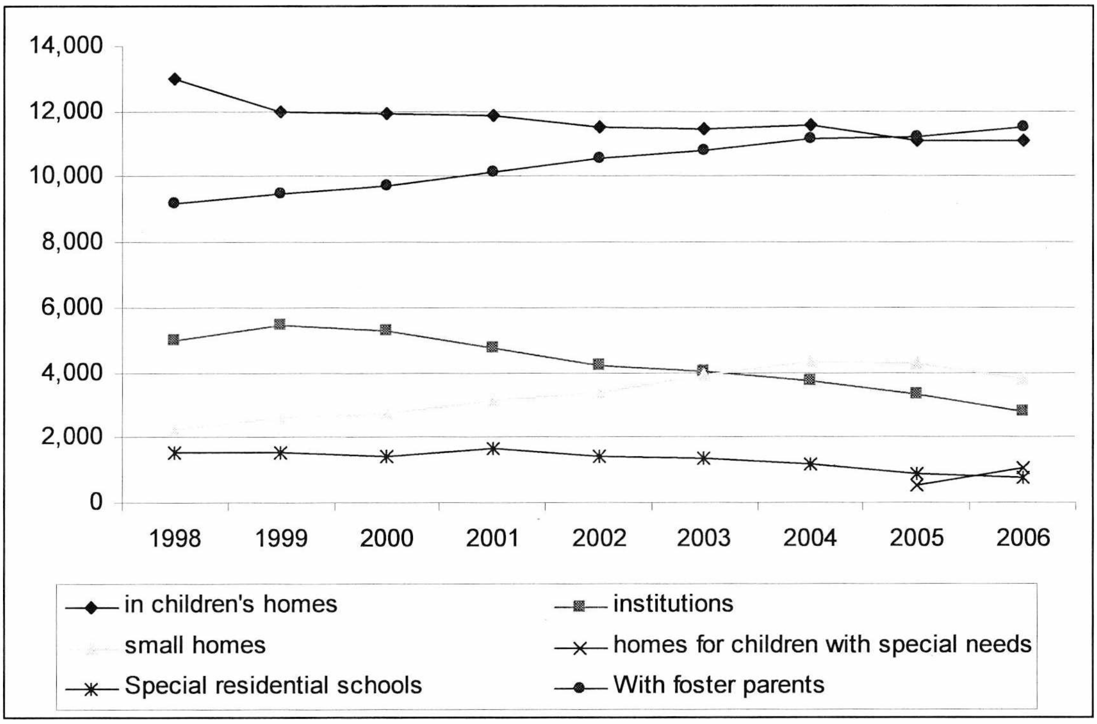
The Roma population faces particular health disadvantages and risks that have so far not been adequately studied and addressed (Zeman, Depken, Schenchina, 2003). A study from the 1970s (Czeizel, 1980) suggested that in over 50% of the cases intellectual disability could be attributed to socio-economic factors among children. Nevertheless very little is known about the implications of these factors for the prevalence of intellectual disability since the 1990s. The poverty of families is usually raised in a different context: the institutionalisation of children in the child protection system.

7.5 Institutionalisation and the child protection system

At the end of 2006 there were 16,909 children and 4,079 young adults aged 18-24 years in the child protection system (Gulyásné & Papházi, 2008). They represented approximately 0.91% of the age group. The rate of children looked after by the state has declined modestly since the early 1990s (Darvas & Tausz, 2007). In 1997 a new Child Protection Act was adopted (1997. évi XXXI. törvény) that aimed to reform the entire system of child protection. The law stipulated that no children should be removed from their family for financial reasons and it also set the objective of deinstitutionalisation in child protection. This was to be achieved by downsizing existing institutional provision initially to 70 places per setting, then 48 and currently 40 and setting up smaller homes for up to 12 children in the community.

There have been some positive developments since the new law. First, the number of children placed with foster parents has steadily increased and since 2005 it has been exceeding that of children looked after in children's homes. The other favourable trend has been the decline in the number of children placed in institutions and an increase in small scale community-based provision. Between 1998 and 2006 institutional placement decreased by 44% and the number of children in group homes increased by 66%. However in 2006 still just over one third of children in residential placement lived in community-based settings. (See Figure 7.4)

Figure 7.4 Trends in the number of children looked after by the state in different types of provision, 1998-2006



Note. Data fromStatistical Bulletin on Child Protection (Gulyásné & Papházi, 2008) published by the Ministry of Social Affairs and Labour

The main shortcoming of the Act is that children with special needs[55] and disabilities can still be looked after in institutions and children with high support needs can be placed in social care homes. The percentage of children labelled as having special needs is very high

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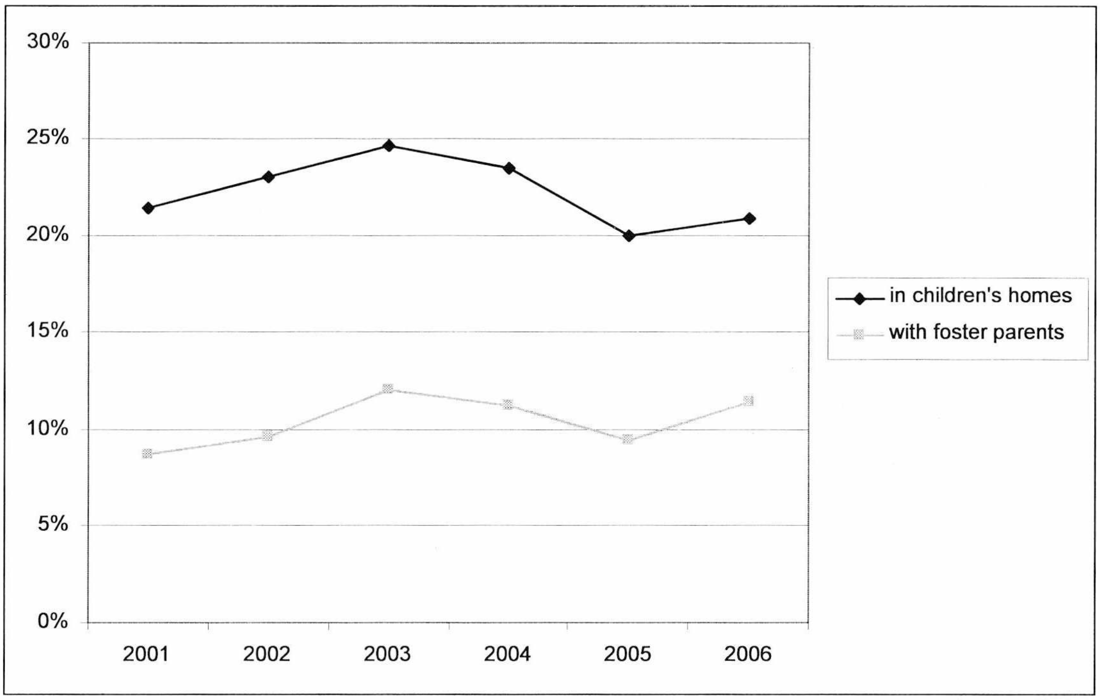
[55] A note on terminology: the term "children with special needs" refers to the Hungarian term "különleges ellátást igénylő gyermek" that include young children under the age of three, children with long-term health problems and children with disabilities. This is different from "speciális szükségletű gyermek" which would also be translated to English as "children with special needs", however according to the law it refers to children with severe anti-social behaviour, and substance abuse. The term "speciális gyermekotthonok" – "special children's home" means secure hostels for children.

in the system: they represented 40% of children looked after by the state. Children with intellectual disabilities were less likely to be placed with foster families – 36% as opposed to 53% within the total). They represented over 20-25% of the population of children's homes while their total share in the system fluctuated between 14.7% and 18.6% (See Figure 7.5).

Figure 7.5 The share of children with intellectual disabilities looked after by the state, 1998-2006



Note. Data from Statistical Bulletin on Child Protection (Gulyásné & Papházi, 2008) published by the Ministry of Social Affairs and Labour

The European Roma Rights Centre published a report in 2007 which showed that Romani children were over-represented in the child protection system (ERRC, 2007). Roma children are estimated to represent around 13% of the total age group however the report suggested that as many as 40% of children could come from an ethnic Roma background and a further 18% from a mixed ethnic background in the child protection system. It was also argued that "Romani children are disproportionately categorised as mentally disabled, which impacts their position in the child protection system and with regard to educational and later-life opportunities" (p. 18). Sixty-three percent of children who participated in the research and were labelled as having special needs or intellectual disabilities were ethnic Roma. It is believed that diagnosis is often wrong or biased, but guardians or underprivileged families are less likely to challenge these decisions (see also Kende & Neményi, 2006).

The report highlighted three issues as negative consequences of growing up in state care: first, large groups of Romani children are brought up "outside the care and protection of their natural families, often in an institutional setting, and are destined to an adult life without any substantial support network" (p. 10). Secondly, these children suffer an identity crisis because in the absence of their community influence. They cannot develop a Romani identity, often they do not even consider themselves Roma, however they are still perceived as Roma by the wider community and as such face double discrimination. Thirdly, growing up in state care creates a vicious cycle, many of the parents of these children had been looked after by the state and many of their children will end up in state care again. Child protection policies have been ineffective in preventing this for many decades.

While all these are valid concerns, the report – or any other policy documents – fail to recognise a fourth issue: how the system fails to prepare most of these children, particularly those labelled as having intellectual disability, to independent adult life. In the absence of social supports, transition planning and meaningful alternatives many of them end up in long-stay institutions. There is no data on how many children, including children with special needs and learning disabilities leave care each year because they turn 18 years old and whether they return to the community to live independently or with their families, or are transferred to adult services. This is also a very vulnerable group that often becomes the victim of exploitation and abuse in the community. Their community integration – and thus deinstitutionalisation – is made more difficult by the double stigma of intellectual disability and Roma ethnic background.[56]

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[56] The Roma are one of the most discriminated groups in Hungary. Csepeli, Fábián and Sik (1998) argued that the attitudes towards Romani people are characterised by social distance, negative attributions and prejudices (see also Koulish, 2003). In a representative survey (N = 2,744) they found that 87% of the population rejected positive discrimination of Roma people, 83% agreed that the Roma do not work because they live off welfare benefits and 47% supported segregation – banning Romani people from pubs and clubs. In 2005 TÁRKI Social Research Institute found that 62% of the Hungarian adult population agreed that "Roma people have a natural tendency towards criminality". Retrieved from: http://www.tarki.hu/tarkitekinto/20060201.html (last accessed: 02/01/2012). A weekly economic magazine in Hungary (HVG) conducted a survey in February 2009 on attitudes towards the Roma. Thirty-six percent of the population said that the Roma should be segregated from the non-Roma population (Venczel 2009). According to a survey by the European Union Agency for Fundamental Rights 90% of Roma respondents said that discrimination on ethnic origin was widespread in Hungary, 62% experienced discrimination in the past 12 months and 32% said they experienced discrimination when looking for work ("Data in Focus Report", 2009). In 2009 there were a number of racially motivated attacks on Roma people. The European elections in 2009 and the national parliamentary elections in April 2010 saw an unprecedented

7.6 Mental (in)capacity of individuals with intellectual disabilities and the institution of guardianship

Mental capacity is about the autonomy of the individual to make decisions for themselves. Mental capacity is also about human dignity, control and self-esteem, and the possibility to lead a fulfilling adult life, the way one wants to live (Verdes, 2008). Traditional guardianship models based on the deprivation of individuals of their rights and the appointment of guardians to make decisions on their behalf have come under increasing criticism internationally and some countries – England and Wales, Scotland among them – introducednew legislation based on the model of supported or assisted decision-making (MDAC, 2007; Williamson, 2007).

The regulation of mental capacity and guardianship in Hungary dates back to the 1950s (1959. évi IV. törvény). Although it has been amended several times to reflect the changes in the administrative system of the country, the main principles remained unchanged. In Hungary the law makes a distinction between *legal capacity* (*jogképesség*) and *capacity to act* (*cselekvőképesség*) (MDAC, 2007). Legal capacity is the general reaffirmation that all persons have rights and can be subject to legal obligations. However, the capacity to act can be limited or taken away by a court decision if the individual is found to "have partial or no capacity to conduct his/her own affairs due to mental health status, mental disability or pathological addiction on a permanent or temporary basis". One's capacity to act can be limited or taken away completely in any or all of the following areas of life by placing the individual under guardianship:

- Claiming social security, social or unemployment assistance, disposing of income above 50% of earnings;
- Possession of material assets and property;
- Family law, including getting married, entering a civil partnership, adoption and deciding about the name of their child etc;
- Making financial decisions regarding alimony;
- Letting or renting of property;
- Inheritance;
- Decisions regarding placement in residential care;
- Health care and treatment;
- Deciding where to live.

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support for the radical right-wing party JOBBIK with open and strong anti-Roma rhetoric that now is the third largest party in the Parliament with 12.2% of the seats. (For a commentary on the situation see for example Kaltenbach and Twigg (2009)).

There are two types of guardianship: plenary and partial. Plenary guardianship is an all-encompassing limitation to act. People who are placed under plenary guardianship by the court cannot make decisions in any of the above areas and they are also deprived of their political rights including the right to vote. All major life decisions must be made by their guardian. The guardian is required to "consult and if feasible take into account the requests and views of the individual if he/she is able to express an opinion" (1959. évi IV. törvény, Art. 16). Plenary guardianship is not reviewed and it is usually irreversible. Partial guardianship is the limitation of the capacity to act in one or more of the above areas. People under partial guardianship usually retain their capacity to act in some areas (e.g. they might be entitled to sign a work contract, make certain financial decisions etc.); however some people have limited capacity in all areas, so-called partial guardianship with general limitations. Partial guardianship must be reviewed on a regular basis, usually up to every five years, and can be reversible.

Guardians are appointed by the local guardianship authority following the court's decision. They can be either family members or professional guardians. Anyone can be a guardian who has *full capacity to act* and no criminal records, however staff in social or health services can no longer be appointed as guardian for their service users. One professional guardian can supervise a maximum of 30 clients, but this is not strictly enforced in the absence of a national register of guardians (MDAC, 2007). Professional guardians receive a small monthly per capita payment from the guardianship authority which creates an incentive to take on more clients.

Guardians are required to safeguard the assets and the financial interest of the individual. They not only need to approve all or certain expenses but they have control over the individual's bank account or cash and have the right to refuse "unreasonable" spending. Professional guardians have to submit detailed financial reports each year to the guardianship authority. Family guardians are exempt from this if the assets and monthly income of the individual remain below a certain level – currently 200,000 forints and 4 or 3 times the national minimum pension (114,000 or 85,500 forints) depending on the proximity of family relationship.

MDAC (2007) assessed Hungary's guardianship legislation along 29 indicators derived from international legal instruments and found that it did not meet international human rights standards. It was argued that guardianship meant an effective ban on adults from exercising fundamental rights such as the right to work, the right to property and the right to freedom of movement. It was also concluded that the regulation of guardianship lacked clarity which led to inconsistency and uncertainty in its implementation. The Report suggested that guardianship wasoverused in Hungary and with very little understanding of its human rights implications. Furthermore the system was found to be open to abuse and without appropriate safeguards to protect the best interest of the individual.

Different data sources report different figures for the number of people under guardianship. According to the National Council of Justice there were 66,000 people under guardianship in 2006 (MDAC, 2007) and 63,000 in 2007 (Verdes & Tóth, 2008). The number reported by the Central Statistical Office was considerably lower than this: 51,361 in 2006 and 51,896 in 2007[57] (Idem.). The reason of the difference is unknown, but both figures are high at 0.7 – 0.83% of the country's adult population. The number of individuals under guardianship rocketed during the years of political and economic transition in the early 1990s suggesting underlying issues of vulnerability, marginalisation and social exclusion. While in 1970 there were less than 11,000 people, 0.1% of the population under guardianship, by 1995 this number tripled and continued to increase until 2007 when it reached nearly 52,000 that was 0.5% of the total population (Verdes, 2008).

The majority of these people are under plenary guardianship. According to the figures of the National Council of Justice – the CSO does not report on type of guardianship – in 2007 65.8% were under plenary guardianship and a further 12.4% under partial guardianship with general limitations which meant that they could not make any decisions, but their guardianship status was reviewed on a regular basis. While the group is extremely heterogeneous, people with intellectual disabilities account for a large share. Verdes (2008) estimated that there were 28,000 individuals with an intellectual disability under guardianship, approximately 70% of the total adult population with intellectual disabilities.

The 2007 Survey found that among people with intellectual disabilities aged 18 years or over (n = 297) 65.3% were under guardianship. Among these (n = 195) 19.2% were under plenary guardianship, 75.2% were under partial guardianship with general limitations and 5.1% were under partial guardianship. The majority of the guardians were family members: 68.2% parents, 2.7% siblings, 2.7% other relatives, and 25.8% were professional guardians.

Guardianship was significantly more common in institutions: nearly 90% of people living in institutions were under guardianship in compared to just over 52% of people living with their family ($\chi^2 = 43.342$, df = 1, $p < 0.001$; n = 296). But there was no significant association between the type of guardianship and residential status. People who lived in

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[57] Retrieved from: http://portal.ksh.hu (last accessed: 02/01/2012).

residential care were significantly more likely to have a professional guardian than a family guardian ($\chi^2 = 57.902$, df = 1, $p < 0.001$; n = 179).

Information from the 2007 Survey revealed that the family initiated the guardianship procedure in nearly half of the cases. Verdes and Tóth (Verdes & Tóth, 2008) suggested that families sacrificed the human rights of their offspring to ensure access to benefits and services. While the argument is compelling and qualitative data (interviews with families) provided interesting insight into the experiences of families, in the 2007 Survey there was no significant relationship between the income and the risk of poverty and guardianship. The only significant association was found between the uptake of disability allowance and guardianship ($\chi^2 = 4.780$, df = 1, $p < 0.05$; n = 216). However, the high share of families seeking to place adults with intellectual disabilities under guardianship and the fact that over 90% of families approved of the system of guardianship, seem to confirm the earlier argument that there is very little understanding of the human rights implications of this legal institution.

In 2007 the Government initiated the review of the Civil Code including the provisions on mental capacity. This was partly made necessary by Hungary's ratification of the United Nation's Convention on the Rights of Persons with Disabilities. The preparatory process was described as "exemplary" by various stakeholders, including representatives of the civil society. The Ministry of Justice worked closely together with organisations representing people with intellectual disabilities and mental health problems (e.g. MDAC). The Government adopted the draft bill in May 2008 and the new regulation was ratified by the Parliament as part of the amended Civil Code in September 2009. It was scheduled to enter into force in May 2010, however its implementation was postponed indefinitely by the Constitutional Court on the initiative of the incoming conservative FIDESZ Government. It was argued that authorities and guardians did not have enough time to prepare for the implementation of the new rules and this would jeopardise the situation of people under guardianship. Advocacy and disability organisations opposed this decision and called for the implementation of the new rules according to the original schedule but their petition was rejected by the Constitutional Court.[58]

The proposed rules represented a departure from the old model and were heavily influenced by recent international trends, including the 2005 Mental Capacity Act in England and Wales.[59] The Bill stipulated that

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[58] For a summary of the events see: http://www.mdac.info/en/constitutional-court-undermines-legal-status-hunga (last accessed: 06/05/2010)

[59] The draft Bill can be downloaded from the website of the Hungarian Parliament: http://www.parlament.hu/irom38/05949/05949.pdf (last accessed: 02/01/2012; in Hungarian only)

nobody should be excluded from decision-making. The new system would have done away with plenary guardianship and introduced the concepts of advance directive and supported decision-making. [60] Guardians would have been required to consult adults with intellectual disabilities, including people with profound intellectual disabilities and no speech, in the most appropriate way regarding any decisions if necessary with the involvement of professionals to facilitate communication.

The implementation of the proposed rules would have had an enormous potential to bring about change in the life of tens of thousands of persons with an intellectual disability who are deprived of choice and autonomy. It would also have had implications for deinstitutionalisation and community living because it would have given the right to service users to decide about where they want to live.

7.7 Conclusion

This chapter has started with the suggestion that institutions are at the intersection of different policy areas the dynamics of the policy system work in favour of institutions and hinder the development of community-based alternatives. The analysis identified a number of issues that legitimise and help to sustain the dominance of institutions. First, the lack of non-residential alternatives in the community, including the scarcity of day supports and the exclusion of people with intellectual disabilities from the labour market encourages the use of residential provision, mainly institutions. At the same time there is a concentration of services in residential settings. Institutions and group homes have become major providers of employment and support services, and there is a chance that they will become main providers of special schools for children with severe disabilities. People using residential provision have access to a variety of other, non-residential services, while those living at home have very limited access to supports they need to live in the community. Second, the education system, particularly the exclusion of children with severe, profound and multiple disabilities from public education, the segregation of children in special schools and the lack of transition planning increase the likelihood of institutionalisation among children and young adults, and fail to prepare them for community living.

The analysis also revealed high levels of poverty and social exclusion among families caring for individuals with intellectual disabilities. Although poverty was not associated with out-of-home placement, the high risk of poverty suggests that many people with

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[60] Nevertheless, people under partial guardianship are still denied political rights, including the right to vote.

intellectual disabilities experience social exclusion in the community. The failures of child protection and social housing policies to support vulnerable groups, such as the Roma, provide a constant demand for residential care among young adults and no ways out of the system. Finally, through the institution of guardianship the majority of adults with an intellectual disability are effectively banned from exercising control and choice over the most important aspects of their lives such as taking up employment, spending their own money and deciding where and with whom to live. This restricts opportunities for independent or supported living in the community. The next part of the thesis will look at the quality and service user outcomes of different residential arrangements.

Part 3

The Quality of Residential Care for People with Intellectual Disabilities. A Field Study

Chapter 8 Methods and Implementation of the Field Work

The empirical field study aimed to collect quantitative information to compare different types of residential services and outcomes for adults with an intellectual disability. In particular it sought to answer the following research questions:

- What are the characteristics of the different residential arrangments and their service users? What are the main differences?
- What are the outcomes of different residential arrangements for service users?
- Do community-based services deliver better outcomes in Hungary?
- How do outcomes compare to those reported in other countries?

The initial hypotheses based on the systematic review of user outcomes were:

- In line with the international experience, smaller scale arrangements in Hungary provide better user outcomes than institutions but there are large variations within types of provision.
- People with more severe disabilities and challenging behaviour experience poorer outcomes in all setting types.

To answer these questions a cross-sectional research design was adopted and data was collected in different residential settings at a single time point. Stratified random sampling techniques were used to select the samples consisting of services and individual service users. In order to ensure comparability of findings with existing research a range of established measures were used to collect data. Another advantage of the use of established measures was that they had acceptable psychometric properties. Factual information was collected using general questionnaires and forms designed for the purpose of the study. This chapter gives a more detailed overview of the methods of data collection and the implementation of the field work.

8.1 Sampling, settings and participants

Two samples were selected in the study. Sample 1 consisted of facilities representing the range of long-stay residential services for adults with an intellectual disability in Hungary. Sample 2,a total of 120 participants, was selected from the residents of the facilities in Sample 1 using random sampling. The size of the samples took into account the requirements of statistical analysis and considerations for feasibility of data collection; Sample 1 included 15 facilities and Sample 2 consisted of 120 service users.

8.1.1 Selection of Sample 1

Facilities were included in the sample if they were registered social care service providers and provided one or more of the following services defined by the law on social care (1993. évi III. törvény): care home[61], rehabilitation home[62], group home[63], or rehabilitiation group home[64] for adults with an intellectual disability as primary diagnosis.
The following facilities were excluded from the sample:

- Long-stay residential services for children with disabilities, even if someservice users were aged 18 years or over.
- Institutions providing services to people with intellectual disabilities and other groups such as people with sensory disabilities, elderly people, people with mental health problems, patients with substance abuse problems and homeless people, unless the ID servicewas registered as a separate "branch" of the main institution.

The list of eligible facilities was generated from an on-line database of the Ministry of Social Affairs and Labour[65]. It had a total of 173 services: 80 institutions, 37 independent and 55 institutional group homes. A limitation of this database was that the latest available data was from 2006. This was not a problem in the case of institutions because no new institutions were opened between 2006 and 2008. However group homes established after 2006 were not included in the sample.
Services were grouped into three categories (see table8.1):

- institutions (predominantly state providers, a few religious and voluntary organisations)
- group homes provided by institutions
- group homes provided by independent organisations.

Lists were randomised and from each category a sample of four services was selected using random numbers. To make sure that Budapest – as the largest city in Hungary and the Municipality of Budapest as the largest service provider – was represented in the sample one service in each category was selected that was either based in Budapest or provided by the Municipality of Budapest.

Although the initial experiences of contacting organisations were positive and most services were interested in taking part in the study

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[61] Articles 67 and 69
[62] Articles 72 and 74
[63] Article 85/A
[64] Article 85/A
[65] "Szociális Ágazati Információs Rendszer" (Social Sectoral Information System) available at https://teir.vati.hu/szoc_agazat/ Registration and password required for access.

there were some organisations that refused to take part. When this happened a similar service in the same county or neighbouring county was approached. This happened in four cases:

- Two institutions refused to take part in the study because they were undergoing reorganisation.
- A group home operated by the Roman Catholic Church refused to participate on ideological grounds; they did not wish to be compared with state institutions.
- An independent group home that initially agreed to take part in the study but the manager was not cooperative (e.g. did not return phone calls, kept postponing appointments etc.). Therefore the setting was replaced with a similar service that showed willingness and commitment to cooperate.

The total number of organisations in the study was 13 because in two cases both the institution and its group home were included. Codes indicating the type of provision were randomly allocated to services. Codes 101-105 for institutions, codes 201-205 for independent group homes, and codes 301-305 for group homes operated by institutions.

Table 8.1 provides an overview of the services in the study by region and type of provider. The achieved sample represented a good mix of services in terms of geographical distribution and type of provider. The institutions in the study had an average of 124 places ranging from 101 to 145, in comparison to an average of 105 places of all institutions ranging from 20 to 255 places. The sample represented the core of residential provision for people with intellectual disabilities in Hungary. Annex 4 provides a brief description of the services.

Table 8.1 Services in the study by region and type of provider

	Institutions		**Group homes**			
			Independent		**Institutional**	
	Total	Selected	Total	Selected	Total	Selected
by region						
Budapest	1	-	6	1	-	-
Southern Great Plain	14	-	7	1	13	1
Southern Transdanubia	12	2	1	-	4	1
Northern Great Plain	10	1	2	-	12	1
Northern Hungary	9	1	2	1	6	1
Central Transdanubia	13	-	2	1	7	-
Central Hungary	11	1	17	1	8	1
Western Transdanubia	10	-	-	-	5	-
by type of provider						
County council	61	3	-	-	47	3
Budapest city council	9	1	-	-	5	1
Church	5	-	2	-	-	-
Public interest company	3	1	3	-	-	-
Non-profit organisation	-	-	32	5	-	-
Central government	2	-	-	-	3	1
Total	***80***	***5***	***37***	***5***	***55***	***5***

8.1.2 Selection of Sample 2

Sample 2 was selected from the residents of services in Sample 1. Managers received the sampling instructions in advance and they were guided through the process over the phone to select a random group of six residents in group homes and 12 residents in institutions.In total 120 participants were selected; 60 service users from institutions, 30 from independent group homes and 30 participants from group homes in institutional provision.

Additional questions regarding the primary disability, gender and age of selected participants and the general service user population of the facility were asked to ensure that only people with intellectual disabilities were selected and the sample was representative of the setting. All individuals met the inclusion criteria. Participants were allocated individual codes made up of the three-digit code for the service and a random number. No names or other personal data (e.g. date of birth) were recorded for individuals.

8.2 *Measures*

The review of evaluation literature on service user outcomes of different residential arrangements in Chapter 3 found that the most frequently used domains in cross-sectional comparisons were community participation, family contact, self-determination, lifestyle and health, medication, social networks and quality of life. The field work explored outcomes in six of these seven domains. Quality of life is a composite measure and includes all of the other domains evaluated here; thus it was not assessed separately.

Three sets of measures were used to collect data on services, service users and the views of managers (see Table 8.2). The English version of the measures can be found in Annex 3.

The Service measure consisted of a general questionnaire, the Management Practices Interview, and the Homelikeness and Room Rating Scales (Raynes, Wright Shiell, & Pettipher,1994). The general service questionnairehad 57 questions, and it was intended to provide basic information on the facility, buildings, residents, staff, funding, services and procedures. It was completed by the manager/deputy manager of the facility.

The Management Practices Interview/Group Homes Management Scale was originally designed by Pratt, Luszcz and Brown (1979) to measure the extent a facility features the characteristics of total institutions; rigidity of routines, block treatment, depersonalisation and social distance between staff and residents (Goffman 1961). Here the version modified by Mansellet al. (2004) was used that contained additional items. This measure was completed in an interview with the manager or a senior staff member of the facility during site visits. Items were asked as open questions and scored according to the answer. Each item was scored on a scale from 0-2, where 0 corresponded to non-institutional practice, 2 to institutional practice and 1 to mixed or intermediate cases. The total score was obtained by summing the scores for all 37 items. The summary score ranged from 0-74, higher scores indicating more institutional practices.

The Questionnaire on Resident Rightswas a set of fixed-choice and open questions on the rights and involvement of residents in the management of the facility, particularly in the areas required by the relevant legislation, including User Councils, complaint procedures and user rights representatives(Hungary 2000). Answers were recorded and coded into nominal categories.

The Homelikeness Scale and the Room Rating Scale (Raynes et al. 1994 cited in Mansell et al., 2004) were observation instruments to assess the homelikeness of settings and the quality of the living areas. It was completed during or shortly after the site visit.

TheService User measures consisted of the following instruments:

- A general questionnaire on demographic and guardianship information, and residential history.
- The short form of Adaptive Behaviour Scale – Residential and Community Part I (SABS) developed by Hatton et al. (Nihira, Leland, & Lambert, 1993; Hatton, et al. 2001) from the original 73-item standardised scale (Nihira, Leland et al. 1993). The short form had 24 items grouped into three adaptive behaviour factors: personal self-sufficiency, community self-sufficiency and personal social responsibility. SABS scores can be converted into full-scale scores using the formula provided by Hatton et al. The scale could be completed by anyone with a good knowledge of the participant.
- The Aberrant Behaviour Checklist (Aman & Singh, 1986) was a 58-item standardised scale to rate the scope and severity of challenging behaviour of persons with intellectual disability. The scale had five sub-scales – irritability, lethargy, stereotypy, hyperactivity and inappropriate speech – and under each sub-scale listing challenging behaviours known to occur in persons with intellectual disabilities. Items were rated on a scale of 0 (not at all a problem) to 3 (the problem is severe in degree). The scale could be completed by anyone with a good knowledge of the participant.
- The Index of Community Involvement (Raynes et al. 1994) contained 15 items and provided information on the community facilities used by the individual within the previous 4 weeks.
- The Index of Participation in Domestic Life (Raynes et al. 1994) was a measure designed to assess the extent to which individual service users were given the opportunity to participate in routine domestic tasks. It had 13 items, each rated on a scale of 0 (no) to 2 (yes, without help).
- The Choice-making Scale was originally developed by Conroy and Feinstein (1986) and it was used by Raynes et al. (1994) to estimate the extent to which service users were encouraged or had the opportunity to make choices. The measure had six sections covering choices related to food, physical environment, clothes, sleeping, recreation and other issues. There were a total of 24 items, rated on a scale of 0-3. Higher scores indicated more choice-making opportunities.
- The Questionnaire on Health and Lifestyle asked question about the health status, long-term health conditions, medications and life-style related risk factors, such as smoking, drinking, and obesity of the participant.
- The questions on family contact asked about family members who were in contact with the individual and the frequency of contact. The

questions on friendships and relationships explored the social network of the individual.

- Direct observation of resident activity using the Engagement in Meaningful Activity and Relationships measure (Mansell & Beadle-Brown 2005). This measure was designed to provide an estimate of how much time participants were involved in meaningful activities and relationships.
- The Active Support Measure (Mansell, Elliot et al. 2005) rated the quality of staff support to participants based on direct observation. The Measure had 15 items, each item was scored on a range from 0 indicating the lowest performance to 3 indicating good performance.

The Manager Questionnairewas a 13-item self-administered questionnaire designed to explore the views of the manager on the service, including the main challenges and problems, and their attitude towards community living of people with an intellectual disability. It was intended to provide background information to the field work and the policy analysis.

The choice of measures was on the one hand justified by the availability of studies that used a similar set of measures in order to compare either resident characteristics or outcomes (such as Aman, Richmond,Stewart, Bell, & Kissel, 1987; Mansellet al. 2008; Emerson et al. 2000). On the other hand these outcome measures have been used in congregate settings beforeand found suitable to assess user outcomes in institutions (Raynes et al., 1994, Mansell, et al., 2004). Where alternative measures existed consideration was given to the validity of the instrument in the Hungarian context. For example the advantage of the Choice-making Scale over the Resident Choice Scale (Hatton et al., 2004) was that its items were less affected by the limitations of capacity and guardianship.Relationships and social networks are important determinants of outcomes and research showed that it is associated with type of residential support. Recent research on social networks and friendships of people with intellectual disabilities focused mainly on quantitative aspects including the size and density of networks, and friendships with non-disabled people, using measures such as the Social Network Map(Robertson et al. 2001), Social Network Guide (Forrester-Jones et al. 2006) and the Social Network Analysis Form (Howe et al. 1998).As Chapter 5 higlighted people living in large institutions have limited contact with family and members of the community (see also Mansell et al., 2004), and most relationships are within the institution. None of these measures were designed for use in institutional environments and their validity was not demonstrated in congregate settings. Therefore the social networks of participants were surveyed using general questions on friendships and relationships.

Table 8.2 Summary of measures

Measure	Domains covered	Technique of data collection
Service Questionnaire	Residents, staff, buildings, services, income and expenditure, procedures	Completed by managers before site visit
Management Practices Interview	Procedures and practices	Completed by researcher at site visit
Questions on Residents' Rights	Resident rights and associated procedures and practices	Interview, completed by researcher at site visit
Homelikeness and Room Rating Scales	Physical conditions	Observation, completed by researcher at site visit
General user questionnaire	Demographic information, services used	Completed by staff before site visit
Short form of Adaptive Behaviour Scale (SABS)	Independent functioning, skills	Completed by staff before site visit
Aberrant Behaviour Checklist (ABC)	Challenging behaviour	Completed by staff before site visit
Index of Community Involvement (ICI)	Use of community facilities	Completed by staff before site visit
Index of Participation in Domestic Life (IPDL)	Opportunities to participate in domestic tasks	Completed by staff before site visit
The Choice-making Scale	Self-determination in everyday issues	Completed by staff before site visit
Questionnaire on Health and Lifestyle	Health status, medication, health-risk factors, sexuality	Completed by staff before site visit
Engagement in activity and staff support		Observation, completed by researcher at site visit
Manager Questionnaire	Views and attitude of manager towards residential care policy and DI	Completed by manager before site visit

8.2.1 Validity, language and cultural issues

The measures were translated from English into Hungarian by the researcher. Two Hungarian colleagues[66] who are familiar with the subject were asked to evaluate the content validity of all measures and check the translation to make sure that instructions and questions were clear and easy to understand. They were asked to point out any issues that needed clarification. According to the reviewers the face validity of measures was good; they made no comments regarding the translation and the use of language in the questionnaires. However, they suggested adding some questions and raising further issues (Table 8.3). Two factors were considered when deciding about the proposed changes: how much they would add to the study and the extra workload on respondents.

Some of the measures (SABS, ABC) were developed and used by researchers in English-speaking Western countries. This raised the question whether it was appropriate to use them in a different context, with different cultural traditions and social norms, and particularly different levels of wealth and development. To make sure that instruments were culturally appropriate and valid, they were reviewed item by item. Only minor issues were identified before and during data collection. These will be taken into account when analysing and interpreting findings. Scoring was however not altered in order to preserve comparability of data with other studies using the same measures.

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[66] The two reviewers were Mr Ákos Pordán, director of Kézenfogva Alapítvány, a Hungarian charity aimed at promoting community-based services in Hungary and Mr Tamás Verdes a PhD student in Sociology at Eötvös Lóránd University and officer of the Hungarian Civil Liberties Union.

Table 8.3 Summary of comments

Recommendation	Response
For the service questionnaire:	
Ask about longitudinal trends: how the number and distribution of places changed since 1998. I.e. did "institutional" capacity increase or are institutions shifting places to small scale settings in the community?	Accepted
Ask for more detailed statistics on guardianship at the level of the organisation.	Declined
Ask specifically whether the institution operates a Residential School.	Accepted
For the manager questionnaire:	
Ask managers to define normalisation in their own words.	Accepted
For the service user measures:	
Ask where the participant is from (to see how far they are from their locality and maybe family)	Partly accepted. A multiple choice question was added to ask whether the participant is from the same locality, same county or from elsewhere.
Ask what services he/she receives in the institution	Accepted
Ask whether he/she is in a relationship, whether he/she is active sexually and future plans regarding starting own family.	Partly accepted. No question on starting a family.

Eating out or visiting/having friends for a meal is uncommon outside major cities, among older people and in lower income groups. Probably most people with disabilities who live in institutions or group home in more rural areas have never had the possibility to eat in restaurants or cafes. Going to the pub is viewed as deviant social behaviour in rural areas. Cafes and restaurants are not widespread outside the centres of major cities, people who live in the country have no or limited access to them. As a result, item "Food/choosing cafes" on the Choice-making scale could not be adequately adapted into Hungarian, people do not eat out on a regular basis, especially in rural areas. Similarly, the item "Recreation/Choice of outings" had to be translated as "Choice of leisure activities (including outings)".

Three items of the Short Adaptive Behaviour Scale raised questions of compatibility, but overall they did not threaten the validity of the measure:

- ABS Item 53 Food Preparation: the highest level (score 4) "Can use microwave correctly to prepare a meal" does not reflect food preparation skills appropriately. Microwave ovens are predominantly used for heating food and thus represent lower skill level than Score 3 "Prepares an adequate complete meal (may use canned or frozen food). Participants with a score of 3 on this item are skilful cooks and can prepare fairly complicated meals by themselves (including measuring quantities).
- ABS Item 55 General Domestic Activity: people in institutions generally do not have access to household appliances and often lack opportunity/motivation to engage in household activity even if they otherwise were capable.
- ABS Item 69 Awareness of Others: Many people in residential services have never met their own family. Participants who do not know their family were usually not scored on "Recognises own family", even if they had fairly high levels of social and interpersonal skills. However, some respondents added the comment "No, because he/she has never met them".

Most adults with an intellectual disability are under guardianship which is a legal institution that prevents them of making certain decisions, particularly those related to managing own finances. Questions on guardianship were incorporated into the measures to provide additional information.

8.3 Data collection

The managers of selected services were contacted by phone to inform them about the research, its aims and procedures, including an approximate workload in hours. If a service refused to take part in the study, a similar service was asked to participate following the procedures described in Sampling Settings and Participants. Managers who agreed to participate received an email (and/or letter) with an introduction to the study(aims, methods, instruments, procedures and deadlines), guidelines for sampling participants and information on consent and confidentiality.Managers were telephoned a week after the letters/emails had been sent to make sure that they received the documents and to confirm their participation. Managers/senior staff members were guided through the process of selecting participants. After the selection of individual participants (Sample 2) services received the self-administered questionnaires by post. The pack was followed up by a phone call a week later to check if they received it, clarify any questions, prompt people to start work, and organise site visits. Services typically received the Service Questionnaire, the Manager Questionnaire and the service user questionnaires three to six weeks before the site visit to allow enough time for completion. In four cases all or some of the questionnaires were not ready by the day of the site visit but in all cases these were sent by post within four weeks after the visit.

Site visits took place between November 2008 and January 2009. Visits lasted one to two days and included an interview with the manager or deputy manager of the service to complete the Management Practices Interview and the Questionnaire on Resident Rights. The duration of the interviews was typically one to two hours. A tour of the facility with a member of staff was used to complete the Homelikeness and the Room Rating scales. During these tours the researcher was introduced to the participants, and there was a possibility to have some informal interaction with residents, staff and observe the daily routines in the service. Tours typically lasted an hour in small homes and three to four hours in institutions. The observation of participants in most services took place between 4-6pm, a period that included the evening meal.There were some cases when observation could not be carried out or was carried out at different times:

- In service 104 the layout of the building made it impossible to observe people without attracting too much attention and therefore causing observer reactivity. It was a cloister-type design with four corridors and an enclosed patio. Rooms opened from both sides of the corridor. Besides a dinning hall and a small common room for people with severe learning disabilities there were no common living areas. Residents typically spent time walking around in the facility or they were in their rooms. In this case a general observation was carried out, a certain amount of time was spent at different points of the building taking notes of residents' activities.
- In service 301 service users were told that I would visit them to talk about their life and experiences in the community. All service users were very able with mild intellectual disability (for example two of them were learning English in their free time), they were independent and articulate. I felt it would be inappropriate to observe them and instead I went along with what they were told and we talked about their lives and their future plans.
- Similarly in service 304 residents had mild learning disabilities and the layout of the building (a block of self-contained studio flats) would have made it obtrusive to use momentary time sampling observation. Instead approximately 20 minutes were spent with each participant talking about their life in the service.

- In service 302 participants were observed between 2-4pm because the last bus with a connecting coach to Budapest left the village before 5pm.
- In service 101 observation was carried out between 1-3pm because of safety concerns in the local area and the management's insistence on leaving the village before dark. There were no accommodation facilities in the village or in the local area to spend the night there.

Table 8.4 indicates the number of completed questionnaires by measure. In addition to the issues outlined above, there were cases when some measures could not be completed for some participants:

- In 23 cases the Active Support Measure could not be completed. In two settings with a total of 10 participants there were no staff present, and another 13 participants from different services were out during the observation period.
- The Engagement in Meaningful Activity and Relationships measure is missing in 37 cases: for 24 participants in services 104, 301 and 303, and a total of 13 participants in other services who were not present during the observation period.

Other than these issues, the questionnaires were generally complete with only few missing data particularly for questions on monthly income and spending money and some questions on choice.

Table 8.4 Completed measures

Measure	Target	Achieved	Comment
Service Questionnaire	15	13	Services 102 and 301, and services 103 and 302 completed one questionnaire.
Management Practices Interview	15	15	
Questions on Residents' Rights	15	13	Services 102 and 301, and services 103 and 302 completed one questionnaire.
Homelikeness and Room Rating Scales	15	24	Participants came from 24 living units. The scale was completed for each living unit.
General user questionnaire	120	120	
Short form of Adaptive Behaviour Scale (SABS)	120	120	
Aberrant Behaviour Checklist (ABC)	120	120	
Index of Community Involvement (ICI)	120	120	
Index of Participation in Domestic Life (IPDL)	120	120	
The Choice-making Scale	120	120	
Questionnaire on Health and Lifestyle	120	120	
Engagement in meaningful activity and relationships (EMACR)	120	83	Missing for all participants in services 104, 301 and 304. Missing for 13 participants in different services because they were out during observation.
Active Support Measure (ASM)	120	97	Could not be completed for participants in service 301 and 303 setting 1 because there was no staff present. Could not be completed for a total of 13 service users in other services because they were not present during the observation.
Manager Questionnaire	15	13	Services 102 and 301, and services 103 and 302 completed one questionnaire.

8.4 Reliability

8.4.1 Reliability of Measures Used in the Study

Reliability looks at the consistency of a measure within itself (internal reliability) or their stability on different occasions (external reliability). Together with validity, reliability is one of the fundamental criteria of scientific research. Some of the measures used in this research have reported psychometric characteristics.Hatton et al. (2001) reported high internal reliability (Crombach's alpha 0.89-0.97) and inter-item correlation (0.54-0.74) for the Short Adaptive Behaviour Scale (SABS). Internal reliability of the Aberrant Behaviour Checklist (ABC) is also known to be high (Crombach's alpha 0.86 – 0.92) and consistent across samples (Aman and Singh 1986). Raynes, Wright et al. (1994) reported high or acceptable internal reliability using Cronbach Alpha for the Index of Participation in Domestic Life (0.93), for the Choice-making Scale (0.96), for the Index of Community Involvement (0.70), for the Group Homes Management Scale (0.84) and the Room Rating Scale (0.64).

Two aspects of external reliability are inter-rater reliability and test-retest reliability. Inter-rater reliability looks at whether the same measure produces similar results when administered by different people. Test-retest reliability considers if the measure produces similar results over time. Aman and Singh (1986) reported high inter-rater and test-retest reliability for the ABC. Inter-rater and test-retest reliability were not reported for SABS (Hatton et al. 2001) however the original ABS-Residential and Community Part 1 showed acceptable external reliability. (Nihira et al. 1993) External reliability was not reported for the Choice-making Scale, the Room Rating Scale and GHMS. Felce et al. (1998) found high item-by-item and total score inter-rater agreement for ICI and IPDL (between 77% and 88%).

8.4.2 Reliability of Data Collected in the Study

Reliability was assessed for 6.6% of the total sample (eight participants). Staff were asked to repeat some measures for one randomly selected participant during the site visit. Time between the first and second questionnaire was one to two weeks. It was not always practicable to have the same member of staff to repeat the measures, especially in smaller services with low levels of staffing. Repeated measures were answered by whoever was available and knew the selected participant. In 75% of cases this was the same person who completed the first questionnaire.

To measure test-retest reliability Cohen's Kappa values and Percentage Agreement scores were calculated for the Short Adaptive Behaviour Scale, the Aberrant Behaviour Scale and the Choice-making scale. For the Index of Participation in Domestic Life in addition to these two indicators, *Spearman's Rho* was also calculated. Test—retest reliability was not assessed for the Index of Community Involvement and the Questionnaire on Family Contact because these measures ask whether the participant used certain community facilities or had contact with family over the previous month and therefore answers are less likely to be stable over time.

The majority of the measures had acceptable test-retest reliability. For the Short Adaptive Behaviour Scale the mean Kappa value was 0.71 and 24% of the items had a Kappa value lower than 0.60 with the lowest value at 0.02. The overall percentage agreement was 88% with item-by-item values ranging from 57 to 100%. Seventy-nine percent of the items had a percentage agreement of 80% or over.The mean Kappa for the Aberrant Behaviour Scale was 0.66, with values ranging from 0.14 and 1.00. In 27% of the cases the Kappa value was lower than 0.60. The mean percentage agreement of answers was 88%ranging from 66 to 100%. Seventy-six percent of the items had a percentage agreement of 80% or over.The mean Kappa value for the Index of Participation in Domestic Life was 0.68, with scores for individual items ranging from 0.25 to 1.00. For 3 out of the 13 items the value of Cohen's Kappa was under 0.60. The mean percentage agreement of scores was 81%, with item-by-item scores ranging from 66 to 100%. Sixty-nine percent of the items had a percentage agreement of 80 or over. The mean *Spearman's Rho* was 0.755 with a range from 0.568 to 1, indicating a strong correlation between scores at t1 and t2.

The only exception was the Choice-making Scale that had a low test-retest reliability with a mean Cohen's Kappa value of 0.51 (range 0 to 1) and a 65% agreement of answers (item-by-item range 33-100%). Two thirds of the items had a Kappa value below 0.60, and 62% of the cases had a percentage agreement score below 80. A recent study in the UK has also found weak inter-rater reliability for the CMS (Higgins & Mansell, 2009). There might be various reasons why the Choice-making Scale had weak inter-rater reliability in Hungarian services. Supporting people with an intellectual disability to make choices is a new concept in Hungarian services. People with intellectual disabilities are often considered unable to make choices and this is also reflected in the laws of the country. The institution of guardianship deprives people of their right to make decisions in major issues of their lives such as where to live, how to spend their own money, undergo health treatment, and even in some minor, everyday questions, like going out of the institution with their friends or on their own. Therefore helping people to exercise choice is not a priority in most services. Any form of self-determination is nearly impossible to fit into the rigid routines of an institution. Some respondents might not have a very clear definition of "choice-making" and self-determination by people with intellectual disabilities or have adjusted their answers to what they thought was appropriate or "progressive". Low test-retest reliability might also be associated with the low number of participants. In any case the Choice-making Scale should be used with caution and these issues should be kept in mind when interpreting the results.

It was not practicable to repeat the observational measures (Homelikeness and Room-rating Scales) or assess inter-observer reliability for the ASM and the EMACR due to the design of the project – allthe data was collected by one person. To ensure acceptable reliability, direct observation was practised using video recordings with one of the supervisors of this thesis, Dr Julie Beadle-Brown. Direct observation was also practised with a researcher from another research project using the same observational measures. Five service users were observed for a period of two hours. The setting chosen for this visit was a larger home with more than 20 places and in many ways similar to those in Hungary. The aim of the visit was to ensure a correct understanding of the definitions of EMACR categories and to develop ability and confidence in applying them consistently in live momentary time sampling observations. Inter-observer agreement for the EMACR and the ASM were calculated using the data collected during this visit.

The overall inter-observer agreement for EMACR was acceptable with a mean Kappa value of 0.63 (range 0.41 to 0.74). Only in one category – Contact from Staff – was Kappa lower than 0.6 (see Table 8.5). Staff contact was scored in 17.5% and 12.5% of time intervals, therefore percentage agreement was calculated using Rtot% and Rocc% for low frequency behaviours. Rocc% is a formula that takes into account the chance agreement on scoring a low-frequency behaviour absent.[67] Rtot% for Staff contact was 85%, while Rocc% was low at 33.3%. The poor inter-observer reliability was the result of a difference in the coding of feeding and contact during feeding. These issues were discussed and clarified by the supervisor of this dissertation.

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[67] (Number of intervals observers agreed that the behaviour occurred/ the number of intervals either observer scored that the behaviour occurred) x 100

Table 8.5 Inter-observer agreement for EMACR

	Kappa value	R%	Rocc%	Rnon-occ%
SA	0.74			
NSA	0.71			
Cont	0.41	85	33.33	83.8
SUCont	0.66			
Asst	-	-	-	-
None	0.65			
Overall	**0.63**			

The mean Kappa value for the Active Support Measure was 0.55 and the item-by-item percentage agreement of scores was 67%. Although these values are not very high, the low case number (N = 5) should be taken into account. On the other hand *Spearman's Rho* showed a high inter-rater agreement (.829; sig <0.001) between the scores by the two observers.

The Service Questionnaire and the questionnaires on the health and lifestyle of residents, and residents' rights provide factual information. Their reliability was not assessed but some data such as the number of residents and staff, and budget were cross-checked from official administrative sources and found to be accurate.

8.5 Ethics

In England any research involving vulnerable participants who might lack capacity to consent is governed by formal ethical procedures. Ethical approval should be sought from the relevant research ethics committee – NHS or Social Care Research. Participants should receive adequate information about the aims and procedures of the project to make an informed decision about participation. If anyone is deemed to lack the capacity to give informed consent, a personal consultee should be asked to advise on whether the person would want to take part in the research, were they able to say so. A personal consultee should be somebody who knows the person well in an unpaid capacity. Where a personal consultee is not available then a nominated consultee can be identified to advise as to whether the person would want to take part.

There are no ethical policies governing social research with vulnerable people, including people with intellectual disabilities in Hungary. Generally verbal, less typically written, consent is sought from research participants at the start. Informed consent is limited by the institution of guardianship that deprives people from the opportunity to make formal decisions even if they have mental capacity. They are not allowed to sign any forms and all decisions should be made by their guardian who is not legally obliged to consult them about their views. The majority of people with intellectual disabilities living in residential facilities are under guardianship.

This study collected information in residential facilities for people with intellectual disabilities in Hungary. The project did not involve any direct assessment or treatment of individuals. Data on individual participants was collected through questionnaires completed by staff and using direct observation. The research did not expose anybody to situations they might have found uncomfortable or embarrassing, or would have felt threatening. The project followed the general ethical guidelines of the Tizard Centre and gained approval from the Tizard Research Ethics Committee. It was important to follow good ethical procedures and make sure that – as far as it was practicable in the Hungarian context – participants had the opportunity to give informed consent. Throughout the fieldwork it was made clear to participating services that the aim of the research was not to criticise individual services but compare models of provision on the basis of objective and comparable indicators. The aim of the project was to contribute to the development of community-based services in Hungary and improve the quality of care. The detailed procedures are described below:

An information pack was sent to selected services to help them make an informed decision regarding participation in the study. This included, also in easy-read format, the description of the study, the methods of data collection and information on anonymity and confidentiality of data. An estimate of the expected workload in hours was also provided. It was also made clear to managers that participation was voluntary and they could withdraw from the study at any time. Managers were asked to inform staff and service users about the project. Some managers declined participation in the study, most often due to the expected workload.

For practical and ethical considerations,I planned to obtain consent directly from participants rather than their guardians. However managers refused to seek written consent from participants because – they argued – it was against the law on guardianship. As a compromise solution participants who had capacity to consent gave verbal consent. For participants who lacked capacity a member of staff who knew the person well, usually a manager or deputy manager, considered whether in their opinion the person would want to take part in the research and that it was in their best interests. Managers then provided written agreement on behalf of all participants for the research to go ahead. Except in two very small services, the manager or deputy manager did not complete questionnaires about the people they supported and in no services were they involved in observations. Individual consent was checked during field work before starting observations. It was made clear that participation was voluntary and participants – staff and service users - could withdraw from the study at any time. For all participants behaviour was monitored throughout the observation and if at any time people appeared uncomfortable or distressed by the researcher's presence advice was sought from staff and where necessary the observations were stopped for that individual. For those who were very able and expressed being uncomfortable with being observed, formal observations were not conducted and instead informal observation and discussion was conducted.

After careful consideration of the ethical implications and financial feasibility of the project, it was decided that a small remuneration would be offered for each completed questionnaire. Originally the aim was to use this as an incentive for staff to respond and as a recognition of their valuable input – particularly in smaller services staff filled in the questionnaires at home in their free time. The payment took into account the amount of time expected to be spent filling out the questionnaires.[68] Some services refused to accept the cash payment and asked to pay the sum as a gift/donation to the organisation.[69] The money then could be used to buy equipment or organise outings for residents. Two services (institutions) completely refused to accept payment. As far as it could be discerned offering payment to organisations did not have any apparent impact on their decision to participate or not in the study or on the implementation of the field work.

The field work followed the Tizard Centre's guidelines on Accuracy and Confidentiality of Data. No names or other personal data (e.g. date of birth etc.) were recorded in data files, participants were identified using a numerical code.

The ethical implications of guardianship requirements highlighted some of the dilemmas and difficulties of conducting intellectual disability research in an international context. The guardianship procedures meant that individuals could only give verbal consent and this was recorded by the manager. Although this was not ideal; it would have been better if the researcher could have informed participants and recorded consent this was not practicable due to guardianship restrictions and practical issues (e.g. arranging travel and overnight stay in remote rural areas). Verbal consent was considered an acceptable solution, also taking into account the low potential harm and risks involved in participation. However this is a clear dilemma and the ethics of doing research with people with

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[68] Thousand forints were offered for each Service Questionnaire and 800 forints for each Service User Questionnaire. The exchange rate was 1 GBP = 320 HUF at the time of the field work.

[69] All independent service providers were registered as charities and some institutions also set up charities to raise additional funds to improve the quality of life of residents.

intellectual disabilities are far from being clear-cut. The system of guardianship puts an unnecessary restriction on the informed consent of those who otherwise have the capacity. This also highlights the ethical issues of international research with vulnerable populations.

8.6 Data Analysis

Data collected in the fieldwork was coded and hand entered into Excel and SPSS for analysis by the researcher. Descriptive and inferential statistics were used to analyse the data. In Chapter 9the analysis is largely descriptive and uses general, service-level data provided by the services or collected during site-visits through observations and interviews with management. Where the data permitted non-parametric tests – *Kruskal-Wallis* with *Mann-Whitney U* post hoc tests – were carried out. In Chapter 10 three statistical methods were used to test differences between groups:

- *Pearson'schi-square* (χ^2) or *Fisher's exact test* to compare categorical variables.
- *Kruskal-Wallis* test (*KW*) with *Mann-Whitney U* post-hoc tests to compare ordinal variables or scale variables that do not meet parametric criteria (normal distribution and homogeneity of variance).
- *ANOVA* (A) with *Tukey post-hoc* tests to compare scale variables that meet conditions for parametric tests.

Test results were summarised in tables with the number of valid cases, valid percentage, counts (in parenthesis), statistical test and significance.

The results of main and post-hoc tests were reported as significant if they reached a significance level of 0.05. In the case of *Chi-square* tests, if more than 20% of the cells had expected count less than 5, the test has been reported as invalid and only descriptive statistics have been presented, where relevant. The decision to use less stringent significance criteria was justified by the exploratory nature of the study and the small size of Sample 1 and matched sub-samples of Sample 2. The choice of significance level influences the likelihood of Type 1 error, that is when a true null hypothesis is rejected, and this should be kept in mind when drawing conclusions from the study.

Chapter 9 Description of residential services

This chapter looks at residential provision for adults with intellectual disabilities. It has two parts; the first part of the chapter describes residential care policies including the regulation and funding of residential care,and it aims is to highlight the implications of the current regulatory environment for community-based care and quality of care. This analysis relies on data from various sources: the service questionnaire of the field work, the 2007 Survey, and statistics and information published by the relevant ministries and the Central Statistical Office (Központi Statisztikai Hivatal, KSH) of Hungary. The second part of the chapter gives an insight into the patterns of residential care in the different types of provision and compares services along important dimensions such as the management of challenging behaviour, policies to prevent abuse, and user involvement, that are important indicators of service qualitybut not necessarily comparable in terms of individual outcomes. This analysis is divided into four sections: the first explores the physical environment and living conditions in services; the second gives an overview of the characteristics of residents and staff; the third part discusses the services provided to users, including health care, treatment and employment; and the fourth part explores management and care practices.

9.1 Residential care policies for adults with intellectual disabilities

9.1.1 Standards

Regulations and written minimum standards are a common way to ensure minimum quality requirements and safeguard the interest of service users in residential services. Standards can also be a powerful tool in improving and monitoring quality of provision, however they can also run the risk of legitimising and preserving existing conditions.

Residential care, including physical conditions, staff numbers and qualifications, and services are regulated by two main legal acts in Hungary: the Act on Social Care and its implementing regulation from 2000 (1993. évi III. törvény; 1/2000. SzCsM rendelet).[70] This section reviews the most important rules concerning the provision of residential care and considers its implication for deinstitutionalisation and community living. It is important to emphasise that in Hungary all aspects of residential provision are regulated by national legislation and services cannot deviate from patterns prescribed by the law.

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[70] All legal acts can be found at https://kereses.magyarorszag.hu/jogszabalykereso (last accessed: 02/01/2012; only in Hungarian).

Currently the law defines five types of residential provision for people with disabilities. All residential service providers have to be registered in one or more of these categories. The number and distribution of services and places are shown in Table 9.1.

- People with disabilities (children, younger and older adults) can be placed in a care institution if their education, training, employment, treatment and care can only be organised in an institutional setting" (Article 69(1)). The law also stipulates that the institutional care of adults with disabilities should be provided with the view to ensuring appropriate autonomy and choice for service users, who are also entitled to participate in employment, treatment, sport and leisure activities (Art. 70(3)).
- Care group homes provide residential and social care for adults with disabilities aged over 16 years. The upper age limit of placement in a group home is 62 years (Art. 85/A).
- Rehabilitation institutions accommodate adults with mild and moderate intellectual disability. The purpose of this type of provision is to develop skills for independent living and "prepare people with disabilities to return to their families or the community" (Art. 74). The maximum term of placement is five years (Art. 112).
- Rehabilitation group homes provide the same service as rehabilitation institutions but in a smaller setting of eight to 14 places.
- Temporary homes provide care for people with disabilities for a period of up to two years. These places are typically part of large institutions and short stays are uncommon.

The law stipulates that "all persons with a disability have the right to choose the type of accommodation – family home, group home or institution – most suitable to their disability and individual circumstances" (1998. évi XXVI. törvény). The law also requires that residential services are conducted in a manner that respects the constitutional rights of the service users, particularly their right to life, dignity, integrity, physical and mental health (1993. évi III. törvény). Residential care providers must ensure:

- The free movement of users within the service and in the community, taking into consideration the rights of other service users;
- The use of personal possessions and everyday objects.
- Service users have the right to maintain relationships with their families and receive visitors.
- Residential care providers should make arrangements to ensure:
- Accessible environment with the necessary adaptations;
- Access to information;
- Access to treatment and support;

- Autonomy and choice, respect for the lifestyle choices of the individual with a disability;

Community integration, interpersonal relationships and access to services (Art 94/F).

Table 9.1 Number and distribution of services and places by type of provision, 2008*

Type of provision	**Services**		**Places**	
	Number	%	Number	%
Care institution *(fogyatékos személyek otthona)*	154	46	12,482	73
Care group home *(fogyatékos személyek ápoló-gondozó célú lakóotthona)*	93	28	1,942	11
Rehabilitation institution *(fogyatékos személyek rehabilitációs intézménye)*	23	7	1,627	9
Rehabilitation group home *(fogyatékos személyek rehabilitációs célú lakóotthona)*	39	12	610	4
Temporary home *(fogyatékos személyek gondozóháza)*	23	7	528	3
Total	**332**	**100**	**17,189**	**100**

Note. Data retrieved from KSH (2009)

* Figures include services for people with all types of disability

9.1.2 Physical environment and living conditions

Requirements regarding the physical environment of the settings are centrally regulated, and they are telling services what “acceptable” or “good enough” conditions are. A rather controversial feature of the regulation is that it also – implicitly or explicitly – defines maximum conditions. The law demands that institutions provide the following facilities:

- bedrooms;
- toilets and bathrooms;
- dining area(s);
- communal area(s);
- treatment and therapy rooms;
- area(s) for visitors.

Services must ensure that facilities meet the following requirements:

- A sitting room of at least 20 square metres for each care group – the size does not depend on the size of the group which can be between 20-50 service users.
- A minimum average surface area of six square metres[71] per service user in bedrooms.
- One shower or bath and one toilet for ten service users.

Bedrooms – as a general rule – should be shared by no more than four service users, however "if justified" more than four people can share a bedroom, as long as the average floor space is no less than six square metres per person. The law considers "above average" conditions any single or double rooms with private bathroom and/or kitchen and with an average living space of ten square metres per user or more.

Group homes – according to the law – provide "modern and high quality accommodation and living conditions, and quality support". Group homes accommodate eight to twelvepersons, or up to 14 persons if the group home is in an existing building and "the size of the building justifies this". There should be two bathrooms for ten service users and two separate toilets. The kitchen or the dining room must be large enough to seat 8-12 service users and the size of the living area should be not less than 20 square metres. Bedrooms – as a general rule – should be shared by two service users, however under certain conditions up to four users are allowed share a bedroom. The average surface area in bedrooms should be not less than eight square metres per user. Group homes for people with disabilities must be fully adapted for people with physical and sensory disabilities (even if service users do not have any physical or sensory impairment), and have access to social and support services, including institutions or day care.

Regulations regarding the environment in residential services are rigid and favour congregate options over individualised supports. They raise a number of problems for the development of community living and deinstitutionalisation:

First, the law makes no mention of "soft" requirements, such as homeliness, cleanliness, good quality furnishing etc. It reduces "quality" into environmental indicators such as the size of rooms or the number of toilets. There is a clear gap between the principles of the law (respect for human rights, privacy, dignity etc) and what it requires from services. The quality of services is not monitored in the absence of standards and quality of life requirements.

Second, people with disabilities need to fit into one of the existing four categories because services do not have the flexibility to adapt to

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[71] Approximately 65 square feet

the needs of service users. The provision of small-scale person-centred services is prevented or made very difficult by the regulation of services.

Thirdly, there seems to be an underlying assumption in the law that people in whatever form of residential care do not need ordinary or decent living conditions. Service providers, particularly independent organisations have been discouraged from creating "above average" conditions by reducing the state funding for this type of provision. At the same time the requirements of the law were accepted by service providers as a guarantee to "quality" provision and it has never been questioned whether they are adequate or acceptable living conditions for people with intellectual disabilities.

Lastly, environmental requirements make it very difficult for community-based providers to operate group homes in ordinary housing due to the general characteristics of the housing stock, particularly in urban areas. Data from the 2005 Microcensus found that only 17% of dwellings had four or more rooms and were therefore potentially suitable for use as a group home. The lack of easily available and affordable housing encourages the development of new-built group homes, often those built in the close proximity or on the grounds of institutions.

The use of new-built facilities is also encouraged by the requirement of accessibility. The regulation states that residential facilities must be adapted to the needs of people with physical and sensory impairments. Accessibility has been a priority of disability policy since 2004. It is understood in the context of the built environment with no consideration for the needs of service users with intellectual disabilities. The concept is applied generally to residential services regardless the needs of individual service users. It has resulted in additional investment in the infrastructure of institutions. The state has provided money to institutions to make adaptations, for example to fit in elevators, build ramps, refurbish bathrooms etc. It has also become one of the key requirements towards new group homes which made it even more difficult to operate in ordinary housing and drove the cost of new places up.

9.1.3 Staffing

Staff numbers in services and required qualifications are regulated by law and are rather inflexible. Services are limited in allocating staff support which is particularly difficult for smaller services and services for people with higher support needs.

The law allows the following staff categories and numbers in rehabilitation homes for each 50 residents:

- five nurses or care workers[72];
- two "developmental pedagogues";
- one employment organiser;
- one physiotherapist;
- two work supervisors; and
- two social or mental health support workers.
- Institutions with 100 or more service users can also employ one social worker.

The numbers are somewhat higher for care institutions. For each 50 residents they can employ:

- fifteen nurses or care workers;
- two developmental pedagogues;
- one employment organiser;
- one leisure organiser;
- one physiotherapist; and
- one social or mental health support worker.

Group homes that are part of an institution are allowed two social support workers (rehabilitation group homes) or three social support workers and one nurse (care group homes). If the group home is run independently, they are allowed one manager, two social support workers, two nurses and one developmental pedagogue.

While the law does not provide for any clerical and auxiliary staff in independent group homes, institutions can employ a number of administrators, cleaners, maintenance workers (plumbers, builders etc.), kitchen and laundry staff. Controversially, the number of staff allowed in these categories is equal or higher to the number of clinical staff allocated to institutions by the law.

9.1.4 Funding

The allocation of funding has a strong influence on the landscape of services in any country. It is also commonly acknowledged that past funding decisions shape present funding and service patterns (Stancliffe & Lakin, 2005). This section gives an overview of the funding situation of residential care including both running costs and capital investment. Data collected from 12 out of the 13 service providers in the study are used to illustrate the arguments. Unless otherwise indicated all figures are from 2007.

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[72] Nurses have health-related qualifications; care workers have social care qualifications.

9.1.4.1 Running costs

Funding for residential providers comes from four sources. The fixed-sum state contribution is a statutory state subsidy which is set in the yearly national budget and is paid for each occupied place. It has no direct link to the actual cost of service provision or to the individual needs of the service user. All registered residential service providers get this regardless the support needs of their service users or the quality of service they provide. To illustrate the size of this contribution, it would not cover the labour costs at the national minimum wage of a half-time support worker with lower secondary education and relevant vocational qualification.[73]

Fees paid by service users are the other main source of income for residential providers. The calculation of fees is regulated by law. Services can set their fees on the basis of the cost of provision, but the actual fee payable by the individual user is means-tested and depends on their income. The third source of income is the top-up contribution from local authorities. This is a lump-sum payment and it is intended to cover the difference between the income of the service from the statutory state funding and user fees, and the actual running expenditure. It is available almost exclusively to services operated by local governments, predominantly institutions. Finally, services can have other income from various activities such as project grants, letting out property, selling goods produced by service users etc.

Data from the field work shows that the average income per resident was HUF 2,000,000 forints in institutions (min. 1,800,000 and max. 2,300,000) and HUF 1,540,000 in independent provision (min. 1,400,000 and max. 1,800,000; outlier 2,900,000). Figure 9.1 shows the distribution of income by source and type of provision. The share of state funding, statutory state subsidy and top-up contribution, was on average 75% in institutions and 62% in independent group homes

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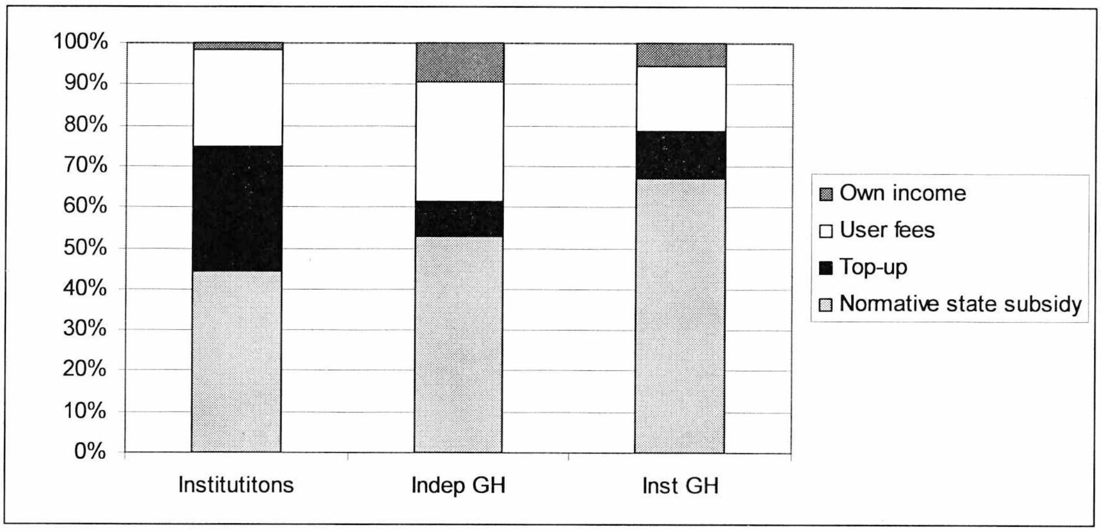
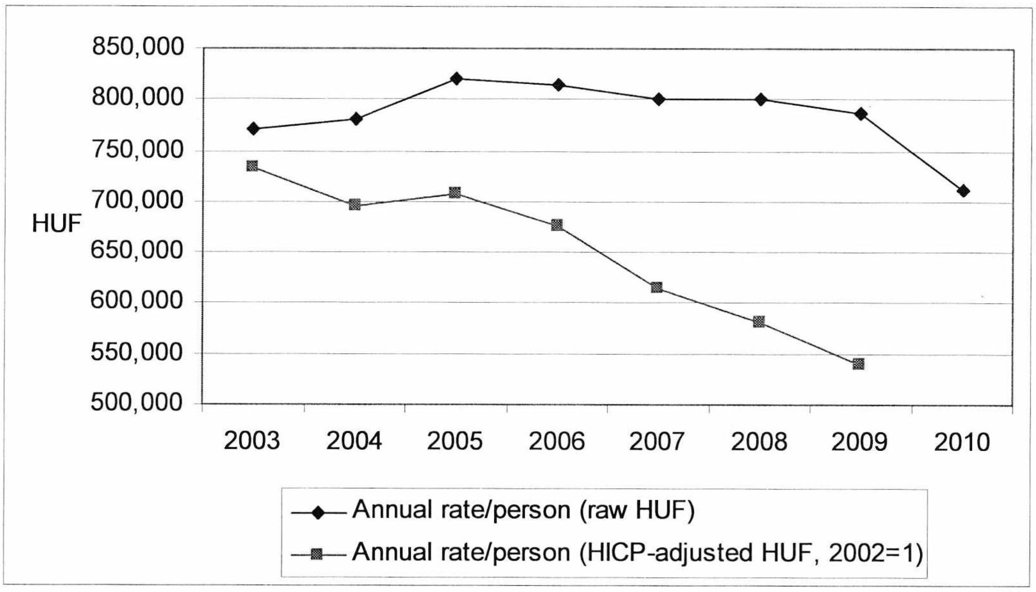
[73] The statutory minimum wage for people with a vocational qualification is 87,500 HUF/month in 2009. With national insurance contributions this amounts to approximately 115,000 HUF/month. Source: http://www.magyarorszag.hu/allampolgar/ugyek/munka/munber20060117/minimalber20090212.html/ugyleirasjogi#paragr3 (last accessed : 02/01/2012)

Figure 9.1 Distribution of income by source and type of provision (%)



Note. Data from the fieldwork

Figure 9.2 Trends in the fixed-sum state contribution for residential provision, 2002-10



Note. Retrieved from annual budget reports (2002. évi LXII. törvény; 2003. évi CXVI. törvény; 2005. évi CLII. törvény; 2006. évi CXXVII. törvény; 2007. évi CLXIX törvény; 2008. évi CII. törvény; 2009. évi CXXX. törvény) and adjusted according to the Harmonised Index of Consumer Prices for Hungary published by Eurostat each year.

There are a number of issues that affect independent providers negatively. Figure 9.2 shows the trend in the unadjusted and inflation-adjusted fixed-sum state contribution. Information about the amount of funding is derived from Hungary's annual budgets. All figures are in forints, the national currency of Hungary.[74] Data on the harmonised indicator of consumer prices (HICP) come from Eurostat.

The negative trends in the statutory funding of residential provision in recent years have affected independent providers more adversely than large state institutions because it makes up a larger share within their total income. The way user fees are set, also affects independent providers. If a service user does not have any income their fee must be reduced or waived. While state providers are compensated for their loss of income from service users who cannot pay their fees, independent providers are not. The regulation is discriminatory because it allocates the "financial burden" of service users who cannot pay for their care to the service rather than to the local authority responsible for the provision of residential support. The law (1993. évi III. törvény) stipulates that anyone can be placed in an institution, while service users in group homes are expected to contribute to the cost of their provision. Community living is seen as a privilege for those who can afford it, and not as a right.

Top-up funding is discretionary and typically paid for institutions by the local government. It is negotiated on a yearly basis and its amount depends on the policy priorities and the financial situation of the local government. It is less common for independent providers to secure any top-up funding; three out of five group homes had access to this but at a substantially lower rate than institutions.

There was a large difference in the share of other sources of income by type of provision. Independent providers relied more on grants, particularly European Social Fund projects, in the provision of their services. For some community-based providers project-funds were an important and regular part of their income and they helped to ensure the survival of the service. Project-based funding nevertheless involves considerable risks because these sources are irregular and erratic and any delay in payment might push services into bankruptcy. There is already some evidence of the distorting effects of European money in social and employment services however its discussion would go beyond the boundaries of this chapter.

Financial insecurity and the lack of sustainability is a major problem in independent provision. In the study 80% (four out five) of managers in independent provision said that the revenues of the service hardly covered the expenses and maintaining the day-to-day operation of the service was a major challenge. In contrast, 25% (two out of eight) managers in state provision indicated financial problems, over 60% (five out of eight) said that their revenues sufficiently covered their running costs and one manager regarded their financial situation very good.

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[74] At the time of writing 1,000 Hungarian forints were equal to 3.2 British Pounds

9.1.4.2 Capital investments

Another aspect of funding in residential care is the issue of capital investments. Evidence from other countries showed that the transition from institutions to community-based provision requires significant capital investment to create the necessary infrastructure of community living and this transition takes many years or even decades. It was argued in Chapter 2 that in some countries the estimated cost of creating satisfactory living conditions in large institutions was a strong argument in favour of reproviding care in the community that was seen as not only a better but also a cheaper option.

The initial situation in Hungary was similar. At the end of the 1990s most residential services were in poor physical condition, the majority of the facilities were built for other purposes before 1945 and in need of significant capital investment to ensure minimally acceptable living conditions (KSH, 2001). Community-based alternatives using ordinary housing were around since the early 1990s and the development of group homes became part of the policy agenda in 1999. Nevertheless, the way funding was distributed to capital investment took no account of these policy objectives and failed to consider alternative and possibly cheaper options in the community. Instead, most funding went into strengthening institutional provision. This section provides an overview of the different investment programmes in residential provision since 1999.

Before 2007 the main source of capital investment in residential care was the regional development fund allocated to local governments by the Ministry of Interior. Local governments could apply for funding for different capital investment projects in the areas of health and social care, education, public infrastructure etc. In addition, the Ministry of Social Affairs also allocated resources to the modernisation of institutions (see Chapter 6). Between 1999 and 2006 in total over 21 intellectual disability institutions received 19.4 billion forints (unadjusted figure) [75] of Government funding either for the renovation and refurbishment of existing facilities or the construction of new facilities (see Table 9.2). Without any exception this money went into funding large institutions or campus-style provision, including the building of a large institution for people with severe intellectual and multiple disabilities in Budapest by the Ministry of Social Affairs in 2003.

In addition to large-scale investment projects, there was additional funding available for institutions to carry out smaller improvements such as modernising the heating system, replacing windows and making the building accessible for people with physical impairments. It is not

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[75] HUF 19.4 billion is equivalent to approximately GBP 61million at the time of writing.

possible to estimate the total amount of funding because it came from various sources including the European Regional Development Fund; however the extent of such investment seems fairly substantial. A survey carried out by the Ministry found that approximately 50% of institutions received funding for capital investment between 2005 and 2010 (Mester, Mészáros & Mód, 2010).

Table 9.2 Investment in institutional provision, 1999-2007

1999	2000	2001	2002	2003	2004	2005	2006	Total
Million HUF (unadjusted)								
578	2,610	1,872	4,366	3,371	2,060	910	3,650	19,416
Number of institutions								
2	4	2	3	4	3	1	3	21

Note. Data from yearly reports on regional development funding for county governments

Community-based provision received substantially less funding in the same period, mostly from non-governmental sources. The largest and most important initiative was The *Fészek* (Nest) Programme in 1997-2000 which supported the establishment of 33 independent group homes in the community with approximately 250 places. The programme encouraged the purchase and conversion of existing buildings rather than purpose-built facilities. The total funding amounted to HUF 372 million and came from various sources; mostly the MATRA Programme of the Netherlands[76], the Hungarian Soros Foundation and to the lesser extent from the Ministry. The average cost of a place was just under 1.5 million forints in 2000 prices.[77]

Between 2001 and 2003 the Government funded "institutional modernisation programmes" with the majority of the money given to institutions to set up group homes. (See Table 9.3)

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[76] The Matra Programme was launched in 1994 by the Dutch Government with the objective of fostering democracy and transition in Central and Eastern Europe. It was a demand-oriented subsidy programme based on the partnership ("twinning") of Dutch and Central and East European organisations working together in implementing projects in the fields of civil society, good governance etc. Retrieved from: http://www.minbuza.nl

[77] Source: personal communication with Ákos Pordán, manager of the Programme.

Table 9.3 Funding for Group Home Development Programmes

2001	2002	2003	Total
million HUF (unadjusted)			
240.0	263.0	136.3	639.3
number of group homes			
24	16	9	49

Note. Data from the Annual Budget Reports of the Ministry of Social Affairs

The most recent Government programme to support the creation of group homes in the community ran between in 2007 and 2009. It provided a total of HUF 575 million to build group homes for people with severe, multiple disabilities or autism living with their families. Two issues seem worth highlighting from the final report of the programme (FSZEK 2007):

Firstly, the relative lack of interest from service providers: originally policy-makers envisaged the support of 20 new group homes for 160-240 service users. The total funding available was 650 million forints. They expected to receive around 80 expressions of interest. Instead, the results were 45 expressions of interest and eight new group homes with a total of 84 places. Considering that this was the first major group home programme since the closure of the Nest Programme in 2000, the lack of interest suggests underlying problems in the sector, particularly issues of uncertainty and insufficient funding for independent group homes.

Secondly, the cost per project was higher than planned. Table 9.4 compares the cost of places in different types of provision and in different programmes. Costs are adjusted to reflect 2008 prices using the Harmonised Index for Consumer Prices from Eurostat[78]. The figures show that the cost of a group home place has risen considerably since 2000 and it was only marginally cheaper than a new place in an institution in 2008. The possible reasons for this are the increasingly stringent and detailed expectations regarding the premises and the environment in group homes. One of the main dangers of this is that it makes group homes and community-based provision even less attractive for policy makers, while also making it more “institutional”.

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[78] Retrieved from: http://eurostat.ec.europa.eu

Table 9.4 Estimated cost of a new place in different types of provision, million HUF

	2000*	2006-08**	2007-08***
Adjusted to 2008 prices	2.37	6.90	7.75
Unadjusted HUF	1.50	6.90	7.75

Note. * Data from the FESZEK Programme; ** Data from the Ministries Group Home Development Programme; *** data from the fieldwork

Data from the field work confirmed the bias of capital investment towards institutional provision. Services were asked to list any capital investments over the value of ten million forints since 2003. Four out of five institutions were rebuilt or refurbished with state funding after 2002. Capital investments in institutional provision added up to 3.143 billion forints in the period between 2003 and 2008. Out of this sum 2 billion forints (63%) were invested in new-built facilities with a total of 258 beds. At the same time independent group homes invested a total of 38 million forints in infrastructure. All this money was used to create the infrastructure for employment within or near the group home. A total of 65 million forints were spent on institutional group homes.

9.2 *Patterns of care*

9.2.1 Physical environment and living conditions in services

Altogether 13 services were visited during the field work. Some services, particularly institutions, had multiple living units. The term "living unit" refers to the buildings where people live. They might be clustered on the same site or dispersed in the community. Living units are not necessarily independent units under the responsibility of a manager or senior member of staff, nor are the functional care units which sometimes include several living units, or one large living unit is divided into several care units.

The 13 services in the sample had a total of 44 living units, of which 40 were in use and 31 were part of institutions. Institutions had on average 4.4 living units, with a range of one to seven. The five independent providers had a total of nine living units (20%), 1.8 on average, ranging from one to four units. The distribution of living units by size is summarised in Table 9.5.

Table 9.5 Distribution of living units by size, % (n)

Places	All living units			Visited living units		
	State	Indep.		State	Indep.	
	providers		Total	Providers		Total
< 8	9 (3)	22 (2)	13 (5)	11 (2)	-	8 (2)
8-14	39 (12)	67 (6)	45 (18)	39 (7)	100 (6)	54 (13)
15-20	13 (4)	11 (1)	13 (5)	17 (3)	-	13 (3)
21-50	13 (4)	-	10 (4)	11 (2)	-	8 (2)
51-100	16 (5)	-	13 (5)	11 (2)	-	8 (2)
100+	10 (3)	-	8 (3)	11 (2)	-	8 (2)
Total	100 (31)	100 (9)	100 (40)	100 (18)	100 (6)	100 (24)

Participants in the sample came from 24 different living units that were visited and assessed during the field work. Thirteen of the remaining 16 living units were also visited but no measures were completed there. Out of the 24 living units, nine (37.5%) were in ordinary houses. Over 70% (17) of the buildings were built after 1980, and 40% (10) were newly built after 2000. Twenty percent of the buildings dated from before the Second World War, however the majority of these buildings were substantially refurbished since the late 1990s.

Half of the living units (12) were purpose-built, and the majority of these (10) were built after 2000. Only two of the purpose-built living units belonged to independent providers and only one was located in the community.

Group homes generally had an ordinary layout with a kitchen, dining- and living rooms, bathrooms/toilets and bedrooms. All independent group homes had an office in the building or on site. Offices or staff rooms were uncommon in institutional group homes – only two out of 11 settings had an office. The most salient feature of institutional living units – besides their size – was the lack of communal areas. One recently refurbished institutional living unit (105) did not have any communal areas except for a central dining hall. People who did not want to stay in their rooms could either walk in the corridor (there were no chairs either) or sit in the dining hall. Other institutions had some communal areas; most often clusters of chairs in the corridor or communal rooms with chairs and a television set. All but one institution had a central dining hall where most residents – except those who required special feeding or were bed-ridden – had to eat their meals. In institutions with more able service users dining halls were self-service. Elsewhere individuals were served and if necessary fed at the tables. Institutions also had a number of extra facilities that included therapy and teaching rooms, workshops, kitchens or "training kitchens"[79], gyms and "wellness rooms".

The quality of the living areas was rated using the Room-rating Scale (Raynes, 1988). This measure rates living areas in five domains: cleanliness, orderliness, window areas, the presence of odours and the quality of furniture. Scores have been converted to percentage scores, higher numbers indicating better quality living environment. The quality of the living areas ranged between 60 and 100 and there were no significant differences between the three models of provision. The mean percentage score for institutions was 79, for independent group homes 83 and for institutional group homes 88.

Table 9.6 gives a summary of the mean percentage scores and standard deviations by each domain. The only significant differences between the three models were in terms of orderliness ($KW\chi^2 = 6.05$; df = 2; $p < 0.05$) and odours ($KW\chi^2 = 16.75$; df = 2; $p < 0.001$). Institutional group homes were significantly more orderly than independent group homes (*Mann-Whitney* post hoc test, $p < 0.05$, 2-tailed) and institutions differed significantly from group home provision in terms of odours (*Mann Whitney U* post-hoc tests, $p < 0.001$, 2-tailed). In most cases odours were not bodily odours such as urine and faeces traditionally associated with large institutions, but odours coming from kitchens or strong cleaning agents (e.g. bleach). Odour associated with smoking was very common in institutional group homes.

Hospital-type furniture was found in three living units for people with severe disabilities and incontinence. Most living units had ordinary furniture with storage for personal items and clothes (e.g. shelves, wardrobes, chest of drawers, TV stands etc.).

Personal decorations were common in group homes where nearly all rooms were personalised with own furniture, wall decorations and personal objects. In institutions personal decorations were less common, particularly in the newer or recently refurbished living units. In these institutions all furniture was centrally provided and residents were "not encouraged" to decorate their rooms in order to preserve the "nicely painted walls". It emerged from the interviews with staff that personal decoration in some institutions was the privilege of a few, more able residents, and less able service users were not offered assistance in decorating their rooms. Elsewhere people, including those with more severe intellectual disabilities, were not only allowed to have personal decorations but they were encouraged and supported in doing this (e.g.

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[79] The difference between the two is that a kitchen can be used any time without or with supervision, while a training kitchen can only be used under supervision at certain times.

choose the colour of the wall, buy their own furniture and accessories such as curtains, carpets, cushions etc.).

Table 9.6 Quality of living areas by domains

	Institution (n = 8)	**Indep GH (n = 5)**	**Inst GH (n = 11)**	**Sig test**
Orderliness				
Mean % score	85.38	72.60	93.91	< .05 (*KW*); df = 2; 6.05
Std dev	12.05	17.99	5.59	
Cleanliness				
Mean % score	82.88	85.00	88.09	ns
Std dev	17.62	19.18	12.65	
Furniture				
Mean % score	84.38	73.80	82.64	ns
Std dev	22.18	16.75	17.91	
Windows				
Mean % score	81.25	91.20	88.64	ns
Std dev	15.40	19.68	13.06	
Odours				
Mean % score	50.00	93.80	86.00	< .001 (*KW*); df = 2; 16.75
Std dev	7.17	7.76	9.78	

Note. GH=group home; *KW*=Kruskal Wallis; ns = not significant

The lack of privacy is often considered a central feature of institutional provision and it has often been associated with overcrowding and lack of adequate facilities (e.g. Horváth, 1988). It has been shown in this Chapter regulations are still rather permissive with regard to privacy in residential settings and as a general rule they permit up to four service users to share a bedroom, and up to ten service users to share a bathroom and a toilet. The minimum and maximum number of people sharing a bedroom was between one and five. More service users shared bedrooms and other facilities in institutions and group homes provided by institutions than in independent group homes. As a general rule, two to four service users shared a bedroom in institutions; only one living unit had larger rooms with up to five beds.[80] Room size in group home provision was somewhat smaller, however single rooms were uncommon. Institutional group homes had mainly double bedrooms in

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[80] In the other living units that were visited but not assessed in this study there were rooms with up to eight beds.

many cases shared by couples. Two group homes had some four-bed rooms. Self-contained bathrooms were uncommon: all but one living unit had shared bathrooms for two to ten service users. All toilets and most showers/bathtubs had partitions and doors, except in one of the newly built institutions where there were several bathtubs in some bathrooms.

Privacy is not guaranteed by small room size or the presence of doors and partitions. It also depends on staff practices and service user routines. Even though the living units in this study by-and-large had adequate facilities to allow for privacy in personal care and hygiene, staff and service users did not always make use of them. Particularly in living units for people with more severe intellectual disabilities or more intensive support needs it was noted during the site visits that doors were often left open by staff while toileting or changing service users, and in one – newly built – institution service users were getting undressed in the corridor while waiting to get into the shower. Many residents in institutions seemed to have no concept of privacy because they had always been deprived of it.

Living areas were also rated on their homelikeness, including typical size, range of furniture, and comfort. Scores range from zero to 100, higher scores indicating more home-like environments. The mean percentage score for institutions was 14, for independent group homes 50.4 and for institutional group homes 41.4. The differences between the three models were significant ($KW\chi^2 = 11.59$; df = 2; $p < 0.01$); institutions were significantly less homelike than group homes (*Mann Whitney* post-hoc tests, $p < 0.01$). Despite relatively good quality physical standards, such as furniture and hygiene, institutions failed to provide home-like environments.

9.2.2 The characteristics of staff

It has been argued that staff numbers and required qualifications are regulated by the law and are rather inflexible. Services have limited possibilities in allocating staff support which is particularly problematic for smaller services and service users with high support needs.

The mean resident to support staff ratio was 3.6 with a range between 2.3 and 6.2. Independent group homes had more favourable ratios (mean 2.9) than institutions (mean 3.8) and institutional group homes (mean 4.3). These numbers were calculated on the basis of total staff numbers, therefore observed staff ratios were considerably worse, particularly during the evening and night periods. In institutions the general practice was to have up to three / four support staff for approximately 50 residents in the evening and up to two staff for the whole institution during the night. This meant a resident to staff ratio of up to 70 in some cases. In independent group homes, there were usually one or two staff present with eight to fourteen residents during the evening and no or one staff during the night. In terms of staffing, institutional group homes were in the relatively easiest position because they could rely on the support services of the main institution and service users often did not need continuous staff support.

The mean resident to clinical staff ratio was 7.75 with a range between 2.1 to 13.6. Mean ratios were more favourable in independent group homes (4.6) than in institutions (9.6), and no institutional group home had their own clinical staff. The category of clinical staff includes a broad range of positions and qualifications: most commonly teachers, orthopedagogues, social workers, leisure coordinators, vocational therapists, physiotherapists, and some institutions had a part-time psychologist. Some of these positions are largely administrative (e.g. social worker) with limited user contact.

To ease staff shortages some independent providers relied on vocational rehabilitation or sheltered employment day programmes running alongside the residential service, often on the same site. This allowed higher overall staff levels and more flexibility in allocating staff support for the evenings. Institutions were more constrained in these practices because their staff are usually public employees. Any changes in the workforce must be approved by the local government/ministry responsible for the institution.

Services reported high levels of qualified staff; on average nearly 90% of staff had the required level of qualification (range: 63-100%) Managers regarded qualified staff as one of the most important factors in the provision of high quality support to people with intellectual disabilities. All organisations supported their staff to participate in some form of education: either to study towards their first qualification or post-graduate degree, or participating in short courses on relevant subject areas such as supporting people with autism, dementia etc. It is a different matter how relevant and useful these qualifications are for providing individualised support for people with an intellectual disability. The present study did not address this question. [81] Therefore high qualification levels, although generally positive, should be taken with some scepticism.

The recruitment and retention of support workers is increasingly difficult in various countries (e.g. USA) where staff shortages threaten quality of care (Hewitt and Larson, 2007). This issue is clearly less important in Hungary, not least because staff levels imposed on services are anyway very low. Nevertheless the issue should not be completely disregarded. Only 2 services – institutions – reported a high level of

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[81] Previous experience suggests that these courses are either too general or are very institutional in their approach, developed by and for people working in institutions.

vacancies at 7.4% and 14.6% of unfilled positions as a result of a freeze on hiring new staff. No independent group homes reported any vacancies – they could not afford to have any unfilled jobs with the low staff levels. Staff turnover was low, under 5% in independent provision and somewhat higher, but still under 10% in institutions.

While most managers agreed that it was easy to recruit workers for auxiliary and support positions with lower or no qualification requirements, they said that it was difficult to find suitable applicants for clinical positions, regardless the labour market situation of the local area. The possibility to hire non-local staff in low-paid positions was constrained by inadequate public transport links and the cost of commuting for both the employer and the employee.

9.2.3 Services received by people

The previous chapter argued that services for adults with intellectual disabilities are concentrated in institutions. Recently residential supports have become increasingly integrated with other services, particularly education and employment. Residential service providers are now major providers of a range of other services, most importantly employment. This section gives an overview of the services provided by institutions and group homes, including health care, development and training, employment and other activities.

9.2.3.1 Health care

Hungary has a universal health care system funded primarily by health insurance contributions paid into the Health Insurance Fund and to a lesser extent by taxes used to finance capital investments. Health care is organised at different levels: municipal governments are responsible for the provision of primary care; county and regional governments provide specialist and hospital care. These services are provided free of charge to people with a valid health insurance or exemption. Dental care and prescriptions (including equipment) as a general rule are only partly funded by the Health Insurance Fund and patients need to contribute to the cost – fully or partly. Certain groups are eligible for free dental care (e.g. children and people aged over 60), or free prescriptions (e.g. those with a long-term condition). There are considerable territorial disparities in terms of access and quality of health care services, underprivileged groups and people living in deprived or rural areas experiencing the worst outcomes (Orosz & Burns 2000).

Institutions are required to organise certain health care services, including prevention and screening, regular health checks, access to specialist and hospital care, medication and equipment, and nursing care. Group homes must ensure adequate access to mainstream health care.

All institutions and two independent group homes employed a general practitioner (GP) who visited the service on a regular basis for health checks and to prescribe medication. Institutions also employed psychiatrists whose role was to prescribe psychiatric drugs. For specialist services (including acute psychiatric treatment) institutions and group homes used their local hospitals and outpatient clinics. Three institutions reported preventative services (smoking advice and STD awareness) and regular screenings (with mobile screening units) including chest x-ray, prostate, cervical and breast cancer.

People with intellectual disabilities have been reported to have higher prevalence of oral health and dental problems than the general population (Ouellette-Kuntz, 2005). This is partly due to inadequate education, prevention and access to dental services (Hallberg & Klingberg, 2007). Oral hygiene has traditionally been a low priority in institutions, and tooth removal was the only dental intervention practised in the dental surgeries of institutions. This practice seems to be changing now and only one institution reported that employed a dentist on site. All other services used dental services – both private and public - in the community.

9.2.3.2 Skills development

Nearly all services offered activities labelled as “individual development” or “development” which is also required by the law (Hungary 2000). These services are provided as part of the ‘residential package’, service users are not required to contribute on an individual basis. Table 9.1 gives a summary of the different types of activities. Institutions, including those operating group homes provided five to seven activities, most commonly ‘skills development’, sports and crafts. Sensory stimulation or ‘snoezelen’ was popular among institutions with more severely disabled service users (Lancioni, Cuvo&O'Reilly 2002); three institutions offered this service. Independent group homes offered three to five different types of activities that were by-and-large similar to those offered by institutions. The category of skills development included a wide range of activities, such as literacy, numeracy and IT classes and more general skills such as self-care, lifestyle, social skills etc.

On paper all service users were required to take part in one or more of these activities on a regular weekly or bi-weekly basis, however only three independent group homes and one institutional group homes had individual weekly schedules for service users. There were two services, one independent group home and one institutional group home that did not offer any ‘individual development’ activities.

Table 9.7 Activities in services

Institutions and institutional group homes
- Snoezelen, sensory stimulation - Cooking - Music - Sports (gym, football, basketball, athletics, table tennis, weight lifting, medicinal gymnastics) - Skills development - Socio-therapy - Crafts (pottery, painting, woodworks etc.) - Drama/theatre group - Puppet therapy
Independent group homes
- Physiotherapy and massage - Sports (swimming, horse riding, medicinal gymnastics) - Skills development - Crafts (pottery, painting, embroidery etc.) - Music

Site visits highlighted four issues. First, the coverage of activities in institutions. Activities often did not include everybody or participation was irregular, infrequent and of a short duration – not more than a few hours per week. People with more severe disabilities or challenging behaviours were more likely to be left out. Some of the activities seemed ad-hoc and people were not scheduled to take part in them. Even though all service users had individual development plans – as required by the law – this was not necessarily translated into individual schedules.

Second, the content of these activities:although most services labelled their activities with titles such as "music therapy", "creative group activities" or "sport therapy", in reality these were no more than people doing colouring, playing board games, spending time in the gym or listening to music with or without supervision. Most of the activities were not planned and implemented by staff with adequate qualifications. Furthermore, they were not embedded in the daily activities of service users and lacked the potential to improve quality of life outcomes through improving self-care and adaptive skills useful for participation in community activities.

Third, the services that provided fewer or no scheduled activities at all had more able service users and seemed to leave more freedom for them to organise their own leisure times, including the use of community facilities (shopping, cinema visits etc.) or hobbies (gardening, computers etc.). Finally, activities typically took place on site and were organised by service staff or external staff which resulted in a limited community presence of service users. Only two independent group homes and one institution used community facilities for scheduled activities (swimming pool, spa, horse riding).

All services reported special events: in most cases these included the celebration of major holidays (such as Easter and Christmas), but there were also parties ("discos") and social events like barbecues where family members or members of the public were invited. In small villages institutions seemed to play a more central role in the life of the community and there were some examples of inclusive activities (for example one institution had an integrated theatre group and they regularly staged shows in the local school).

9.2.3.3 Employment

It was argued in Chapter 7 that residential services became major providers of employment services as a result of recent reforms. The findings of the fieldwork confirmed this. Two forms of work activity were available in residential provision: vocational rehabilitation and developmental-preparatory employment. Vocational rehabilitation is organised by the residential service provider and it is open to all service users, including people under plenary guardianship. Activities in vocational rehabilitation can include tasks in and around the service (e.g. cleaning, assisting in the kitchen etc.) and arts and crafts type activities. Participation in developmental-preparatory employment is restricted to people with full or partial legal capacity. It is typically jointly organised by a sheltered company and the residential service provider and includes easy manufacturing activities (e.g. assembly of objects etc.). Work was typically facility-based and carried out on site. Exceptions included agricultural activities and one institution renting an industrial site elsewhere. Service users can also have a job in the open labour market or with a sheltered company. While people with severe disabilities were typically excluded from employment in services, participation in either vocational rehabilitation or developmental-preparatory work was more dependent on the individual's guardianship status and availability of work opportunities; vocational rehabilitation being easier to organise but also financially less rewarding. In some cases the same work tasks were carried out in both forms of employment.

Services in the study had a total of 733 service users in some form of employment which represented 66% of all service users. It emerged from the managerial interviews that some services (n = 2) had introduced employment recently or had expanded activities (n = 2) to include more people. The majority (95%, n = 697) of service users in work were in facility-based employment, 55% (n = 403) in paid work and 40% (n = 294) in vocational rehabilitation. Only 5% (n = 36), coming from

3 services were in non-facility based employment, mainly with sheltered companies. Only one person out of 733 had a mainstream job.

There was a significant difference in the number of service users who were in employment in the three models ($KW\chi^2 = 12.91$; df = 2; $p < 0.01$. While virtually 100% of service users worked in both types of group home provision, this percentage was significantly lower in institutions. Just over half of the service users who worked (55%) were in developmental-preparatory employment, 40% in vocational rehabilitation and only 5% had a job outside the service either at a sheltered company or with a mainstream employer. There were no significant differences in the employment patterns between the three types of provision.

There was a wide variation in work activities available to service users in vocational rehabilitation and developmental-preparatory work. Table 9.8 gives an overview of these. In some services individuals could choose between work activities, elsewhere only one option was offered. Working time was four to six hours per day in vocational rehabilitation, six hours in developmental-preparatory work and six to eight hours in regular employment.

Vocational rehabilitation was available in all institutions and two independent group homes. The majority of activities in institutions were directly linked to the daily functioning of the service and included auxiliary activities such as cleaning and assistance in the kitchen. Independent group homes did not employ service users in auxiliary positions, those activities were part of the normal daily routine. There was one institution where less disabled users were involved in the provision of personal care to other severely disabled residents – a rather controversial practice. However, there were good practices as well: service users in one institution made home decorations and jewellery using natural materials collected by service users and staff (e.g. dried flowers, feather, shells etc.). Tasks were broken down to suit individual abilities, and included simple activities like treating branches of wood with sand paper and complex, creative activities like painting motives on wood. People could move between activities. Products were sold at local markets and fairs.

Table 9.8 Typical work activities in services

<table>
<tr><th>In vocational rehabilitation</th><th>In developmental-preparatory work</th></tr>
<tr><td colspan="2">Institutions</td></tr>
<tr><td>- Kitchen assistance*
- Cleaning*
- Gardening*
- Laundry assistance*
- Horticulture
- Receptionist*
- Recycling
- Broom-making
- Providing care to other residents*
- Handicrafts
- Agriculture</td><td>- Assembly jobs (cushions, textile toys, buttons, beanbags etc)
- Packaging and gift-wrapping
- Handicraft/art work (e.g. wood work, candle-making, carpet weaving etc.)
- Agriculture (farming)
- Cleaning*
- Gardening (service provided to external organisations and private households)
- Recycling</td></tr>
<tr><td colspan="2">Independent provision</td></tr>
<tr><td>- Handicrafts (wooden toys, jewellery)</td><td>- Making dried fruits and fruit preserves
- Producing organic glue
- Packaging and gift-wrapping
Handicraft/art work (e.g. wood work, candle-making, carpet weaving etc.)
- Agriculture (farming)
- Gardening (service provided to external organisations and private households)</td></tr>
</table>

Note. * These are tasks that are directly related to the daily operations of the service.

Developmental-preparatory work was available in 80% of institutions and 60% of independent group homes. Institutions organised employment themselves (contract-work) or in cooperation with major sheltered companies, independent service providers worked with non-profit companies, often set-up and run by the same people who were running the residential service. A major difference was that while institutions only provided employment for their service users, independent providers also offered work to people with disabilities living in the community with their families or independently. The nature of tasks varied greatly but typically it consisted of unskilled or simple skilled tasks. Independent providers organised vocational training for users. Institutions on the other hand only provided hands-on, on-the-job training.

The share of people with a job outside the service was marginal (5%) in all types of provision and typically they were in some form of sheltered employment; only one person was reported to have a mainstream job in the open labour market. There was no evidence of efforts to support vocational development or the labour market integration of service users – contrary to the stated aims of the Act.

9.2.4 Management and care practices

9.2.4.1 Management practices

This section explores issues linked to the management of services and care practices, including policies to prevent abuse, the treatment of challenging behaviours and user involvement. Management and care practices were measured by the Group Home Management Interview (Raynes 1988; Raynes, et al., 1994). This instrument measures management practices along the four dimensions of total institutions: rigidity of routines, block treatment, depersonalisation and social distance (Goffman, 1961). The total score indicates to what extent care practices are user-oriented or institutionally-oriented (King, Raynes, & Tizard, 1971). Rigidity of routine explores to what extent different aspects of life are regulated and scheduled in the service, such as morning routines, meals, evening routines, visiting times and the use of certain facilities. Block treatment considers to what extent users are treated alike and activities take place in large groups. Depersonalisation refers to the deprivation of individuals of their identity and the possibility of self-expression, the removal of personal objects, clothes, hobbies and important life events such as birthdays. Social distance indicates the divide between staff and residents, the extent to which residents are viewed as "not like us" by staff.

There were significant differences in all four dimensions between the three models (see Table 9.9): rigidity of routine, depersonalisation and social distance. Institutions had significantly less user-oriented practices than both types of group home provision (*Mann-Whitney* post-hoc tests, $p < 0.05$). Institutions were characterised by very rigid morning routines and set meal times, however generally there was more flexibility and seasonal variation in evening meals and routines. In group homes weekend routines differed from weekdays. Social distance was very high in institutions, which might also be linked to staff shortages. Staff in institutions typically ate their meals in separate dining areas and did not have time to join in the evening activities of services users (e.g. watching television, hobbies etc.).

Table 9.9 Group Home Management Interview, mean percentage scores by domain and model of provision

	Institutions	Indep GH	Inst GH	Sig test
Rigidity				
Mean % score	45.40	5.60	3.20	< .01 (*KW*); df = 2; 10.47
Std. dev.	16.92	2.19	3.34	
Block treatment				
Mean % score	37.00	14.00	12.00	< .05 (*KW*); df = 2; 9.06
Std. dev.	12.04	10.84	8.37	
Depersonalisation				
Mean % score	36.80	20.20	14.00	< .01 (*KW*); df = 2; 10.69
Std. dev.	8.44	4.55	6.28	
Social distance				
Mean % score	71.60	10.00	23.20	< .01 (*KW*); df = 2; 10.22
Std. dev.	9.48	10.93	18.13	
Total GHMI				
Mean % score	45.20	12.80	11.80	< .01 (*KW*); df = 2; 9.47
Std. dev.	9.12	3.42	1.30	

Note. GH=group home; *KW*=Kruskal Wallis

There were two domains – block treatment and depersonalisation – where services, including institutions achieved better scores. There was some individual treatment in all services and service users were allowed the possibility of self-expression, particularly more able people. The majority of service users had personal possessions – clothes and objects – stored in private storage, and were allowed to have personal decorations in their rooms. All services allowed and encouraged service users to have hobbies, including complex activities such as embroidery, drawing and painting, gardening, dj-ing, and sports. They also received support from staff (for example to go to specialist shops, order things from the Internet etc.). Many people had simple and repetitive hobbies, such as collecting items and there was no evidence of support given to people with severe intellectual disabilities to develop their own hobbies.

The majority of services (11; 73.3%) allowed service users to have individual pets (e.g. fishes, hamsters, guinea pigs, parrots, cats, dogs and even goats, rabbits, pigs) as long as they were willing to look after their own pets, with minimal support if needed. One institution and one independent group home (13.3%), only allowed common pets, and one institution and one independent group home did not allow any pets. Birthdays were celebrated in most services; joint parties were more common in institutions while group homes typically had individual parties and presents.

9.2.4.2 Policies to Prevent and Detect Abuse

People with intellectual disabilities are particularly vulnerable to become victims of abuse, which remains largely invisible in our society (Wardaugh & Wilding, 1993; Reiter, Bryen, & Schachar, 2007). The term abuse includes a wide range of behaviours such as neglect, physical, verbal, behavioural and sexual abuse, and exploitation and intimidation. Abuse can be perpetrated by staff, other service users, and family members of service users (McCartney & Campbell, 1998). Abuse can happen in institutions and in the community as well, however certain characteristics of institutional provision, such and depersonalisation and social distance are thought to increase the risk of abuse (Goffman 1961; McCartney and Campbell ibid.).

Wardaugh and Wilding (1993) identified eight conditions that increase the risk of – what they term – “the corruption of care” in organisations. First, they (1993) suggest that the corruption of care is more likely when people are regarded as “less than fully human” or “beyond the normal bounds of moral behaviour”. Dehumanisation happens through ritualised admissions procedures, the bureaucratisation of the individual and depersonalisation. Second, the corruption of care is closely connected with the balance of power and powerlessness in the organisation: those who suffer abuse are typically powerless, weak and vulnerable; they have little awareness and means to assert their rights. Staff – who are also often powerless, overworked, under-qualified and underpaid – often have almost absolute power over vulnerable service users through the routines of everyday life. Third, particular pressures increase the likelihood of the corruption of care. Groups that are more at risk of becoming victims of abuse are those who are undervalued in our society which also affects the resources made available for their care. Fourth, there is often a management failure underlying the corruption of care in organisations, including a failure to set clear aims and objectives and allowing staff to become professionally isolated. Fifth, abuse is more likely to happen in enclosed, inward-looking organisations that can easily suppress criticism and complaints, lack new ideas and judge its practices by its internal standards. Sixth, the absence of clear lines and mechanisms of accountability, the lack of control and inspection by user organisations, relatives and independent authorities. Seventh, certain organisational characteristics also increase the risk of the corruption of care, including hierarchical structures, bureaucratic procedures and size.

Finally, the nature of certain client groups: Wardaugh and Wilding highlight that people with intellectual disabilities, mental health problems, children and elderly people are more likely to become victims of abuse.

Hungarian organisations, particularly institutions are at increased risk of corruption of care. It has been shown that there is a relatively high level of rigidity and social distance in services that are also chronically and severely under-resourced. Funding has been steadily decreasing over the recent years and there is a shortage of staff imposed on services by the law. This chapter has revealed insufficient staff numbers particularly in evening and night shifts. Buildings are typically large with toilets and bathroom facilities shared by a large number of service users. On the other hand services are not equipped to deal with service users with challenging behaviour – they lack staff and infrastructure (e.g. single rooms). Many of the settings are found in small communities with high unemployment where internal criticism can easily be suppressed by "staff solidarity" or a direct threat to loosing one's job and thus their livelihood. In addition there is no effective system of external control in service settings. Municipalities and financial authorities are responsible for the inspection of services however these only concentrate on procedural and financial issues and they are not independent – they are directly responsible for the provision of these services.

Incidents of abuse reported by the media and experiences of the site visits – mainly in the form of informal conversations with staff – suggested that abuse is a serious and widespread problem in services in all its forms from financial exploitation to sexual abuse. The fieldwork did not investigate incidents of abuse but surveyed whether services had policies in place to detect and prevent maltreatment.

All institutions were visited on a monthly basis by user rights representatives, while two out of five independent group homes reported less frequent visits.[82] User rights representatives were generally seen as

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[82] The Public Foundation for Patient, User and Children's Rights was set up by the Government and it operates an advocacy service with 43 paid and volunteer advocates across the country (Szabó 2008). The system has several weaknesses that might compromise its effectiveness. First, the advocates are not independent, they must have previous experience in the provision or administration of social care and many of them actually work in services. In 2006 over 60% user rights advocates were managers of institutions. Second, the service is not accessible for people with severe disabilities who cannot make a verbal or written complaint. Representatives cannot initiate any investigation without a complaint.Third, advocates have a heavy caseload. On average one representative was responsible for 1,641 service users and 25 residential services in 2007 (Szabó 2008). Finally, they lack specialist ID knowledge because the majority of them are responsible for a catchment area where they cover all types of personal social services for younger and older adults. As of 2011 the Foundation has been merged into the National Office for Rehabilitation and Social Care (Nemzeti Rehabilitációs és Szociális Hivatal) that is part of the Ministry of National Resources and responsible for the assessment of people with disabilities for vocational rehabilitation and disability-related benefits.

having a marginal role. One of the managers in an independent group home had been an advocate but decided to leave because of the "frustration by the inability to change things".

One out of five institutions, two independent group homes and three institutional group homes reported policies to detect and prevent abuse. There was a difference in the interpretation of abuse in independent and state provision: while independent providers understood the term more broadly and their anti-abuse policies were usually part of the code of conduct for staff and were aimed at preventing neglect, maltreatment and physical abuse, state providers generally focused on preventing sexual abuse among service users. Their anti-abuse policies consisted mainly of sexual education and empowerment of service users, and they generally had no code of conduct for staff. There was also an awareness of the potential financial exploitation of service users by family guardians. Nearly all institutions mentioned this as a problem and pointed out that their means were rather limited in safeguarding the best interest of the individual against the family.

9.4.2.3 The management of challenging behaviour and psychotropic medication in services

The management of challenging behaviour is a key issue in residential provision for people with intellectual disabilities. Challenging behaviour has been associated with a number of negative outcomes for service users including a higher risk of becoming a victim of abuse (Emerson, Robertson et al. 2000). This section explores how services deal with challenging behaviours and what strategies they use to manage episodes.

The most commonly used technique reported by services to manage challenging behaviour was medication/sedation which was used in all institutions and the majority of group homes (60%). Seclusion was less common and typically consisted of the removal/redirection of individuals from certain situations to other areas, including their own room. None of the services had a seclusion room. Physical and mechanical restraints were uncommon, one institution and one institutional group home used these techniques. Nevertheless, 11 out of 13 (85%) services had a written policy on restraint and in over half of the cases staff received training in restraint. One independent and two institutional group homes reported no use of any pharmacological or physical behaviour restraint methods (Table 9.10).

Table 9.10 Services using different techniques to manage challenging behaviour, by type of provision,% (n)

	Institutions	**Indep GH**	**Inst GH**
Medication	100 (5)	60 (3)	60 (3)
Seclusion	40 (2)	40 (2)	20 (1)
Physical restraint	20 (1)	20 (1)	20 (1)
Mechanical restraint	20 (1)	-	20 (1)
No intervention	-	20 (1)	40 (2)

Note. GH=group home

Psychotropic medication is frequently prescribed to people with intellectual disabilities and its use exceeds the estimated prevalence of psychotic disorders. The most common reason for the use of psychotropic drugs is to control challenging behaviours even though their effectiveness has not been demonstrated (Ahmedet al., 2000; Robertson et al., 2000; McGillivray & McCabe, 2005).This study found high levels of psychotropic medication in all models of provision. Services were asked to report the total number of service users receiving psycholeptic medication and psychoanaleptic medication. Psycholeptic medication includes drugs that produce a calming effect on the individual, such as antipsychotics, anxiolytics, hypnotics and sedatives. Psychoanaleptic drugs have a stimulating effect on the individual and include antidepressants, psycho-stimulants and anti-dementia drugs.

Table 9.11Service users taking psychotropic medication by type of provision, %

	Institutions N = 4	**Indep GH** N = 4	**Inst GH** N = 3	**Sig test**
% (n) on psycholeptic medication	58.50	20.75	7.67	< .05 (*KW*); df = 2; 6.52
% (n) on psychoanaleptic medication	38.25	20.50	17.67	ns

Note. GH=group home; *KW*=Kruskal Wallis; ns = not significant

The differences between the three models were significant in terms of the number of people taking psycholeptic medication (Table 9.11). Reports showed a high use of psychotropic medication in services. This issue will be further explored, including the individual patterns of psychotropic medication in Chapter 10.

9.4.2.4 User involvement

The law (1993. évi III. törvény) provides for the "representation and protection of the interests of service users" in services by setting up so-called User Councils. These are directly elected consultative bodies comprising of representatives of service users, staff, family members or guardians, the organisation responsible for the management of the service (i.e. municipality, church or board). The local user rights representative might also be invited to the meetings.

The law grants a wide range of rights to User Councils:

- It must be consulted on the yearly work programme, the strategy and decisions affecting the life of residents in the service.
- It discusses complaints of service users and proposes solutions to the management.
- It can ask for information on any aspect of the service from the management.
- It can report any (suspected) infringement of user rights and initiate action with the relevant management bodies or authorities.

While setting up a User Council is required by the law, users can also set up a "self-government" that ensures more involvement in the everyday life of the service.

User involvement is a relatively new concept in Hungarian services – it was introduced in 1998 – and it has received virtually no policy attention at all. The field work aimed to explore how organisations implement these rules and whether users are given any opportunities to shape the services they receive (see the Questionnaire on Resident Rights in Annex 3). From the interviews in emerged that user involvement, particularly user councils were seen as another administrative requirement imposed on services by the law. Most services complied with the regulations however in most cases no effort went into supporting service users to have a say in the affairs of the organisation, consult them and keep them informed about any planned changes potentially affecting their lives. There were no differences between state and independent providers in terms of their approach to user involvement.

Nine out of 13 services said that they had a User Council which met once or twice a year. User councils had no formal roles; they were informed about proposed changes. In addition to user councils, most services had further forums for parents and guardians. One service, an independent group home, did not have a user council and the manager was not aware of the requirement. Three services – two institutions and one independent group home – reported more regular user involvement: In one institution user representatives were directly elected after a formal nomination procedure and campaign. The User Council met at least twice a year and user representatives were consulted mainly on leisure activities and special events (e.g. planning holidays etc.). The other institution had a self-government alongside the User Council. The members of the self-government were delegated by each living unit. While the User Council was a more formal body, the self-government was involved in the everyday issues of the service

- They made proposals for events organised in the institution and other leisure activities.
- They were responsible for consulting service user on menus: collected suggestions and recorded weekly menu choices for all service users (this service offered a choice between two menu options for the main meal).
- They participated in editing the institution's own magazine.
- They were consulted on proposed changes affecting the life of service users.

The self-government received support from staff to organise the meetings, moderate discussions and take notes.

9.5 Conclusion

The analysis of residential care policies found that some aspects favoured institutions. The restrictive regulations make it very difficult to provide individualised supports to people with intellectual disabilities, particularly those with higher support needs in the community. Residential services operate in a very rigid and restrictive regulatory environment that was designed to regulate institutional provision. Currently itrepresents an outdated approach with crowded conditions and inadequate staff levels. The regulation of group homes developed along a service-based "institutional" approach, and increasingly moved away from the approach of "ordinary housing in an ordinary community" towards more elaborate and "institutional" requirements, which restrict the development of community-based services and innovation, and promote more congregate arrangements.

There was a substantial capital investment in institutional provision after 1999 which included the building of new facilities without considering alternative, community-based options. Although this helped to improve living conditions and reduce extreme physical deprivation in institutions, they do not provide home-like and personalised living environments. The way funding is allocated to service providers it favours state provision and discriminates against independent organisations that are more likely to provide community-based services. This has important implications for the availability of community-based supports that are seen as non-viable by many stakeholders.

The analysis of care practices revealed that although on paper institutions provided a variety of services to their residents, in reality these were erratic, lacked the potential to improve people's quality of life through the development of adaptive behaviours and people with more severe intellectual disabilities were often excluded. The community presence and participation, including the use of mainstream facilities by people with intellectual disabilities was rather limited in all forms of provision, some services organised and provided a variety of activities on their premises. Some of the results of this chapter highlighted some variation of practices within services: more able service users enjoying more freedom and better access to support. The next chapter will compare the service user outcomes of different residential arrangments using matched groups of participants.

Chapter 10 Characteristics of service users and a comparison of individual outcomes

This chapter has two main sections: the first part looks at the characteristics of services users in the three models of residential provision – institutions, group homes run by independent organisations and group homes run by institutions – based on a random sample in each setting with a total of 120 participants. Its aim is to explore and compare the service user population of the three service models and establish if there are any significant differences between them. The second part is a cross-sectional comparison of the service user outcomes in the three models of provision using a matched subsample of 60 participants. The evaluation presents outcomes in nine domains including community participation, social networks and friendships, family contact, self-determination and choice, material wellbeing, health and lifestyle-related risks, psychotropic medication; engagement in meaningful activities, and quality of staff support. The chapter concludes with a summary of the findings and a consideration of policy implications.

The full sample was selected from the residents of 13 services participating in the study and it included six individuals from each group home, and 12 individuals from each institution; a total of 120 participants. Participants represented 14.2% of the total user population with variations according the type of provision: in institutions 8.7%, in independent group homes 51.7% and in institutional group homes 31.2% of the service users were surveyed. The measures and methods of data collection are described in more detail in Chapter 8 on methodology.

10.1 The characteristics and needs of service users

This section looks at the characteristics of service users across the three types of provision, including age, adaptive and challenging behaviours, and residential history based on the data from Sample 2. It aims to explore the differences between the three models: do they serve different populations? If yes, what are the main differences and what are the possible implications for service provision?

Table 10.1 presents summary information on the gender and age of participants. There were significant differences in terms of age ($KW\chi^2 = 15.72$; df = 2; $p < 0.001$); people living in independent group homes were significantly younger than people who lived in institutions or institutional group homes (*Mann-Whitney U* post-hoc tests, $p < 0.05$). The youngest participant was 21, and the oldest participant was 68 years old in the sample.

Table 10.1 Gender and age of participants

	Institutions	Indep GH	Inst GH	Sig (test)
Gender				
	N = 60	*N* = 30	*N* = 30	
% men	58.3	46.7	56.7	ns
Age				
	N = 60	*N* = 30	*N* = 30	
mean	42.35	32.27	38.43	< 0.001 (*KW*)
Range	*23-68*	*21-59*	*21-60*	
Std. dev.	*11.76*	*10.60*	*9.33*	

Note. GH=group home; *KW*=Kruskal Wallis; ns = not significant

Table 10.2 gives information on the residential history of service users. People living in independent group homes had the shortest placements, on average 5.43 years compared to 14.64 years in institutions and 16.88 in institutional group homes. The difference was significant (*KW*χ^2 = 23.66; df = 2; p <0.001; *Mann-Whitney U* post-hoc test, p <0.001).

Table 10.2 Residential history

	Institutions	Indep GH	Inst GH	Sig (test)
Mean years	14.64	5.43	16.88	< 0.001 (*KW*)
Range	*0.5-36*	*0.5-8*	*0.5-35*	
Std. dev.	*11.76*	*10.60*	*9.33*	
Previous placement %				
	N = 58	*N* = 30	*N* = 30	
Family home	31.00	36.70	16.70	ns
Children's home	32.80	23.30	60.00	< 0.01 (χ^2)
Social care inst.	24.10	16.70	20.00	ns
Other	12.10	23.30	3.30	

Note. GH=group home; *KW*=Kruskal Wallis; ns = not significant

As regards the previous placement the only significant difference between the three models was the number of users who had moved to the service from the child protection system: 60% of people living in institutional group homes had been placed in a children's home, while the same share was 32.8% in institutions and 23.3% in independent group homes (χ^2 = 9.62; df = 2; p <0.01).

It is worth noting that over a third of users came from their family home in institutions and in independent group homes, while only 16.7%

of people in institutional group homes had lived with their families previously, although these differences were not significant. The share of people who had been placed in another social care setting (e.g. another institution or group home) was relatively low (16.7-24.10%) and differences between models were not significant. This does not include people who had moved out from the institution to live in the group home run by the same service; nearly all users in the institutional group homes had previously lived in the institution. The category *"Other"* includes service users who had moved to the service from a residential school (n = 8; most common in independent group homes), had been placed with a foster family (n = 4; most common in institutions and institutional group homes) or had been homeless (n = 3; most common in institutions).

Table 10.3 Percentage and number of service users with additional impairments

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
	N = 60	N = 30	N = 30	
Autism	0.0 (0)	26.7 (8)	0.0 (0)	< 0.001 (*Fisher's* Test)
Physical impairment	15.0 (9)	3.3 (1)	6.7 (2)	
Hearing impairment	6.7 (4)	10.0 (3)	3.3 (1)	
Visual impairment	1.7 (1)	6.7 (2)	6.7 (2)	
Speech impairment	30.0 (18)	0.0 (0)	23.3 (7)	< 0.01 (*Pears.* χ^2); df = 2; 11.06
Psychiatric illness	15.0 (9)	6.7 (2)	0.0 (0)	invalid
Two or more impairments	60.0 (36)	66.7 (20)	33.3 (10)	< 0.05 (*Pears.*χ^2), df = 2; 7.95
Epilepsy	21.7 (13)	26.7 (8)	0.0 (0)	< 0.05 (*Pears.*χ^2), df = 2; 8.83
Non-verbal	11.7 (7)	3.3 (1)	0.0 (0)	

Note. GH=group home; *ns = not significant*

All service users in the sample had – or were thought to have – an intellectual disability, however some of them had additional impairments as well. Table 10.3 gives an overview of these. People living in institutions were significantly more likely to have a speech impairment ($\chi^2 = 11.06$; df = 2; $p < 0.01$), epilepsy ($\chi^2 = 8.83$; df = 2; $p < 0.05$), autism (*Fisher's* exact test, 2-sided; $p < 0.001$) and they were also more likely to have 2 or more impairments ($\chi^2 = 7.95$; df = 2; $p < 0.05$). Other tests had invalid results nevertheless some issues might be worth highlighting:

- Fifteen percent of users in institutions (nine users), and 6.7% of individuals (four persons) living in independent group homes had a dual diagnosis of intellectual disability and psychiatric illness. Institutional group homes reported no users with psychiatric illness.

Nearly 12%, seven individuals living in institutions were non-verbal (one of them had a hearing impairment as well), compared to 3.3% (one person) in independent group homes and nobody in institutional group home provision.

Services were also asked to indicate if a participant had a diagnosis of any syndromes or conditions associated with intellectual disability. These figures were so low that they are not reported in a table. Down's syndrome was the most common diagnosis: one service user (1.6%) in institutions, two in independent group homes (6.6%) and two in institutional group homes (6.6%). In addition, one independent group home reported one user with William's syndrome.

The Short Adaptive Behaviour Scale was used to measure the adaptive skills of participants. Table 10.4 gives a summary of the results. The three models of provision differed significantly in terms of the adaptive skills of service users (F = 34.43; df = 2; $p < 0.001$). Overall, people living in institutions were significantly more disabled than people living in independent group homes or institutional group homes (*Tukey* post-hoc test, $p < 0.001$) and people living in institutional group homes were significantly more able than people in institutions or independent group homes (*Tukey* post-hoc test, $p < 0.001$). Institutions – and to a lesser extent independent group homes – provided for individuals of a wide range of abilities including people with profound and multiple disabilities and people with mild intellectual disabilities. The SABS mean score ranged from six to 106, with a standard deviation of 22.6 in institutions, and ranged from 39 to 107 in independent group home with a standard deviation of 17.19. At the same time all service users in institutional group homes were relatively able and had low support needs.

SABS scores were converted into SABS percentage scores and estimated ABS Part 1 scores were calculated using the formula described by Hatton et al. (2001) to allow comparisons with other studies. Participants in this study were considerably more able than those in other studies. For example Emerson et al. (2000) reported ABS Part 1 scores of 195.4 for residents living in village communities, 103.9 for service users living in residential campuses and 150.2 for people living in community-based houses. Mansell et al. (2008) reported SABS percentage scores of 55.32 for service users living in residential homes in England. People living in institutions in Hungary are as able as people living in community-based group homes in other countries (see Table 10.4).

Table 10.4 Adaptive and challenging behaviours

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
	N = 60	N = 30	N = 30	
Adaptive behaviours				
SABS mean score	56.42	78.13	90.57	< 0.001 (A), df = 2; F = 34.43
SABS % score	*49.51*	*68.89*	*79.63*	
Range	*6-106*	*39-107*	*60-110*	
Std. deviation	*22.60*	*17.19*	*13.11*	
ABS Part 1	155.12	206.37	235.72	
Challenging behaviours				
	N = 60	N = 30	N = 30	
ABC mean score	28.58	28.47	5.47	< .001 (*KW*)
range	*0-112*	*0-62*	*0-31*	
Std. deviation	*27.04*	*18.80*	*7.49*	
Irritability	6.83	7.60	2.20	< .01 (*KW*); df = 2; 13.63
Lethargy	8.02	9.47	0.87	< .001 (*KW*); df = 2; 28.65
Stereotypy	2.57	2.23	0.33	< .001 (*KW*); df = 2; 17.10
Hyperactivity	8.77	7.47	1.67	< .001 (*KW*); df = 2; 23.34
Inappropriate speech	1.80	1.70	0.40	< .01 (*KW*); df = 2; 13.72

Note. GH=group home; *KW*=Kruskal Wallis

There were significant differences between the three types of provision in terms of challenging behaviour on all subscales (*KW*χ^2 range =13.63-32.9; df = 2; p<0.001 for full scale, lethargy, stereotypy, hyperactivity; p<0.01 for irritability and inappropriate speech). *Mann-*

Whitney post-hoc tests showed no significant difference in any dimensions of CB between institutions and independent group homes. Service users in institutional group homes displayed significantly less challenging behaviour than service users in independent group homes ($p < 0.001$ for all subscales) and institutions ($p < .001$ for lethargy, stereotypy and hyperactivity; $p < .01$ for irritability and $p < .05$ for inappropriate speech). People in institutions displayed a wider range of challenging behaviours (scores ranged from nil to 112) than people in independent group homes (scores ranged from nil to 62).

Table 10.5 compares challenging behaviour scores found in this research with those reported by other studies (Aman et al. 1987; Emerson, Robertson et al. 2000; Mansell et al. 2008).

Table 10.5 Comparison of ABC scores with other studies

	This study			**Aman, Richmond, Stewart, Bell & Kissel (1987)**	**Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson (2008)**		**Emerson et al. (2000)**		
	Inst	Indep GH	Inst GH		GH1	GH2	VC	RS	SH
ABC mean score	28.58	28.47	5.47	–			18.0	31.9	19.1
Irritability	6.83	7.60	2.20	6.49	5.87	6.47		–	
Lethargy	8.02	9.47	0.87	4.95	6.14	6.49		–	
Stereotypy	2.57	2.23	0.33	1.63	2.01	3.35		–	
Hyperactivity	8.77	7.47	1.67	6.88	6.28	6.97		–	
Inappropriate speech	1.80	1.70	0.40	1.48	1.76	2.68		–	

Note. GH=group home; VC=village community; RS=residential campus; SH=staffed housing

This study found somewhat higher scores among people living in institutions and independent group homes, and considerably lower levels of challenging behaviour among people who lived in institutional group homes than other studies. Another important difference is the relatively high level of challenging behaviour among people living in independent group homes in Hungary in comparison to people living in community-based staffed housing in the UK.

In conclusion, the three models differed markedly in terms of their service users:

- People living in institutions were the most heterogeneous group in terms of age, adaptive and challenging behaviours. On average they were more severely disabled than people living in group home provision, however there were also some more able people living in institutions.
- People living in independent group homes were significantly younger than people in state provision. On average they were significantly more able than people in institutions but more disabled than people in institutional group homes.
- People who lived in institutional group homes were a relatively homogeneous group in terms of adaptive and challenging behaviours. They were significantly more able than people in the other two models and had less challenging behaviour. They were less likely to have multiple impairments and epilepsy, and no users were reported to have autism or psychiatric illness. They were more likely to have been in the child protection system then service users in institutions or independent group homes.

10.2 A comparison of individual outcomes in the three different types of residential provision

The evaluation of individual outcomes follows the structure of the review in Chapter 3. It presents user outcomes in seven out of the ten domains and two additional areas commonly used by evaluation studies. These are: 1) community participation; 2) social networks and friendships; 3) family contact, 4) self-determination and choice; 5) material wellbeing (quality of life); 6) health and lifestyle-related risk factors; 7) psychotropic medication; 8) engagement; and 9) quality of staff support. This study is a cross-sectional comparison of matched groups of service users in different types of provision, therefore adaptive and challenging behaviours are not used as outcome variable. User and family views were not included in this study due to methodological issues, particularly the disempowerment of people with intellectual disabilities living in institutions and the high number of people using residential services with no family contact.

The findings of the survey are presented by domain and following the order of questions in the questionnaire. Each section gives an overview of the general results, highlights the factors associated with variation and any methodological limitations. Where possible, findings are compared with results reported in other evaluation studies from any countries. Statistical results are summarised in tables, including tests used and significance levels.

To ensure comparability of results a sub-sample (N = 60) of three matched groups were selected on the basis of age, gender and adaptive skills (SABS score). Statistical tests, including post-hoc tests showed no significant differences between the matched groups. Their characteristics are summarised in Table 10.6. It should be noted, however, that the institutional sub-sample differed from the non-matched service users: they were younger, significantly less severely disabled and showed less challenging behaviour. On the other hand, individuals selected in institutional group homes were significantly more disabled than their non-selected peers.

Table 10.6 Characteristics of the matched-groups

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
Age				
Mean	36.00	33.35	36.55	ns (*KW*)
Std. deviation	9.80	10.22	9.45	ns
Gender				
% men	55	45	60	ns
Adaptive behaviour				
SABS mean score	77.60	78.85	85.50	ns (*KW*)
SABS % score	68.07	69.17	75.29	ns (*KW*)
Range	*57-106*	*56-106*	*60-105*	
Std. deviation	*13.37*	*12.92*	*11.93*	
ABS Part 1	*205.12*	*208.07*	*223.76*	ns (*KW*)

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant

There were significant differences between the three groups in terms of challenging behaviour ($KW\chi^2 = 20.08$; df = 2; $p < 0.001$). Overall service users in independent group homes were reported to show significantly more challenging behaviour, than people living in institutions, who in turn displayed more challenging behaviour than people in institutional group homes (*Mann-Whitney U* post-hoc tests, $p < 0.05$). A more detailed analysis shows that there were significant differences (*Mann-Whitney U* post-hoc tests, $p < 0.05$)in the level of challenging behaviour in all but two subscales, namely irritability and stereotypy (See Table 10.7). It must be noted that people in the institutional matched group had significantly less challenging behaviour than those in the non-matched group (*Mann-Whitney U* = 261; n = 60, $p < 0.05$).

Table 10.7 Levels of challenging behaviour in the matched groups

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
	N = 20	N = 20	N = 20	
ABC				
Mean score	18.75	30.75	5.60	$p < .001$ (*KW*), df = 2; χ^2 =20.08
Range	*0-64*	*3-62*	*0-31*	
Std. deviation	*21.48*	*18.95*	*8.05*	
Irritability	4.85	8.35	2.20	$p < .01$ (*KW*), df = 2; χ^2=10.87
Lethargy	5.00	10.05	1.05	$p < .001$ (*KW*), df = 2; χ^2 =19.62
Stereotypy	2.10	2.20	0.45	$p < .05$ (*KW*), df = 2; χ^2 =8.65
Hyperactivity	5.35	8.15	1.70	$p < .001$ (*KW*), df = 2; χ^2 =15.89
Inappropriate speech	1.45	2.00	0.20	$p < .001$ (*KW*), df = 2; χ^2 =21.11

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant

Table 10.8 gives an overview of the additional impairments of service users in the sub-sample. A relatively large number of service users had additional impairments in all models of provision: 45% in institutions, 55% in independent group homes and 40% in institutional group homes (nine, 11 and eight persons respectively). However, no significant differences were found between the groups.

Table 10.8 Additional impairments in the matched groups

	Institution	Indep GH	Inst GH	Sig (test)
	N = 20	N = 20	N = 20	
% (n) of users with				
Autism	0.0 (0)	20.0 (4)	0.0 (0)	invalid
Physical impairment	10.0 (2)	5.0 (1)	5.0 (1)	invalid
Hearing impairment	5.0 (1)	10.0 (2)	5.0 (1)	invalid
Visual impairment	0.0 (0)	5.0 (1)	5.0 (1)	invalid
Speech impairment	15.0 (3)	0.0 (0)	35.0 (7)	invalid
Psychiatric illness	15.0 (3)	10.0 (2)	0.0 (0)	invalid
Two or more impairments	45.0 (9)	55.0 (11)	40.0 (8)	ns
Epilepsy	20.0 (4)	20.0 (4)	0.0 (0)	invalid

Note. GH=group home

Table 10.9 Residential history of service users in the matched groups

	Institutions	**Indep GH**	**Inst GH**	**Sig (test)**
Time in current service				
	N = 19	*N = 18*	*N = 20*	
Mean years	11.16	5.67	14.27	< 0.05 (*KW*), 8.13, df = 2
Range	*4-25*	*1-8*	*0.5-30*	
Std. dev.	*6.58*	*1.97*	*9.83*	
Previous placement % (n)				
	N = 20	*N = 20*	*N = 20*	
Family home	25.0 (5)	25.7 (5)	15.7 (3)	invalid
Children's home	25.0 (5)	30.0 (6)	60.0 (12)	< 0.05 (χ^2), 6.06, df = 2
Social care inst.	25.0 (5)	15.0 (3)	20.0 (4)	invalid

Note. GH=group home; *KW*=Kruskal Wallis

In the residential history of users in the sub-sample – similarly to the full sample – the only significant difference was the number of people who had moved to the service from the child protection system (χ^2 = 6.06; df=

2; p <0.05). This was twice as high in institutional group homes than in both institutions and institutional group homes. (See Table 10.9)

10.2.1 Health, lifestyle psychotropic medication

Section 2, questions 41-56 of the questionnaire collected information on the health needs, lifestyle-related risk factors and psychotropic medication of service users. The data are summarised in Tables 10.10 to 10.12.

There were no significant differences in the number of users reporting long term health problems. The most commonly reported health problems were epilepsy (eight persons) and hypertonia (two persons); other reported conditions included duodenitis, scoliosis, spastic hemiparesis, osteoporosis, cataract, coeliac disease and lactose intolerance. The number of service users with mental health problems was relatively low: 15% of service users (three persons) in institutions and 10% of users (two persons) in independent group home provision were reported to have a psychiatric illness. Twenty percent of users (four persons) had epilepsy in institutions and in independent group homes. Independent group homes reported no users with either psychiatric illness or epilepsy.

These figures are in sharp contrast with the high number of people who were reported to receive (non-psychotropic and psychotropic) medication on a regular basis, which was highest, 95% (19 persons) in institutions, 70% (14 persons) in independent group homes and 55% (11 persons) in institutional group homes. The difference between the three models was significant ($\chi^2 = 8.35$, df = 2, $p < 0.05$).

Psychotropic medication is frequently prescribed to people with intellectual disabilities, anti-psychotics being the most commonly administered drugs. Its use exceeds the estimated prevalence of psychotic disorders. The most common reason for the prescription of anti-psychotic drugs is to control challenging behaviours even though their effectiveness has not been demonstrated (Ahmed et al. 2000; Robertson et al. 2000; McGillivray & McCabe 2005). There are also ethical concerns, people with intellectual disabilities have been found to have very little information and lack of choice about their medication (Crossley & Withers 2009). In the UK reported rates of prescription of anti-psychotic medication ranged from 25-50% in NHS intellectual disability hospitals and 20-50% in community-based residential services (Robertson et al. 2000). Emerson et al. (2000) reported that 17% of service users in village communities, 56% of users living in residential campuses and 27% of users in community-based residential homes were prescribed antipsychotic medication.

This study found high rates of psychotropic medication among service users. There were significant differences in the number of people reported to receive regular psychotropic medication ($\chi^2 = 14.26$, df = 2, $p < 0.01$). In institutions 89.5% of users (17 persons), in independent group homes 52.6% (ten persons) and in institutional group homes 30% (six persons) were receiving psychotropic medication on a regular basis. The association between psychotropic medication and psychiatric illness was not significant in institutions and in independent group homes (*Fisher's* exact test, 2-sided $p = 1.000$ and $p=0.474$ respectively); institutional group homes reported no users with psychiatric illness. To put it differently, 82.4% (14 out of 17) of people who were administered psychotropic medication in institutions had no psychiatric illness. The same figure was 80% (eight out of ten) in independent group homes and 100% (six out of six) in institutional group homes. This also meant that 87.5% (14 out of 16) users with no psychiatric problems were receiving psychotropic drugs in institutions. The same figure was 47.1% (eight out of 17) in independent group homes, and 30% (6 out of 20) in institutional group homes.

Psychotropic polypharmacy, defined as the regular use of two or more psychotropic drugs (Fulton & Allen 2005), was also relatively common: 57.9% (11 users) in institutions, 47.4% (nine) in independent group homes and 10% (two users) in institutional group homes. The difference between the three models was significant ($\chi^2 = 10.56$, df = 2, $p < 0.01$). Another definition of polypharmacy is the use of four or more drugs (ibid), which was 15.8% (three users) in both institutions and independent group homes; in institutional group homes no users met this definition.

Most commonly, service users were administered anti-psychotic medication in institutions and in independent group homes (68.4% and 31.6%), while in institutional group homes the most common types of drugs were anxiolitycs and anti-depressants (15%). The differences between the three models in the proportion of users taking anti-psychotic drugs on a regular basis were significant ($\chi^2 = 14.66$, df = 2; $p < 0.001$). It was highest in institutions (68.4%, 13 persons) and lowest in institutional group homes (10%, two persons). Again, the relationship between anti-psychotic medication and psychiatric illness was not significant in institutions (*Fisher's* exact test, 2-sided $p = 0.088$) and in independent group homes (*Fisher's* exact test 2-sided $p = 0.517$), institutional group homes reported no users with psychiatric illness. This also meant that the majority of those taking anti-psychotic drugs - 76.9% (ten persons) in institutions and 66.7% (four persons) in independent group homes – were not reported to have any psychiatric illness.

Table 10.10 Health and psychtropic medication in the matched groups, % (n) of users

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
Health % (n)				
	N = 19	N = 17	N = 20	
Long term health condition	36.8 (7)	47.1 (8)	15.0 (3)	ns
Medication % (n)				
	N = 20	N = 20	N = 20	
Regular medication	95.0 (19)	70.0 (14)	55.0 (11)	< 0.05 (*Pears.*χ^2); df = 2; 8.35
Mental health % (n)				
Psychiatric illness	15.0 (3)	10.0 (2)	0.0 (0)	Invalid
Epilepsy % (n)				
Epilepsy	20.0 (4)	20.0 (4)	0.0	Invalid
Psychotropic drugs % (n)				
	N = 19	N = 19	N = 20	
Psychotropic drugs	89.5 (17)	52.6 (10)	30.0 (6)	< 0.01 (*Pears.*χ^2); df = 2; 14.26
Anxiolitycs & hypnotics	15.8 (3)	10.5 (2)	15.0 (3)	Invalid
Anti-psychotics	68.4 (13)	31.6 (6)	10.0 (2)	=0.001 (*Pears.*χ^2), df = 2; 14.66
Anti-depressants	26.3 (5)	10.5 (2)	15.0 (3)	invalid
Anti-epileptics	36.8 (7)	42.1 (8)	0.0 (0)	invalid
Psychotropic polypharmacy				
Two or more drugs	57.9 (11)	47.4 (9)	10.0 (2)	< 0.01 (*Pears.*χ^2)
Four or more drugs	15.8 (3)	15.8 (3)	0.0 (1)	invalid

Note. GH=group home; ns=not significant

People with higher ABC total scores were more likely to receive anti-psychotic medication (*Mann-Whitney U* = 148.500; N = 58; p

<0.001). However no significant association was found between severe challenging behaviour – defined as more than five behaviours rated as "severe" on the Aberrant Behaviour Checklist – and psychotropic medication (*Fisher's* exact test, 2-sided p = 1.000) It should be noted, that only 5% of service users (three persons) were rated as having severe challenging behaviour in this sample.[83]

There was a significant association between epilepsy and the use of epileptic drugs (*Fisher's* exact test p <0.001), however an analysis by type of provision showed no significant relationship in institutions, where over half of those (57.1%, four out of seven persons) taking antiepileptic drugs were not reported to have epilepsy.

There were no significant differences in the use of health services – visits to a general practitioner or a specialist/consultant – between the three groups (see Table 10.11). There were two incidents of hospitalisation in the 12 months prior to the survey: one minor surgery and one admission to a psychiatric hospital due to depression and self-harm following the loss of a partner.

Table 10.11 Use of health services in the matched groups

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
GP (past three months)				
	N = 19	N = 20	N = 20	
% (n) visited GP	42.0 (8)	40.0 (8)	25.0 (5)	ns
Mean no. of visits	1.9	2.9	3.6	
Specialist (past three months)				
	N = 19	N = 20	N = 20	
% (n) visited specialist	20.0 (4)	50.0 (10)	35.0 (7)	ns
Mean no. of visits	1	3.7	1.3	
Hospital (past 12 months)				
	N = 20	N = 19	N = 20	
% (n) hospitalised	0.0 (0)	5.3 (1)	5.0 (1)	ns

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant

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[83] The same test was repeated for the full sample (n = 117) and it also showed no significant association between severe challenging behaviour and psychotropic drug use.

Hungary ranks unfavourably in international comparisons of life-style related health-risks, such as smoking, alcohol-consumption, poor diet and physical inactivity (Orosz & Burns 2000; White & Holmes 2006). The life expectancy of both men and women are well below the EU average (CSO 2008). Little information is available on the lifestyle-related health risks affecting people with intellectual disabilities. A number of studies found a similar or higher prevalence of inactivity and obesity than in the general population among people with intellectual disabilities, however the prevalence of smoking and alcohol abuse was found to be lower (Robertson et al. 2000; Melville et al., 2008). Other studies suggested that the prevalence of smoking is higher among people with mild intellectual disabilities (Steinberg, Heimlich & Williams, 2009). The prevalence of smoking was found to be higher in less restrictive settings, where people also smoked more cigarettes per day (Robertson et al. 2000; Steinberg et al., 2009).

Table 10.12 summarises data on lifestyle-related risk factors of service users. There was a high proportion of smokers, particularly in the most restrictive settings: in institutions 57.9%, (11 persons), in institutional group homes 30% (six persons), while in independent group homes only 10% of the service users (two persons) smoked. The difference between the three groups was significant ($\chi^2 = 10.30$, df = 2, $p < 0.01$). The mean number of cigarettes people smoked was relatively high in all settings, people on average smoked 12-16 cigarettes a day. Staff purchased and rationed cigarettes to service users in institutions in over half of the cases. The overall rate of smokers was comparable to the general population: in the sample 35% of male service users (n = 31) smoked compared to 37.1% in the general population, for females the rate was 28.6% among services users (n = 28) and 24.6% in the general population (KSH, 2008). However, rates in institutions were well above those of the general population: 70% among men and 44.4% among women.

Respondents were asked to rate the level of alcohol consumption of participants using three categories: non-drinker, moderate/occasional consumption of alcohol, heavy drinker. Alcohol units/measurements were not used because staff may not necessarily be aware of the exact amounts of alcohol consumed by individuals, particularly in the case of less severely disabled service users living in homes with no continuous staff presence. The aim was to find out whether one's consumption of alcohol was considered excessive or a problem. There were no significant differences between the three groups, 21% of users (four persons) living in institutions and independent group homes consumed moderate amounts of alcohol occasionally, while in institutional group homes twice as many service users (42%, eight persons) were reported to consume alcohol. Heavy drinking was uncommon, only one person who lived in one of the institutions was reported to be a heavy drinker whose alcohol addiction was considered to be a problem.[84]

Table 10.12 Life-style related risk factors in the matched groups

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
Smoking				
	N = 19	N = 20	N = 20	
% (n) smoker	57.9 (11)	10.0 (2)	30.0 (6)	< 0.01 (*Pears.*χ^2), df = 2; 10.30
Mean no. of cigarettes	13	12	16	
Who buys cigarettes				
% Staff	54.5	50.0	0.0	
Coffee				
	N = 19	N = 20	N = 20	
% (n) drinks coffee regularly	52.6 (10)	30.0 (6)	65.0 (13)	ns
Alcohol consumption, % (n)				
	N = 19	N = 19	N = 19	
Drinks alcohol	21.1 (4)	21.1 (4)	42.1 (8)	ns
Considered heavy drinker	5.3 (1)	0.0	0.0	
Body Mass Index, % (n)				
	N = 19	N = 20	N = 20	
Underweight	5.3 (1)	25.0 (5)	5.0 (1)	invalid
Normal weight	52.6 (10)	40.0 (8)	50.0 (10)	ns
Overweight	21.1 (4)	5.0 (1)	35.0 (7)	invalid
Obese	21.1 (4)	30.0 (6)	10.0 (2)	invalid
Exercise, % (n)				
	N = 20	N = 20	N = 19	
at least weekly	35.0 (7)	50.0 (10)	36.8 (7)	ns
less than monthly	45.0 (9)	40.0 (8)	57.9 (11)	ns

Note. GH=group home; ns=not significant

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[84] In the full sample two persons were reported to be heavy drinkers which represented 1.7% of participants (n = 115).

Caffeine is considered by some as the most widely used psychostimulant drug in the world. The most common sources of caffeine in an adult's diet are coffee, tea and certain soft drinks. There are variations in the consumption patterns of caffeine, with some countries consuming more coffee while elsewhere tea is an important source of daily caffeine intake. In Hungary 76% of the population consumes coffee on a regular basis, of which 60% drinks at least one cup of coffee a day.[85]

There have been a number of benefits attached to the consumption of caffeine in healthy adults and most of the commonly perceived risks have not been confirmed. There are no studies on the effects of caffeine on people with intellectual disabilities. Nevertheless, there are some potentially relevant aspects. First, the consumption of caffeine was shown to interfere with sleep, although individuals usually control their intake to avoid interference with sleep (Smith, 2002). People with intellectual disabilities might have an impaired ability to control their consumption and thus might be at increased risk of disturbed sleep, although there is limited evidence (Brylewski & Wiggs, 1998). Second, caffeine-withdrawal, even overnight, can have negative effects including fatigue, depressed mood and headache (Rogers & Dernoncourt, 1998). Third, caffeine has been shown to have adverse behavioural effects, such as increased anxiety and psycho-motor problems, when given to sensitive individuals, including people with psychiatric problems (Smith, 2002). These might aggravate existing challenging behaviours or interfere with the effect of psychotropic medication, which is particularly high in this population.

The patterns of coffee consumption found in this study were by-and-large similar to that of the general population: Over 52% (ten persons) of service users in institutions, 30% (six persons) in independent group homes and 65% (13 persons) in institutional group homes were regular coffee-drinkers and typically consumed more than one cup of coffee each day. There were no significant differences between the groups.

Another important aspect of life-style related risk factors are obesity and physical inactivity. Obesity has been associated with a number of health problems including heart disease, Type 2 diabetes etc. Obesity has been shown to be an important contribution to the increased health problems of people with intellectual disabilities (Melville, Hamilton, Hankey, Miller, & Boyle, 2007). High prevalence of obesity was reported by various studies. Women, people living in less restrictive settings, and those using psychotropic medication were found to be at higher risk of

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[85] Retrieved from: http://medizona.hu/egeszseg/20090416_eszpresszo_kavezas.aspx (last accessed: 02/01/2012).

obesity, while people were more severe disabilities were at lower risk (Emerson 2005; Melville et al. 2007; 2008).

In this sample there were no significant differences between the three groups; the majority of service users were of normal weight, on average 20% were overweight (range 5-35%) or obese (range 10-30%) using the World Health Organisation classification. By gender, 19.4% of male service users were overweight and 12.9% were obese (n = 31); rates were higher among women with 21.4% of service users reported to be overweight and 28.6% obese (n = 28). The prevalence of obesity was lower among male service users than in the general population (19.6%) and higher among female users (18% in the general population) (CSO 2008). Also, while in the general population males have a higher prevalence of obesity, among service users this is not the case.

A relatively large number of service users exercised on a regular – at least weekly – basis in all types of settings. But at the same time an even larger number exercised very infrequently, less than monthly. There were no significant differences between the three models in terms of physical activity; however there were differences in the way people exercised. While people living in institutions and institutional group homes exercised more on-site using the gym and institutional facilities, people living in independent group homes used community-based facilities, such as swimming pool, horse-riding etc. (see also Chapter 9).

10.2.2 Relationships

Questions 59-68 of the questionnaire collected information on family contacts, friendships and relationships of service users. The data are summarised in Table 10.13. Family contact in the survey has been defined broadly and included any contact with parents, siblings or extended family (i.e. grandparents, aunts and uncles etc.) regardless its frequency.

There were significant differences between the models in terms of family contact ($\chi^2 = 7.92$, df = 2, $p < 0.05$). People living in independent group homes were more likely to be in contact with their families than people living in institutions and institutional group homes. Family contact has been associated with a number of factors including distance from the family home, the age of the individual and the previous residence in the literature (see Chapter 3).

Possible associations with these factors are considered below:

- The survey did not ask the distance between the family home and the setting, it only asked whether the last known residence of the family was a) in the same town/city; b) in the same county; or c) elsewhere. This was later recoded into two categories: same county or elsewhere. Although this only provides an approximate measure of distance and accessibility, it is probably useful enough for this purpose because travelling (by public transport) within a county is generally easier and more affordable. However there was no association between the place of residence and family contact, in both groups approximately the same proportion of people (60%) had contact with their families.

- Although there were no differences between the three groups in terms of age, the relationship between the individual's age and family contact was also tested separately using *Mann-Whitney U* statistics. No differences were found between the two groups (i.e. those with and without family contact); in fact both had very similar average age (35.04 and 35.47 years).
- There was a significant association between family home as previous residence and family contact ($\chi^2 = 11.06$, df = 1, $p<0.01$). All people who moved into their current placement from their family home maintained some sort of contact with them. The association between family contact and children's service as previous placement was not significant and over half (56.5%) of the individuals who had been in the child protection system had some sort of contact with their families, although most often not with their parents.

Contact with parents was relatively low in all models, however a higher proportion of people in independent group homes (55%, 11 persons) had contact with either parents in contrast to 5% (one person) in institutions and 10% (two persons). Statistical tests were invalid due to the small number of cases. It is also worth noting that while in independent group homes the mother was the closest family member in the majority of cases (58%), in institutional settings siblings were the main family contact in over 70% of cases. There were no significant differences in the size of family networks and they tended to be rather small (one to four members). The size of family networks was by-and-large comparable to that reported by Emerson et al. (2000) in UK services (1.5-1.9 members).

Table 10.13 Relationships in the matched groups

	Institution	Indep GH	Inst GH	Sig (test)
Family contact, % (n)				
	N = 20	N = 20	N = 20	
Family contact	45.0 (9)	85 (17)	50 (10)	< 0.05 (*Pears.*χ^2), df = 2; 7.92
Contact with either parent	5.0 (1)	55.0 (11)	10.0 (2)	invalid
Frequency (among those who have contact)				
	N = 9	N = 17	N = 10	
At least fortnightly	11.1 (1)	76.6 (13)	40.0 (4)	invalid
Closest family member, % (n)				
	N = 7	N = 17	N = 10	
Mother	14.3 (1)	58.8 (10)	10.0 (1)	
Father	0.0	5.9 (1)	10.0 (1)	
Siblings	71.4 (5)	29.4 (5)	70.0 (7)	
Grandparents	14.3 (1)	0.0	10.0 (1)	
Other relatives	0.0	5.9 (1)	0.0	
Mean number of family members	1.22	1.71	1.10	ns
Range	*1-2*	*1-4*	*1-2*	
Std. deviation	*0.44*	*1.05*	*0.32*	
Friends, % (n)				
	N = 20	N = 20	N = 20	
No friends	10.0 (2)	10.0 (2)	5.0 (1)	invalid
Only in the service	70.0 (14)	30.0 (6)	85.0 (17)	< .01 (*Pears.*χ^2), df = 2; 13.68
In and outside the service	20.0 (4)	55.0 (11)	10.0 (2)	< .01 (*Pears.*χ^2), df = 2; 11.00
Relationships, % (n)				
	N = 20	N = 20	N = 20	
In a relationship	40.0 (8)	20.0 (4)	55.0 (11)	ns
of this long-term	62.5 (5)	25.0 (1)	100.0 (11)	
	N = 7	N = 4	N = 11	
Living together	14.3 (1)	0.0 (0)	45.5 (5)	invalid
Possibility to spend time together	100.0 (7)	50.0 (2)	100.0 (11)	invalid

People living in independent group homes seemed to have more frequent - at least fortnightly – contact with their families (76.6%, 13 persons) than people in institutional group homes (40%, four persons) or in institutions (11%, one person) although the results were not valid statistically.

The survey asked respondents to indicate whether the service users had any friends in the service, outside the service or in and outside the service. No questions were asked regarding the number of friends or the reciprocity of these relationships. There were no differences in the number of people reported to have friends (18-19 persons) in the three groups, however people living in institutions or institutional group homes were significantly less likely to have any friends outside the service than people living in independent group homes ($\chi^2 = 11.00$, df = 2, $p < 0.01$).

There has been very little research on relationships and cohabitation of people with intellectual disabilities, most research – and practice – around this topic has focused on the capacity to consent and sexual abuse, or more recently supporting parents who have intellectual disability. Nevertheless relationships also form an important part of an adult's life experience. There were no significant differences in the number of people who were reported to have a relationship in the three models. The number was highest in institutional group homes where 55% (11) service users were reported to be in a relationship, all of them long-term. Nearly half of them (45%, five persons) lived together with their partner (i.e. sharing a bedroom). In institutions 40% (eight) of participants were reported to be in a relationship, 60% of which were long-term. However, only one of them (14%) lived together with their partner. In independent group homes four persons (20%) had a relationship and only one was thought to be long-term by the respondents, none of them lived together and only half of them had the possibility to spend time together with their partner – in comparison to 100% in institutions.

10.2.3 Choice and self-determination

To collect information on the choice-making opportunities and self-determination of service users the Choice-making Scale (Conroy & Feinstein, 1986 in Raynes, Wright et al. 1994) and questions on the guardianship status were used (Questions 9 and 70-75). It has been argued in Chapter 7 that guardianship, particularly plenary guardianship, means an effective ban on exercising human rights and decision-making in a number of important areas of everyday life, including spending own income, and choosing where to live. The results are summarised in Table 10.14.

The majority of service users were under guardianship in each type of provision: 100% in institutions, 90% in independent group homes and 70% in institutional group homes. There were no significant differences in the proportions of users under plenary and partial guardianship. However, there was a significant difference in the guardianship status according to the level of disability (Mann Whitney U = 98.000; $p < 0.05$). People who were under guardianship were more disabled (Mean SABS score: 79.1, range: 56-106; std. deviation = 12.9) then those who had full mental capacity (Mean SABS score: 90.75, range: 76-106; std. deviation = 9.1). However, in the light of the relatively high SABS scores in both groups, it is likely that they would have some capacity or be supported to make decisions.

The extent to which service users could make choices in their everyday lives (such as when to go to bed, what to wear etc.) was measured using the Choice Scale. The advantage of using the Choice-making Scale was that its dimensions do not overlap with areas affected by guardianship rules with the exception of spending money (one out of 24 areas). However, it should be noted that the test-retest reliability for the Scale was weak with a mean Cohen's Kappa value of 0.51 and a 65% agreement of answers (See Chapter 8.4.2).

There were significant differences between the three models ($KW\chi^2 = 18.28$, df = 2, $p < 0.001$) in terms of choice-making as measured by the Scale. Service users living in institutional group homes were reported to have more choice than people living in institutions (*Mann-Whitney U* post-hoc test = 52.500; $p < 0.001$) or independent group homes (*Mann-Whitney U* post-hoc test = 90.500; $p < 0.01$). The difference between institutions and independent group homes in terms of choice-making was not significant.

The Choice-making score was also converted into percentage score to allow comparison with other studies. Choice-making in Hungarian services was considerably lower than those reported by UK studies – 80-85% - for people with more severe intellectual disabilities in community-based residential homes (Beadle-Brown, Hutchinson& Mansell, 2008; Mansellet al., 2008).[86]

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[86] Choice-making percentage scores in the full sample were as follows: institutions = 53.6; independent group homes = 71.78; institutional group homes = 87.5.

Table 10.14 Choice and self-determination in the matched groups

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
Guardianship, % (n)				
	N = 20	N = 20	N = 20	
Guardianship	100.0 (20)	90.0 (18)	70.0 (14)	invalid
Plenary guardianship	30.0 (6)	45.0 (9)	25.0 (5)	ns
Partial guardianship	70.0 (14)	45.0 (9)	45.0 (9)	ns
Choice				
	N = 20	N = 20	N = 20	
Choice-making mean score*	46.95	52.55	64.45	< 0.001 (*KW*); df = 2; χ^2: 18.28
Range	*27-63*	*36-69*	*44-72*	
Std. dev.	*10.56*	*9.70*	*8.72*	
Choice-making percentage score	*65.7*	*75.1*	*87.1*	

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant.

* Higher score indicates more choice; the maximum score is 72.

It was shown in Chapter 3 that choice-making was commonly associated with adaptive and challenging behaviours and the quality of support in evaluation research. Here, a significant although moderate positive correlation between choice and adaptive behaviours ($\rho = 0.334$, N = 60; $p < 0.01$, 2-tailed) and a negative correlation between choice and challenging behaviours was found ($\rho = -0.265$; N=60; $p < 0.05$, 2-tailed).

Choice-making was related to management practices and the quality of staff support. Choice-making was positively correlated with more user-centred management practices ($\rho = 0.531$; N=60; $p < 0.01$, 2-tailed) and better staff support as measured by the ASM ($\rho = 0.358$; N=60; $p < 0.05$, 2-tailed). It seems therefore that structure and the quality of support were more strongly related to everyday choice than individual ability or challenging behaviour.

10.2.4 *Material well-being*

Material well-being is an area rarely explored by more recent evaluation research, however it is an important aspect of quality of life and it is particularly relevant in the context of Central and Eastern Europe where situations of extreme material deprivation in institutions were reported by the media and international organisations.[87] Life in institutions is often been associated with extremely poor living conditions. Information on material well-being were collected using the Homelikeness Scale and the Quality of Living Areas Scale (Raynes et al., 1994) and generic questions on the income, spending money and personal possessions of service users (questions 76-81). The results are summarised in Table 10.15.

Significant differences were found between the three models in terms of homelikeness ($KW\chi^2 = 38.33$, df = 2, $p < 0.001$) and the quality of living areas ($KW\chi^2 = 9.47$, df = 2, $p < 0.01$). Institutions were significantly less homelike than both types of group home provision (*Mann-Whitney U* post-hoc tests, $p < 0.001$). Service users in institutions had significantly poorer living conditions – as measured by the Quality of Living Areas Scale – than individuals in independent group homes (*Mann-Whitney U* post-hoc test, $p < 0.05$) or institutional group homes (*Mann-Whitney U* post-hoc test, $p < 0.01$) – however no situations of severe material deprivation were found. Conditions in independent and institutional group homes did not differ significantly.

Another important aspect of living conditions is privacy, the number of other service users an individual has to share a room with. The number of room-mates was significantly different in the three models ($KW\chi^2 = 16.42$, df = 2, $p < 0.001$). People living in independent group homes had to share with fewer other users than people in institutions and institutional group homes (*Mann-Whitney U* post-hoc tests, $p < 0.05$). The number of people sharing one bedroom ranged between one to three in independent provision, two to five in institutions and one to four in institutional group homes. In independent group homes 30%, and in institutional provision 10% of service users had single rooms. However a fairly large proportion of individuals (25%) were sharing a bedroom with their partners. Furthermore, 30% of users shared with at least two others. There were no single rooms in institutions and 72.2% of service users had to share a bedroom with at least two other people (27.8% with at least three people).

The role of employment in services was presented in Chapter 9. All but one participant worked either in vocational rehabilitation or

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[87] See for example: http://news.bbc.co.uk/1/hi/8425001.stm (Last accessed: 31/01/2010)

developmental-preparatory work. This was also reflected in their monthly income. The majority of service users – 75% in institutions and independent group homes (n = 20), and 100% (n = 15) in institutional group homes – had a net monthly income of more than 60,000 forints, the equivalent of the net minimum wage at the time of the survey. Similarly, the majority of participants were reported to have savings. This might be linked to guardianship; guardians often see their main role as safeguarding the financial situation of people with intellectual disabilities, i.e. saving money.

Despite the similar financial situation of users, there were significant differences between the three groups in terms of their monthly spending money ($KW\chi^2 = 13.23$, df = 2, $p < 0.01$). Service users in independent group homes had significantly less money to spend than people in institutional provision (*Mann-Whitney U* post-hoc tests, $p < 0.01$). The reason is unclear, one possible explanation might be more contact with parents who might buy what the individual needs (i.e. clothes, snacks, mobile phone top-ups, CDs etc.), while in institutional provision these expenses come from user's own income.[88] Another possible reason is the higher fees in independent group homes that might leave users with less disposable income.

In terms of personal possessions, there were significant differences in the number of service users who had their own furniture ($\chi^2 = 8.35$, df = 2, $p < 0.05$). Nearly all users (95%, 19 persons) in independent group homes, 70% (14 persons) in institutional group homes and just over half (55%, 11 persons) in institutions had their own furniture. This was also reflected in the homelikeness and quality of living areas scores. There were no significant differences in the number of users who had different electrical devices such as televisions, DVD players, CD players etc. These were quite common in all types of provision. However significantly more people had mobile phones in group homes (45-50%) than in institutions (15%) ($\chi^2 = 6.17$, df = 2, $p < 0.05$). All users had their own clothes, including underwear and outer clothing.[89]

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[88] The relationship between family contact and spending money was significant (*Mann-Whitney U*-123.500, $p < 0.01$) however this might be a spurious relationship because the majority of people who had parental contact lived in independent group homes.

[89] Patterns in the total sample were similar with regard to personal possessions. There was one service users who did not have own outer clothing and seven users who did not have own underwear. They were among the most disabled services users (SABS mean score 30.6 and ABC mean score 62.9).They all lived in institutions where they represented 11.7% of service users.

Table 10.15 Material well-being in the matched group

	Institution	Indep GH	Inst GH	Sig (test)
Homelikeness				
Homelikeness Scale*	21.70	13.05	12.85	< 0.001 (*KW*); df = 2; 38.33
Living areas				
Quality of living areas**	62.20	67.45	69.75	< .01 (*KW*), df = 2; χ^2=9.47
Rooms				
	N = 18	N = 20	N = 20	
Mean no. of roommates	1.94	0.75	1.40	< 0.001 (*KW*); df = 2; χ^2=16.42
range	1-4	0-2	0-3	
Resident income/month				
% (n) with an income	N = 20	N = 20	N = 15	
> 60,000 HUF	75 (15)	75 (15)	100 (15)	invalid
41,000-60,000 HUF	20 (4)	25 (5)	-	
21,000-40,000 HUF	5 (1)	-	-	
	N = 20	N = 19	N = 18	
Mean spending money (HUF, monthly)	13,900	6,600	13,700	< 0.01 (*KW*), df = 2; χ^2 = 13.230
	N = 20	N = 19	N = 15	
% (n) has savings	80.0 (16)	78.9 (15)	100.0 (15)	invalid
Personal possessions, % (n)				
	N = 20	N = 20	N = 20	
furniture	55.0 (11)	95.0 (19)	70.0 (14)	< 0.05 (*Pears.*χ^2), df = 2; 8.35
fridge	15.0 (3)	5.0 (1)	10.0 (2)	ns
television	50.0 (10)	45.0 (9)	70.0 (14)	ns
computer	0.0	15.0 (3)	5.0 (1)	ns
DVD player	15.0 (3)	20.0 (4)	35.0 (7)	ns
CD player	45.0 (9)	30.0 (6)	50.0 (10)	ns
mobile phone	15.0 (3)	45.0 (9)	50.0 (10)	< 0.05 (*Pears.*χ^2), df = 2; 6.17

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant.

*Higher scores indicate less homelike environment.

**Higher scores indicate better quality living conditions.

10.2.5 *Community participation*

To collect information on the community participation of service users the Index of Community Involvement (Raynes, Wright et al. 1994) was used (questions 57-58). The results are summarised in Table 10.16.

Overall, community participation was relatively low and there were significant differences between the three groups (*$KW\chi^2$* = 16.56, df = 2, p <0.001).[90] People living in independent group homes accessed more community facilities than people in either institutions (*Mann-Whitney U* post-hoc test, p <0.01) or institutional group homes (*Mann-Whitney U* post-hoc test, p <0.001). The latter two groups had similar levels of community involvement. The significant difference between independent and institutional group homes suggests that there might be other factors influencing community involvement:

- The location of the settings. Villages or rural towns lack opportunities for community involvement not only for people with intellectual disabilities but for everyone. Service users living in towns had significantly higher levels of community involvement (Mean score = 4.8, N = 35) than people who lived in a village (Mean score = 3.5, N = 23), (*Mann-Whitney U* = 266.500, N = 58, p <0.05).[91] While half of the service users in institutions and institutional group homes lived in villages, the same share was only 15% in people in independent group homes.
- The instrument gives relatively high weight to areas directly linked to family contact – four out of 16 questions assume some sort of family or external contact. It has been shown that people living in independent group homes had significantly more contact with their families than people in the other two types of provision. Indeed, there was a significant difference between the community participation of people with and without family contact (*Mann-Whitney U*=204.000, N = 60, p <0.01). People who were in contact with their family had a higher community participation score (5.17, n = 36) than those who had no family contact (3.21, n = 24).

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[90] Scores for the full sample were: institutions = 2.17; independent group homes = 5.87; institutional group homes = 3.33).

[91] The mean score for people living in a city was 7.5 (n = 2).

Table 10.16 Community participation in the matched groups

	Institution	Indep GH	Inst GH	Sig (test)
Participation				
	N = 20	N = 20	N = 20	
Index of Community Involvement*	3.85	6.15	3.15	< 0.001 (*KW*); df = 2; 16.56
	N = 20	N = 19	N = 18	
% (n) been on a holiday	75 (15)	100 (19)	94.4 (17)	Invalid

Note. GH=group home; *KW*=Kruskal Wallis.

*Maximum score: 16, higher scores indicate more community participation.

The number of people who had been on a holiday in the previous 12 months was by-and-large similar in the three models (75-100%) and the statistical tests did not give significant results.

10.2.6 Engagement

Two instruments were used to measure meaningful engagement in daily activities: the Index of Participation in Domestic Life (Raynes et al., 1994) in question 69, and the Engagement in Meaningful Activities and Relationships - EMACR (Mansell and Beadle-Brown 2005). The PDA measures involvement in everyday chores such as cleaning, washing up, ironing, food-shopping etc. The results are summarised in Table 10.17.

The difference between the three models was significant in terms of participation in domestic tasks ($KW\chi^2 = 8.58$, df = 2, $p < 0.05$). People living in group home settings participated in significantly more domestic tasks than people who lived in institutions (*Mann-Whitney U* post hoc tests, $p < 0.05$). Involvement in domestic tasks had different patterns in the different models. People who lived in group homes were significantly more likely to participate in including food preparation, setting tables, serving meals, cleaning kitchen and washing up than people in institutions (*Mann-Whitney U* post-hoc tests, $p < 0.05$). For example while 65% of people in independent group homes was involved in preparing meals, 95% in washing up, and everybody helped in the kitchen (e.g. setting the table, serving meals etc.), in institutions only 20% of individuals participated in food preparation and around 50% helped in the kitchen (some of them were paid to do so as part of vocational rehabilitation). The differences between people living in institutions and institutional group homes were significant in the areas of shopping for food and supplies, cleaning the kitchen and the living room, and gardening (*Mann-Whitney U* post-hoc tests, p <0.05). People who lived in institutional group homes were more likely to do gardening and cleaning the bathroom than their peers in independent group homes (*Mann-Whitney U* post-hoc tests, p <0.05).

There were no gender differences in terms of participation in domestic tasks; although female users had slightly higher scores (mean score: 14.11, N = 28) than male users (mean score: 11.34, N = 32), these differences were not significant.

Levels of participation in activities of daily living were lower in institutions and comparable in group homes to those put forward by studies in the UK; Beadle-Brown et al. (2008) and Mansell et al. (2003) reported average percentage scores of 45-50% for UK community-based residential homes, however it should be noted that their service users had more severe disabilities.

Direct momentary-time sampling observations using EMACR were carried out in most services (on difficulties, missing data and other issues see Chapter 8). It is important to note that observations took place during December and January which might have an effect on the levels of activity observed, particularly in settings situated in rural areas. Data is available for a total of 44 service users: 12 in institutions, 12 in institutional group homes and 20 service users in independent group homes.

There were no significant differences between the three models in terms of involvement in meaningful activities and challenging behaviour. Engagement in meaningful activity ranged from 65% of time observed in institutional group homes to 71.25% institutions. These rates were comparable to levels of engagement reported by Mansell et al. (2008) – 70% – for people in community-based residential homes in the UK, however there were considerable differences in the SABS scores, with service users in Hungary being considerable more able (SABS percentage score 68-75) than service users in England (SABS percentage score 55-58).

Table 10.17 Engagement in activities in the matched groups

	Institution	Indep GH	Inst GH	Sig (test)
Domestic tasks				
	N = 20	N = 20	N = 20	
PDA*	8.95	13.80	15.15	< 0.05 (*KW*); df = 2; 8.58
PDA % score	34.4	53.1	58.3	
Engagement in meaningful activity and relationships, %				
Social activity	8.96	21.45	15.32	ns (p = 0.56)
Non-social activity	65.21	49.71	50.94	ns
Assistance	2.08	0.58	0.42	ns
Staff contact	3.54	7.88	3.33	ns
Service user contact	5.21	7.80	10.14	ns
None	28.75	28.91	26.94	ns
Missed	2.5	16.00	12.50	ns
Meaningful engagement (total)	***71.25***	***68.57***	***64.99***	***ns***
Contact (total)	***8.33***	***16.01***	***13.47***	***ns***
Challenging behaviours, %				
Self-injury	0.00	0.77	0.00	ns
Other CB	0.00	0.50	2.08	ns
Challenging behaviour (total)	***0.00***	***1.27***	***2.08***	***ns***

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant

*Higher scores indicate more involvement in domestic tasks. The maximum score is 26.

Non-social activities accounted for most of the engagement: residents were involved in non-social activities in 65.2% of the time observed in institutions, 49.7% in independent group homes and 51% in institutional group homes. Although the percentage of time spent in non-social activities was highest in institutions, the range of activities was the most limited here and it included watching television, listening to music, working and helping out in the setting, tidying up room, and eating dinner. Nevertheless, the number of people who were out in the community during observation was also the highest here, altogether 5 service users (25%) were not present in the setting (they were out playing football, seeing a girlfriend who lived in other settings or in the pub) when observations were taking place. The range of non-social activities observed in independent and institutional group home settings were by-and-large similar and included watching television, listening to music, housework (food preparation, washing up, ironing, tidying up, washing clothes etc.), eating, self-care (showering etc.) and hobbies (drawing, embroidery, feeding and playing with pets). Organised activities that aimed to develop the skills of service users were observed in two independent settings and included different games (e.g. card games and board games).

The level of social activity and contact (staff and service user) was generally low, particularly in institutions (8.9% and 8.3% respectively). Independent group homes had the highest rates of social activity (21.45%) and contact (16%), although differences between the models were not significant. The levels of staff contact were very low in institutions and institutional group homes (3.5% and 3.3%) which partly reflected the unfavourable resident to staff ratios. Assistance was observed on one occasion in each type of setting and it consisted of verbal guidance for simple activities (e.g. putting away clothes, setting table etc.). The observations of Felce, De Kock & Repp (1986) in British institutions in the mid-1980s seem particularly accurate here: they noted that institutional settings were very permissive, physical guidance was practically absent and staff did not try to encourage or discourage service user behaviours.

No incidents of challenging behaviour were recorded in institutions and very low levels of problem behaviour were observed in group home settings (two settings, on average 1.3% and 2% of time spent engaged in challenging behaviours). The behaviours observed in the independent group home included hand-biting, body rocking and jumping, while in the institutional group home setting it was a temper tantrum with verbal aggression towards staff and other residents.

Meaningful engagement was found to be associated with two factors in the evaluation literature: the quality of staff support and adaptive behaviour (Mansell et al. 2003). In addition to these, possible correlations with challenging behaviour, age and gender were tested but no significant associations were found with any of them.

The picture is quite different if the full sample is considered and not only the relatively more able service users in the matched groups. The levels of engagement in daily activities were significantly different in the three groups: people in independent group homes were significantly more involved in domestic tasks than people living in institutions (*Mann-Whitney* post-hoc test, $p < 0.001$) however they were less involved than service users in institutional group homes (*Mann Whitney* post-hoc test, $p < 0.01$).

Engagement in meaningful activities was markedly lower among participants in institutions, but the differences were not significant between the three models. There were two domains where the differences were significant: social activity and staff contact. Service users in independent group homes experienced significantly more staff contact than people in institutions or institutional group homes (*Mann-Whitney* post-hoc tests, p <0.001 and p <0.05), and people in both group home models spent significantly more time engaged in social activities than service users living in institutions (*Mann-Whitney* post-hoc tests, p <0.05). The amount of time service users spent not engaged in any meaningful activity was considerably more in institutions in the full sample (50.39% as opposed to 28.75% in the matched group).

Table 10.18 Engagement in activities in the full sample

	Institution	**Indep GH**	**Inst GH**	**Sig (test)**
Domestic tasks				
	N = 59	N = 30	N = 30	
PDA[*]	4.44	13.14	17.13	< 0.001 (*KW*); df = 2; 55.930
PDA % score	17.08	51.79	65.90	
Engagement in meaningful activity and relationships, %				
	N = 38	N = 29	N = 16	
Social activity	9.14	21.33	14.67	< 0.001 (*KW*); df = 2; 16.568
Non-social activity	41.91	49.87	60.34	ns
Assistance	1.18	0.40	0.31	ns
Staff contact	1.91	8.99	2.83	< 0.001 (*KW*); df = 2; 15.880
Service user contact	7.43	8.62	10.12	ns
None	50.39	29.17	20.53	ns
Meaningful engagement (total)	***48.82***	***68.21***	***73.41***	***ns***
Contact (total)	***9.74***	***17.40***	***12.95***	***< 0.01 (KW); df = 2; 10.19***
Challenging behaviours, %				
Self-injury	0.00	0.56	0.00	ns
Other CB	1.58	0.33	1.56	ns
Challenging behaviour (total)	1.58	0.88	1.56	ns

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant

[*] Higher scores indicate more involvement in domestic tasks. The maximum score is 26.

Significant medium effect positive correlation was found between the percentage of time spent in meaningful engagement and the quality of staff support, as measured by the Active Support Measure ($r = 0.46$, $p < 0.001$; *Spearman's*$\rho = 0.32$, $p < 0.01$) as well as adaptive behaviour ($r = 0.48$, $p < 0.001$, *Spearman's*$\rho = 0.38$, $p < 0.001$). There was a medium effect negative correlation between age and meaningful engagement ($r = -0.340$, $p < 0.01$), older people spent less time engaged in activities. There was no correlation between challenging behaviour (ABC percentage score) and engagement in meaningful activities.

10.2.7 Quality of support

The quality of support provided by staff was measured using two instruments: the Active Support Measure (ASM) (Mansell et al., 2005) and the Group Home Management Interview (GHMI) (Raynes et al., 1994). The ASM measures to what extent the principles of active support are implemented by the service. The results are summarised in Table 10.19.

There were significant differences between the three models ($KW\chi^2 = 17.27$, df = 2, $p < 0.001$). The quality of support was significantly better in independent group homes (mean score: 29.82, *Mann-Whitney U* post-hoc test, $p < 0.001$) and institutional group homes (mean score: 28.75, *Mann-Whitney U* post-hoc test, $p < 0.01$) than in institutions (mean score: 15.22). ASM scores in group homes were comparable to those reported by Mansell et al. (2008) and Beadle-Brown et al. (2008) in English services (54-65%).

The ratio of service users to staff present was high in all three models, but there were significant differences between institutions and group homes, where staff presence was somewhat more favourable ($KW\chi^2 = 22.59$, df = 2, $p < 0.001$; *Mann-Whitney U* post-hoc tests, $p < 0.001$). In contrast, Mansell et al. (2008) reported mean ratios of 1.37 and 1.22 staff in post to service users in English services.

Table 10.19 Quality of staff support

	Institution	Indep GH	Inst GH	Sig (test)
Active Support Measure				
Mean score*	15.22	29.82	28.75	< 0.001 (*KW*), df = 2; χ^2 = 17.27
range	*2-25*	*21-40*	*19-35*	
Std. deviation	*5.99*	*5.18*	*5.82*	
ASM percentage score	42.92	65.03	65.75	
Staff presence				
Ratio of residents to staff (mean)	22.98	8.00	10.45	< 0.001 (*KW*) χ^2 = 22.59, df = 2
Range	14.0-35.2	4.5-14.0	0.0-20.0	
GHMI, % score				
Mean total	41.70	12.65	12.15	< 0.001 (*KW*), df = 2; χ^2 = 39.98
Rigidity	39.30	5.40	3.60	< 0.001 (*KW*); df = 2; χ^2 = 43.23
Block treatment	33.00	15.25	11.00	< 0.001 (*KW*), df = 2; χ^2 = 39.07
Depersonalisation	34.10	19.40	14.45	< 0.001 (*KW*), df = 2; χ^2 = 43.52
Social distance	71.50	10.35	24.50	< 0.001 (*KW*), df = 2; χ^2 = 43.38

Note. GH=group home; *KW*=Kruskal Wallis; ns=not significant
*Higher scores indicate better practices, the maximum score is 45.

There was a significant negative relationship between the quality of staff support and the resident to staff in post ratio (*Pearson correlation* = -0.316, n = 44, $p < 0.05$). With the low staff levels, the presence of additional staff seems to improve the quality of support provided to service user, however some caution is necessary here. Early evaluation studies (for example Felce, Mansell, & Kushlick, 1980; Felce et al. 1986) warned that there was no linear relationship between staff ratio and resident activity and increasing staff ratios diminishing returns and no gains were realised by allocating more staff to large groups (i.e. in institutions). Instead, the organisational features of small homes accounted for the difference in staff performance.

The GHMI measures whether practices are user-centred or service-centred. Higher scores indicate more service-centred practices. It has been shown in the previous chapter as well that the three models differed significantly in terms of their practices in all dimensions ($KW\chi^2$ = 17.27-43.38, df = 2, p <0.001). Institutions had more service-centred practices, including more rigidity of routines, block treatment, depersonalisation and social distance between staff and users than group homes (*Mann-Whitney U* post-hoc tests, p <0.001). Differences between independent and institutional group homes were significant in two areas: independent group homes did worse in depersonalisation (*Mann-Whitney U* post-hoc test, p <0.01), however there was less social distance between staff and users (*Mann-Whitney U* post-hoc test, p <0.01).

10.3 Conclusion

Table 10.20 gives a summary of the main findings, the positive and negative outcomes associated with each type of provision by domain.

Table 10.20 Summary of findings by outcome domains

Domains	**Findings**
Community participation	There were significant differences in the community participation: people living in independent group homes enjoyed more community participation than people in institutions and institutional group homes. Community participation was associated with the location of the setting – lower in villages, higher in towns and cities – and family contact.
Friendships and relationships	There were no differences in the number of users reported to have friends in the three models, but people living in independent group homes were more likely to have friends outside the service as well.
Family contact	There were significant differences in family contact: people living in independent group homes were more likely to be in contact with their families than people in the other two types of provision.
Self-determination and choice	There were no significant differences in the number of people under guardianship in the three models. Guardianship was associated with severity of disability. There were significant differences in choice-making: people living in institutional group homes had more choice in everyday routine activities than people in institutions and independent group homes. Choice-making was also associated with the quality of staff support and service practices.
Material well-being	There were significant differences in the living conditions: people living in group homes had significantly better living conditions than people in institutions. Service users in independent group homes had to share bedrooms with fewer other users than

	people in institutions or institutional group homes. However, single, en-suite rooms were uncommon. There were no differences in the number of people having an income of approximately the national minimum wage or savings. However, people living in independent group homes had less spending money than users in the other two types of provision. Service users had a range of personal objects in each type of provision, including own clothes; however people living in independent group homes were more likely to have their own furniture.
Health and lifestyle-related risks	There were no differences in the number of people reporting long-term health problems in the three types of provision. There were significant differences in the number of people who were smokers: there were more smokers in institutions and institutional group homes than in independent group homes. There were no significant differences in other lifestyle risks, such as drinking, obesity and lack of physical exercise.
Psychotropic medication	There were significant differences in the number of people receiving regular anti-psychotic medication: this was highest in institutions and lowest in institutional group homes. No relationship was found between anti-psychotic medication and psychiatric illness or severe challenging behaviour. There were also significant differences in terms of psychotropic polypharmacy: it was less common in institutional group homes than in the other two types of provision.
Engagement	There were significant differences in terms of involvement in domestic activities. People living in

	independent group homes participated in more domestic tasks than people in institutions. There were no differences in terms of engagement in meaningful activity, contact and challenging behaviour between the three models. Meaningful engagement was not associated with any other factors such as adaptive behaviours and staff practices either. High levels of non-social activity and low levels of contact, particularly staff contact were found in all three types of provision.
Quality of staff support	There were significant differences in the quality of staff support: service users in independent and institutional group homes had better quality staff support than people living in institutions.

The findings suggested that smaller scale arrangements provided better individual outcomes than institutions, particularly in three areas: material conditions and living standards; living environments; and staff support. Substantial variations were found within the group home model; in some areas independent group homes provided better outcomes than institutional group homes, including community participation, relationships and participation in domestic tasks. Service users in institutional group homes had more choice over daily routine issues, andwere less likely to experience psychotropic polypharmacy.Finally, there were also considerable variations within models and some larger settings provided comparable outcomes to smaller, community-based settings in some domains, such as community participation, choice over everyday issues etc. The next chapter will discuss the findings and their policy implications in more detail.

Chapter 11 Discussionand Final Conclusions

This dissertation set out to explore policy change together with the challenges and outcomes of deinstitutionalisation and community-based care in Hungary. Previous research on deinstitutionalisation focused on English-speaking countries such as the United Kingdom and the United States. Analysis in these countries showed that implementation depends on the local context; however there is limited understanding of how local circumstances influence implementation in other countries where progress is slow and institutions seem resistant to change. The dissertation aimed to address this gap and sought to answer the following questions: Is residential policy changing in Hungary? What is the direction of this change? Is it a transition from institutions to community-based care? What makes institutions so resistant to change in Hungary? What are the characteristics of the alternative arrangements? Do community-based settings provide similar outcomes to service users as in other countries where deinstitutionalisation and community-based care is well advanced? Itlooked at two areas for answers: the societal and policy context of institutions and community living, and the characteristics and quality residential services and revealed some important issues that help to understand the different dynamics of residential care and policy change. This chapter discusses these issues together with the limitations of the thesis and formulates some policy lessons and recommendations.

11.1 What are the outcomes of community-based arrangements in Hungary?

The field work confirmed that smaller-scale community-based arrangements have similar advantages to those in other countries.The initial hypothesis that smaller scale arrangements provide better outcomes was confirmed. There were no benefits associated with institutional provision in any of the quality of life domains. There were advantages associated with smaller scale, community-based group homes but considerable variations were found within the group home model.In some areas, such as community participation, relationships and involvement in domestic tasks, independent group homes provided better outcomes than institutional group homes.Service users living in institutional group homes on the other hand,had more choice over daily routine issues and were less likely to experience psychotropic polypharmacy.There were also considerable variations within models and some larger settings provided comparable outcomes to smaller, community-based settings in some domains, such as community participation, choice over everyday issues etc.

How do these findings compare to international experiences? Do smaller scale community-based settings in Hungary provide similar benefits to their users as those reported elsewhere? Are these "good enough" outcomes? Do people with intellectual disabilities living in residential settings have an "acceptable quality of life" (Emerson and Hatton, 1994)?

The outcomes above seem consistent with patterns reported by international reviews (Emerson & Hatton, 1994; Noonan Walsh et al. 2007) and those put forward in Chapter 3 in that 1) smaller scale arrangements are superior to large, congregate settings in most areas of quality of life; 2) there is considerable variability in individual outcomes based on individual and service characteristics; 3) there are some areas, such as psychotropic medication, where community-based services do not provide better outcomes. Hungarian services also seem to have the weaknesses of community-based services reported elsewhere, particularly the re-emergence or survival of institutional care practices (Mansell 1996; Mansell & Ericsson 1996; Mansell 2005). It is also true that smaller size and ordinary environments do not guarantee high quality service, available activity, staff support and service design are key determinants of outcomes in Hungary as well (Felce, 1998).

It has also been shown that people in Hungarian services experienced worse outcomes than – more severely disabled – service users in residential homes in the United Kingdom in a number of areas. They

- experienced higher levels of psychotropic medication;
- had less choice over everyday aspects of their lives;
- used less community-based facilities;
- spent less time engaged in domestic tasks and meaningful activities.

11.2 What makes institutions and institutional practices so resistant to change?

Mansell and Ericsson (1996) offer various explanations for the re-emergence or continuation of institutional care practices in community-based services. One set of explanations focuses on implementation issues. They argue that the survival of institutional care practices is the result of weak implementation, "the implementation process becomes bureaucratic and proceduralized". (p. 248) They also suggest that institutional practices in community-based services may reflect the failure of people responsible for planning and managing services to understand "the relationship between the quality of service user lifestyle, patterns of staff performance and management and organization of the service". They highlight that decision-makers often "focus on too limited a set of issues (e.g. concern about buildings and locations) and, when they have achieved what they want in these areas they neglect to follow-through on other, less immediately obvious issues" (p. 249). The other approach proposes that the problems are linked to the old institutional ideology surviving in community-based services. It is argued that decision-makers might not be committed "to improving services above a tolerable level" (ibid. idem.) and they also suggest that the outcomes of services might also be linked to the way society treats people with intellectual disability.

These arguments offer useful approaches to explain the failure of community-based services to deliver quality of life outcomes superior to institutions, and thus provide the "unequivocal evidence" that community services are better for everyone, all of the time" (Mansell, 2006). Chapter 9 showed that services in Hungary are very strictly regulated including the number of residents, staff and the features of the building, some of which restrict the possibilities of services. The findings of this evaluation suggested that the regulatory and policy environment is inadequate to provide the appropriate context (Felce, 1998) for services to achieve high quality user outcomes, even for service users with limited support needs. The focus of decision-makers on limiting the resources of services and thus keeping the quality of services just above "a tolerable level" but failing to recognise the real issues, such as the quality of staff support and care practices has a clear impact on service provision and quality of life. Chapter 9 also highlighted that substantial resources went into the development of institutional infrastructure; although this improved material standards, it had no impact on the quality of care.

The relatively weak performance of services in Hungary should also be interpreted in the broader societal context. Social values are an important factor in shaping service provision. It was also shown in Chapter 7 that people with intellectual disabilities are a marginalised group – in other words, they are not valued members in the society. They are effectively excluded from decision-making over important aspects of their lives and they are deprived of the rights of ownership and political participation through the institution of guardianship. There is an inherent contradiction in trying to promote values in services that are not part of the societal and policy context. The right of people with intellectual disability to live in the community is not recognised, institutions still enjoy considerable legitimacy and their philosophy survives in community-based settings as well. For example four out of six managers in independent group homes participating in the study disagreed with the statement that "all people with intellectual disabilities could be supported to live in small, community-based settings instead of institutions."

Institutions are at the intersection of different policy areas and Chapter 7 showed that the dynamics of the policy system work in favour of institutions too. The lack of non-residential alternatives in the community, including the scarcity of day supports and the exclusion of people with intellectual disabilities from the labour market encourages the use of residential provision, mainly institutions. At the same time there is a concentration of services in residential settings. Institutions and group homes were found to be major providers of employment and support services. This is an ‘all-or-nothing’ situation: those using residential provision have access to a variety of other, non-residential services, while those living at home have very limited access to supports they need to live in the community. High levels of poverty and social exclusion were found among families caring for individuals with an intellectual disability. Although poverty was not found to be associated with the out-of-home placement, the results suggest that many people with intellectual disabilities experience social exclusion in the community. The failures of child protection and social housing policies to support vulnerable groups, such as the Roma, provide a constant demand for residential care among young adults who made up a sizeable group of service users in state-run group home provision.

It is also important to compare the quality of life outcomes of people using residential services and those living with their families in the community. In the absence of adequate data these comparisons are very limited.Nevertheless some tentative findings might be highlighted here. Using the data from the 2007 national survey of the living conditions of people with intellectual disabilities, it emerges that people with moderate intellectual disabilities who lived with their families[92] in the community also experienced poor, in some respects inferior quality of life outcomes than those living in residential settings. For example:

- Many of them lacked the opportunity to make their own decisions and their families controlled their income: 44% were under guardianship.
- They were socially isolated: 54.2% were reported to have no friends and 40% had no opportunity to spend time in a peer group.
- Many of them lived in poverty: 27% lived in absolute poverty (the per capita income in the family was less than the national minimum

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[92] People aged 18 or over were included in the comparison who were reported to have “mild” or “moderate” intellectual disability, and had limited support needs defined as “can be left alone for a few hours” (n = 145). The average age of selected participants was 26.7 years, somewhat younger than the service user sample (33-36 years). Nearly 98% of them could feed independently and 89% were verbal. The number of people with autism and epilepsy was somewhat higher in this group (12.6% and 24.5% respectively) than in the service user sample, however comparable to the independent group home user sub-sample. Just over 90% were reported to have no or mild challenging behaviour.

pension)[93] and 11.6% said that their income was not enough to buy food.

- Housing conditions were poor: 40% of these adults had to share a room with at least one other family member and 18.6% of the families had no bathroom in their home (house or flat).
- Many people faced similar obstacles to community participation to those living in institutions and institutional group homes: 39% lived in villages.
- Only 14.4% had a job.
- Most people lacked meaningful daytime opportunities[94]: self-care and eating accounted for most of their daily activities – 57.7% of people were reported to spend at least four hours engaged in these activities. Doing nothing was also very common, 70.4% of people were reported to "do nothing" for at least some length of time, over 35% spent at least four hours alone in passivity. Forty-six percent of people were reported to have no social activity and 65% were not engaged in any housework or other work. Twenty-six percent had access to training/education/day programme, but only 11% of the total for more than six hours a day.

The situation of people with intellectual disability living in the community provides a strong legitimacy for institutions because there is a sizeable group of people who are perceived to have a "better life" in residential settings – even in poorer quality services and institutions.

11.3 What are the dynamics of policy change?

Is there a transition from institutions to community living? What are prospects of large scale deinstitutionalisation in Hungary? The analysis in Chapter 6highlighted a path-dependent pattern of policy change in which structural forces prevented major change and suggested that this is unlikely to come from domestic sources. It identified a potential source of policy change in the form of policy transfer resulting from external pressures, particularly the UN Convention on the Rights of Persons with Disabilities and the expectations of the European Commission.

The United Nations Conventions on the Rights of Persons with Disabilities makes the unjustified segregation of people with disabilities in congregate settings a violation of human rights and calls on states to

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[93] Twenty-six thousand Hungarian forints/month in 2007, equivalent to approximately 90 British pounds.

[94] Respondents (mainly parents) were asked to describe a typical day of the individual using 2-hour time-slots between 6am and 24pm (nine slots in total). These were then classified into the following categories: sleeping, self-care/eating, none (alone and doing nothing), social activity, work, housework, exercising, commuting, playing, attending training/college/day programme.

take "effective and appropriate measures" to facilitate full enjoyment of this right, the full inclusion and participation of people with disabilities in the community (Article 19). The Convention, potentially, provides an instrument that can transform the way laws and policies are made as well as their content by imposing obligations on governments and empowering people with disabilities to take part in the democratic process (Quinn, 2009). Hungary ratified the Convention as well as the Optional Protocol and thus agreed to "lay down a positive dynamic of change that will lead to results within a reasonable time frame" (page number not available). It also accepted a complaints mechanism that enables the UN Committee on the Rights of Persons with Disabilities to investigate individual and group complaints. However international law has its limitations and any potential impact is mitigated by the domestic political and policy context. In the words of Quinn (2009) "there is no transmission belt to ensure that the fresh air of international law can reach into and revive the domestic reform process". To facilitate the implementation of the Convention it prescribes certain coordination mechanisms. The Hungarian Government designated the National Council on Disability Affairs to act as "focal point" for implementation. The Council's marginal role in shaping disability policy, make it unlikely that it can initiate major policy change in a highly complex area such as deinstitutionalisation. Similarly, the prospect of a policy transfer motivated by the pursuit of Hungary's international acceptance is rather unlikely in the current political and economic context. Resistance to deinstitutionalisation and the perceived cost of community-based care outweigh the symbolic benefits associated with compliance and any negative consequences of non-compliance by the Government. Whether this can change in the future depends on the international implementation of the CRPD, particularly the role of the Committee on the Rights of Persons with Disabilities and the Conference of States parties.

The other possible driver for change is the European Commission. The EU's ratification of the Convention in 2010 has the potential to influence the legislative proposals and the policies of the European Commission, although only if the EU has legal competence in a given area. In social inclusion this is rather limited because the EU relies on the Open Method of Coordination (OMC), a non-legislative mode of policy making and governance. The OMC aims to alter the domestic policy context by changing the beliefs and expectations of policy actors and thus lead to the convergence of policy outputs across the EU (Porte, 2002). Structural Funds support the implementation of the EU's common objectives. Although long-term residential provision is virtually absent in the OMC, the European Regional Development Fund finances investment in social infrastructure in the new Member States. At the moment this money is used to renovate old and build new institutions in Hungary, however the European Commission seems reluctant to intervene in an area that is considered the competence of Member States, instead it uses persuasion and other "soft" mechanisms. The success of this strategy remains to be seen, particularly in a domestic political environment characterised by increasing opposition to dictates "from Brussels or anywhere else".[95] Whether the European Commission will align the regulation of the Structural Funds, particularly the European Regional Development Fund and the European Social Fund, with the principles of the CRPD is unclear yet. The Structural Funds are politically and economically high profile instruments in the New Member States, therefore such a move would put new impetus into the process of deinstitutionalisation and the development of community-based care in Central and Eastern Europe. For now, institutions for people with intellectual disabilities are deeply embedded in the policy system.

In 2007 the international project Deinstitutionalisation and Community Living: Outcomes and Costs (Mansell et al. 2007) put forward an agenda for governments planning to implement deinstitutionalisation. Their recommendations centred around four themes. First, strengthening the vision of new possibilities in the community among others by adopting policies and legislation in favour of inclusion, strengthening the voice of people with disabilities, their families and advocates in the policy process, and learning from best practices in other countries. Second, sustaining public dissatisfaction with current institutional arrangements among others by opening institutions to independent scrutiny and emphasising comparisons of quality of life. Third, creating some practical demonstrations of how things can be better by creating innovative services and including people with severe intellectual disabilities and complex needs from the start.And finally, reducing resistance to change by managing incentives for different actors in the process among others by creating new funding opportunities and removing obstacles to the development of community-based services.

Although these recommendations are generally relevant in the Hungarian context, this research has revealed specific issues that explain why institutions have been so resistant to reform and highlighted some policy implications. Despite the many similarities between the institutions of 1960s and 1970s in the English speaking countries and the current institutional provision in Hungary, there are some very important differences between the socio-political context of institutions, the facilities and the institutional population. Hungary experienced the rise of poverty, social exclusion and discrimination after the collapse of

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[95] Retrieved from: http://blogs.wsj.com/new-europe/2011/03/16/hungary-pm-rejects-diktats-from-brussels/?mod = google_news_blog (last accessed: 02/01/2012).

the Communist regime. Institutions are typically located in villages and in disadvantaged local areas where the majority of the population experiences poverty and often extremely poor living conditions. A sizeable proportion of service users are people with mild and moderate intellectual disabilities who come from the child protection system, many of them Roma thus experience the double stigma of intellectual disability and ethnic minority status.

Effective deinstitutionalisation policies therefore need to address the broader policy context and take action in a number of other areas. First, they need to reduce the demand for institutional provision by creating support systems for parents and families of children with intellectual disabilities to help them remain in the community, particularly ensuring equal access to education, reforming the child protection system to prevent the out-of-home placement of children with disabilities and disadvantaged children and supporting young people leaving care to live independently, and last but not least separating residential and non-residential services and ensuring equal access for all people with intellectual disabilities to non-residential services.

Second, the Government must combat poverty and social exclusion of people with intellectual and disabilities and their families through changes to the benefit system and employment supports. Third, the Government together with advocacy organisations and organisation of disabled people should increase awareness of the human rights of people with intellectual disabilitiesand present institutions and deinstitutionalisation as a human rights issue. Fourth, the the attention in the policy debate should shift from the infrastructure of provision to individual outcomes and quality of staff support and create a favourable policy context for community-based provision. Community-based alternatives to institutions already exist but they fail to achieve their full potential because of the rigid regulatory environment and the lack of resources. Although they achieve better overall outcomes than institutions, this is not strong enough to make the case for the replacement of institutions with community-based provision. Finally, independent policy advocacy and entrepreneurship should be strengthened. Advocacy organisations are weak and divided on the issue of deinstitutionalisation. Some of them are reluctant to oppose government policies because they are dependent on state funding which can be reduced or withdrawn.

The findings of this thesis also have some implications for international organisations and countries that already made the transition from institutions to community-based care. Countries in the first wave of deinstitutionalisation should initiate policy transfer and promote good practices of community-based care.Policy transfer can be a powerful driver of policy change, however successful transfer is constrained by a number of factors including the complexity of issues, access to information, resources and administrative structures in the receiving country. Policy transfer can also fail if it is based on insufficient information or key elements are left out in the transfer process. Successful policy transfers in Hungary were initiated by the source country and were characterised by their active involvement, including the provision of resources.

It should also be recognised that different models of care co-exist within Europe with differing degrees of institutional provision in Germany, Austria, the Netherlands and France (IDRES Network 2003; Mansell et al. 2007). These countries seem to exert a greater policy influence on the countries of Central and Eastern Europe due to historical/cultural reasons than the countries in the first wave that are often perceived as different and distant. The discourse on deinstitutionalisation and community-based care should shift from Central and Eastern Europe towards a more general and global approach.Most of the media and policy attention has so far concentrated on Central and Eastern Europe, which together with the former Soviet Union has probably the largest institutional population and the poorest quality provision. Nevertheless, institutions also exist elsewhere, including Western Europe, but they are rarely the focus of international policy debates. This hinders the process of deinstitutionalisation in two ways: firstly legitimises institutions and secondly, implying that the process is mainly about infrastructure, the size and quality of buildings.

Deinstitutionalisation therefore should be a global agenda with an emphasis on the human rights of people with intellectual disabilities. The UN Convention has a crucial role in this process. Countries that have already made the transition from institutions to community-based care should take the leadership in the implementation of Article 19 and the European Commission should make sure that its policies are aligned with the Convention and the Structural Funds can no longer be used to modernise institutions.

11.4 Limitations and future research

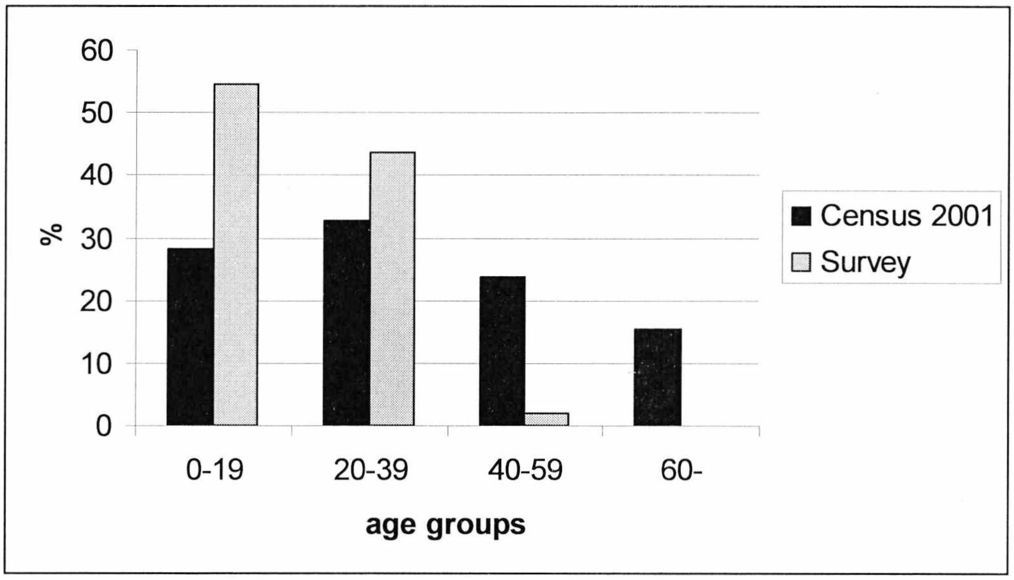
The dissertation had a number of limitations in terms of its research design and data. The analysis to a large extent relied on official statistics and administrative data sources whose accuracy and reliability could not be assessed. It also used data collected as part of another research project, the *Survey on the living conditions of people with intellectual disabilities* in 2007. The design of this survey had a number of weaknesses that must be taken into account when interpreting the results:

- The age of the sample. The sample was considerably younger than the population with intellectual disabilities (see Figure 11.1). The oldest participant was 50 years old. This is due to the fact that Expert and Rehabilitation Committees started to assess children in the 1970s, therefore older generations are not found in their database.
- The questionnaire did not use established measures of adaptive and challenging behaviours but it recorded the levels reported by proxy respondents. This might have compromised the validity and reliability of data. It is also impossible to make comparisons with other studies.
- The use of proxy respondents is a common practice in intellectual disability research and they have been considered as a reliable source of information on objective living conditions (Umb-Carlsson & Sonnander 2006). However, respondents were very heterogeneous for people living in residential settings. While for those who lived with their families 88% of the respondents were the mother or the father, 7% other relative and 5% others, in the case of people living in institutions, 29% of the respondents were one of the parents, 3% other relative, 29% care worker and 39% other (e.g. head nurse, director of the institution etc.) This might have impacted on the accuracy of the information because parents might not have adequate information on living conditions in the residential setting and staff often knew very little about users' family background.
- As a result of inadequate training or confusing questionnaire layout proved there was a large amount of missing data for participants in residential care.
- There was no information on the reliability of the data.

The field work used measures developed in other countries without formally validating them. This decision was justified by the limited resources and time scale of the research. Although the experiences of the field work suggested that the measures were valid and culturally appropriate in the Hungarian context, the results should be interpreted with caution.

The inter-rater reliability of observational measures collected in the field work could not be adequately assessed due to the design of the project. The sample size was relatively small, particularly the number of services in Sample 1 and the matched groups of Sample 2, and it did not allow more complex statistical tests (e.g. 3-way *ANOVA* etc.) to detect multifaceted relationships between variables. Also on a number of occasions statistical tests proved invalid due to small sample size and therefore significant relationships might have been missed.

Figure 11.1 Population with intellectual disability by age groups, %



The selection of measures has focused on a fairly limited set of relatively widely used instruments, however excluded others. In hindsight, using more standardised instruments on social networks and relationships, health- and lifestyles would have added value to the analysis of individual outcomes and strengthened the comparability of findings to international research.

The research depicted the quality of life outcomes of a fairly restricted group of service users. The participants selected for the subsamples were significantly less disabled than the average service users in institutions – the individuals in non-matched group. These service users were significantly more disabled (*Mann-Whitney U* = 86.000, n = 60, p <0.001) and had more challenging behaviour (*Mann-Whitney U* = 261.000, n = 60, p <0.05) than those in the matched group. They also experienced worse outcomes in the main outcome domains than their less disabled peers living in the same settings, namely:

- They had less choice over routine daily issues (Mean score: 34.25, *Mann-Whitney U* = 209.000, n = 60, p <0.01);
- They had less opportunity to participate in domestic activities (Mean score: 2.13, *Mann-Whitney U* = 128.500, n = 59, p <0.001)
- Had less access to community facilities (Mean score: 1.32, *Mann-Whitney U* = 120.00, n = 60, p <0.001)
- They spent less time engaged in meaningful activities (Mean engagement: 38%, *Mann-Whitney U* = 90.000, n = 38, p <0.05) and longer time doing nothing (60.8% of their time, *Mann-Whitney U* = 91.000, n = 38, p <0.05). Staff contact accounted for 10% of the time, mainly associated with personal care.

- They experienced poorer quality staff support (Mean ASM score: 13.2, *Mann-Whitney U* = 80.000, n = 49, $p < 0.001$).

Further research would be necessary to explore the quality of life outcomes of people with severe and profound intellectual disabilities and complex support needs.

Finally, the dissertation focussed on a single coutry and comparisons with outcomes in other countries are very tentative and limited. They only indicate possible differences that should be explored even further with wider cross-sectional studies designed for this purpose.

This dissertation hopefully contributed to a clearer understanding of the situation of people with intellectual disabilities and the policy dynamics of residential care in Hungary. Nevertheless, it was just a first step and it left many areas unexplored. It did not provide any information on the relationship between costs and individual outcomes. Future research should concentrate on exploring and comparing the costs of different residential arrangements. There was also very limited information on the quality of life outcomes of people with severe intellectual disabilities. The experiences and satisfaction of service users were another unmapped area of this research where further investigation is necessary. Finally, although there seem to be many similarities in the situation of Central and Eastern European countries, it needs to be explored to what extent these experiences are comparable and what the main differences are across countries.

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Annexes

Annex 1 Translated Questionnaire for the 2007 Survey

Respondent: mother/father/sibling/other relative/carer/other

1. Composition of the family where the Individual lives or lived before moving to the institution. List all persons who live together with X. (Relationship to X, gender, age, education, activity (i.e. working, retired, on benefit etc.), (last) job)

2. Does X have any siblings who no longer live with the family? Please list them.

3. Does any of the siblings have a disability? If yes, which sibling and what disability?

4. What is X's ethnicity?

5. Where does the family live?

6. Who owns the property where the family lives? (own, council, private rent etc.)

7. Type of the dwelling: detached house, flat etc.

8. Size of the flat

9. How many rooms are there?

10. Does X have his/her own room? If not, who does X share with?

11. Is there a bathroom?

12. Did you have to move because of X? If yes, why?

13. Is there anything in the layout or furnishing of the house/flat that makes everyday life and care for X and the family more difficult? If yes, what?

14. Did you refurbish the flat because of X's special needs? If yes, what were the alterations?

15. What are the regular income sources of the family? Wage, unemployment benefit, old-age pension, disability pension, disability benefit, child care benefit, carer's allowance, family allowance, social welfare benefit, disability allowance, other

16. What was the total net income of the family last month?

17. Is your income enough for

	Not enough	Barely enough	Enough	Don't spend on this	I don't know
food					
clothing					
leisure					
education					
Special needs of X					

18. How much do you spend on housing? (bills, mortgage if applicable etc.)

19. Do you have any expenses related to X's needs? How much did you spend on the following things last year? Medication, medical treatment, aids, special food, diapers, childcare, therapy, holiday, transport?

20. Is there anything that would be necessary for X but you can't afford it? What is this? How much would it be?

21. How would you describe your family's situation? Not poor, sometimes, from some aspects poor, totally poor.

22. How would you describe your family's situation before X was born?

23. What do you think, your situation in the coming years will improve/stay the same/deteriorate?

24. Have you ever heard about the following benefits? Have you ever applied for any of them? Have you received any of them?

25. Taking everything into account, have you ever decided not to apply for a benefit even though you thought you were eligible/entitled? If yes, wh?

26. Has it ever happened that you applied for a benefit but did not get it? If yes, why?

27. Do you know any of these professionals in your area? Are you in contact? Are you satisfied with them? Nurse, paediatrician, psychologist, orthopedagogue, social worker, priest, association, voluntary organisation

28. Did you use any social services last year? If yes, how often and what? If not, why not?

30. Who noticed X's problem first? Parent, member of the family, friend/neighbour, nurse, doctor, child minder etc.

31. How old was X then?

32. When was X first diagnosed?

33. Where was he diagnosed? Ante-natal clinic, maternity hospital, GP, assessment committee etc.

34. What was the diagnosis?

35. Who informed you about the diagnosis? (nurse, doctor, psychologist etc.) Who else was present? Where did it happen? In what manner?

36. Did you receive any information regarding available benefits and supports? If yes, what were you told?

37. Has anyone else in the family had a learning disability? If yes, what and who?

38. What is the height and weight of X?

39. Does X have any other impairments?

	No	Mild	Moderate	Severe
Physical impairment				
Visual impairment				
Hearing impairment				
Speech impairment				
Challenging behaviour				
Autism				
Other				

40. How many times was X ill last year? At home? Hospitalised?

41. Is X on regular medication (excluding vitamins and food supplements)

42. Does he have epilepsy?

43. Can X eat independently?

44. Does X need any special food?

45. Does X have any problems with eating?

46. Can X walk?

47. Self care skills of X

48. Does X do the following independently or with support: eating, toileting, getting dressed, showering, getting around in the house, getting around in the street.

49. What describes best X's communication skills?

50. How did you choose your GP? (If X was turned down by local GPs)

51. Has X ever been to the dentist? If not, why not?

52. List the aids used by X (list)

53. Does X get adequate medical treatment?

54. Have you ever experienced any of the following in the past 5 years? Direct/indirect discrimination, negative comments, other

55. Has X ever been declined medical treatment because of his/her disability? If yes, please elaborate!

56. What type of early development services did X receive up to the age of 5 years? (list of different services/therapies)

57. How old was X when she/he was first assessed by the Assessment Committee? What was the outcome? Did you agree or did you appeal? Why?

58. What kind of education did X receive, when and where? (list of different options)

60. Did X change schools? If yes, why?

61. Are you satisfied with her/his education?

62. Do you get enough information on X's progress?

63. Does X have vocational qualification? If yes, what?

64. Is X employed?

65-82. Questions on employment

83. Does X have an ID card?
84. Is X under guardianship?
85-92. Questions on guardianship

93-110. Questions were not answered for people in institutions.

93. Who has the closest relationship with X in the family? How would you describe X's relationship with their siblings?

94. Are you in regular contact with any of your relatives? (at least once a month)

95. Do you have any relatives or neighbours you can rely on? (no, relative, neighbour, friend, colleague, other person)

96. Can you discuss issues/feelings related to X's upbringing with anyone? (no, relative, neighbour, friend, colleague, professional, other person)

97. Do you attend a support group, meet other parents?

98. Did you have more friends before X was born or now?

99. Does X have friends outside the family?

100. Does X have the possibility to be in an informal peer group?

101. Does X have a relationship? If not, does he/she express wishes for a relationship? If yes, please tell us more about it.

102. Please, describe X's daily routine. (Time, activity, who supports X)

103. Have you been on holiday together in the past two years? (No, own holiday house, with relatives, in a hotel, resort in Hungary, abroad, other) Has X been on holiday elsewhere?

104. When was the last time when you went

	Last month	In the past 2-12 month	Longer
To the cinema			
To the theatre			
To a restaurant:			
To visit friends			

105. If you for any reason won't be able to take care of X, who can you rely on?

106. Have you ever considered placing X in an institution? If not, why not, if yes, where and why?

107. Are you member of an advocacy group/organisation?

108. Is any of you religious? Do you regularly go to church?
109. Have you ever experienced stigma or discrimination against X? what was this? Tell us a few examples.

110. What is your biggest problem at the moment?

Institutional questionnaire

111. Type of institution, size, provider.

112. Where is it?

113. How long has X been here?

114. Where did X live before? (family, another residential institution, don't know) What was the reason of institutionalisation?

115. How long X can stay here?

116. Does X have any external contacts? Frequency and type of contact.

117. Does X have friends in the institution?

118. Does X have a relationship? If yes, is it in the institution? Is it long term? Do they have the possibility to be on their own? Did X receive any sexual education?

119. How would you describe X's relationship with staff?

120. How many room mates does X have?

121. Do they have conflicts? (no, occasionally minor conflicts, regularly minor conflicts, serious and frequent conflicts)

122. What have you done to manage/mitigate conflicts?

123. The decoration of the room

	X's own	**Institution's**	**Someone else's**
furniture			
Other material goods			
Personal objects			

124. Did X have a say in the decoration of the room? (it's not possible, she/he is not able, does not care, had ideas, his/her decision)

125. Can X have a say in what to wear?

126. What services are provided by the institution:

	On site	**Off site, segregated**	**mainstream**
GP			
Dentist			
Specialist medical care			
Physiotherapy etc.			
Development, education			
Employment			
Sport			
Culture			
Religion			
Hairdresser			
Other:			

127. Can X leave the institution to go out to shops etc? (no, can't get around independently, no, rules don't allow it, yes, with staff, yes, independently)

128. Can X manage his/her own money? Can X buy clothes, food, or other goods? (no, other buy everything for X, yes, with support, yes, independently)

Annex 2 Fieldwork Measures

Service measure

General questions

1. Name of the facility:

2. Type of provision:

- Care home ☐
- Rehabilitation home ☐
- Care group home ☐
- Rehabilitation group home ☐

3. Provider:

- County Council ☐
- City Council ☐
- Church ☐
- State ☐
- Independent ☐
- Other: ☐

4. Year of establishment:

5. Buildings and facilities

Please, list all the buildings that belong to the institution. Include group homes and any workshops, sports facilities etc even if they are not used for accommodating residents. *(If necessary, you can insert additional rows in the table or continue at the end of the questionnaire.)*

Building 1:	
Location	On-site Off-site but same village/town/city Other village/town/city
When was it built?	
Is it purpose-built?	Yes No Original purpose:
Number of residents (if used for residential purpose)	
Number of rooms (if used for residential purpose)	
Building 2:	

Location	On-site Off-site but same village/town/city Other village/town/city
When was it built?	
Is it purpose-built?	Yes No Original purpose:
Number of residents (if used for residential purposes)	
Number of rooms (if used for residential purposes)	
Building 3:	
Location	On-site Off-site but same village/town/city Other village/town/city
When was it built?	
Is it purpose-built?	Yes No Original purpose:
Number of residents (if used for residential purposes)	
Number of rooms (if used for residential purposes)	
Building 4:	
Location	On-site Off-site but same village/town/city Other village/town/city
When was it built?	
Is it purpose-built?	Yes No Original purpose:
Number of residents (if used for residential purposes)	
Number of rooms (if used for residential purposes)	
Building 5:	
Location	On-site Off-site but same village/town/city Other village/town/city
When was it built?	
Is it purpose-built?	Yes No Original purpose:

Number of residents (if used for residential purposes)	
Number of rooms (if used for residential purposes)	

6. Type of registration:

Temporary ☐ Please, specify until which year:
Permanent ☐
None ☐

7. Total number of registered places:

8. Types of places

If relevant, please provide a breakdown of registered places by type (e.g. for elderly people, people with mental health problems etc.)

Type of place	Number of places

9. Did the number of places change since 2003?

☐ No
☐ Increased, please indicate by how many places:
☐ Decreased, please indicate by how many places:

10. If the number of places increased, please indicate where this happened:

☐ In the main buildings of the institution
☐ In group home in the community
☐ In group home on the site of the institution
☐ Other, please specify:

11. What is the size of bedrooms?

Minimum: persons
Maximum: persons

12. What is the size of care units?

Minimum: persons
Maximum: persons

13. Capital Investments

Please list any capital investments – new building, renovation, refurbishment – above the value of UF 10,000,000 (£ 30,000) since 2003 using the below grid. *(You can add rows if necessary or continue at the end of the questionnaire.)*

Purpose of investment 1:	
Year	
Total cost	
Source of funding	provider state aid grant own resource other (please, specify):
Purpose of investment 2:	
Year	
Total cost	
Source of funding	provider state aid grant own resource other (please, specify):
Purpose of investment 3:	
Year	
Total cost	
Source of funding	provider state aid grant own resource other (please, specify):

Questions on service users

14. Total number of residents:

15. User groups

If relevant, please provide a breakdown of residents by main user groups (e.g. for elderly people, people with mental health problems etc.)

Type of place	Number of places

16. Number of residents by gender:

Male:
Female:

17. Number of residents by age

Under 18 years:
19-39 years:
40-59 years:
Over 60 years:

18. Number of residents by type of disability (primary disability):

Intellectual disability
Physical disability
Sensory impairment
Mental health problem:
Other (pl. dementia, substance abuse etc.)

19. Number of residents by severity of intellectual disability:

Mild:
Moderate:
Severe/profound:

20. How many residents have challenging behaviour[96]?

Moderate:
Severe:

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[96] Challenging behaviour refers to behaviour that puts the physical safety of the person or others in jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities.

Questions on staff

21. Total number of staff:

22. Number of staff by gender
Male:
Female:

23. Number of staff by category
Manager:
Nurse:
Support worker (non-health qualification):
Orthopedagogue:
Psychologist:
Teacher:
Vocational therapist:
Speech and language therapist:
Physiotherapist:
Leisure coordinator:
General practitioner:
Psychiatrist:
Social or mental health worker:
Auxiliary (finance, administration, maintenance):

24. Number of staff (excluding auxiliary staff) with relevant qualifications:

25. Staff training
What training has been provided for staff in 2007? Please also include individuals who are studying towards relevant qualifications if this is supported by the institution. If necessary, continue on additional sheets.

Training (subject)	Duration	Number of participants

26. Number of unfilled posts/vacancies:

27. Number of staff that has left since January 2008:

28. How many of these posts were filled?

Financial situation of the institution

29. Revenues and expenditures

Please present the revenues and expenditures of the service for the financial year of 2007. Where possible provide numbers by settings. *(If necessary, you can add columns to the table or continue at the end of the questionnaire.)*

Revenues	Total	Setting 1	Setting 2	Setting 3
Fixed-sum state subsidy				
Additional state funding (i.e. from provider)				
Income from fees				
Grants				
Other income (e.g. from renting out property etc.)				
Total revenues:				

Expenditures	Total	Setting 1	Setting 2	Setting 3
Staff costs				
Payments for residents				
Running costs				
Investment (capital + goods)				
Other expenditure				
Total expenditure				

Questions on services

30. Type of services provided
Which of the following services are available for your residents and where the service is provided.*(Tick the appropriate box.)*

1=Onsite by staff of the institution
2=Onsite by external staff
3=Offsite, specialised service
4= Offsite, mainstream, community-based service
5= Not available

	1	2	3	4	5
Medical doctor					
Dentist					
Social work					
Orthopedagogue					
Psychologist					
Occupational therapist					
Speech & language therapist					
Physiotherapist					
Special school					
Education					
Work/vocational rehabilitation					
Information, advocacy					
Other (please specify)					

31. Therapy services
Please list all the therapy services (e.g. physiotherapy etc.) available to your residents, including whether it is provided on-site or in the community, the number of people using them and the frequency. (If necessary, continue on a separate sheet.)

Therapy service	On-site/off-site	Frequency	Number of users

If the service does **NOT** provide employment, please go to question 36.
If the service organises employment for residents, please answer questions 32-35.

32. Who organises employment?
The institution ☐
Outsourced to a company ☐
Other, please specify ☐

33. How many residents take partin:[97]

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[97] "Vocational therapy" and "vocational rehabilitation" are categories defined by the law.

Vocational therapy on site:
Vocational therapy outside the service:
Vocational rehabilitation on site:
Vocational rehabilitation outside the service:

34. What type of jobs are carried out by people in vocational therapy?

35. What type of jobs are carried out by people in vocational rehabilitation?

36. Number of residents in mainstream employment:

37. Does the institution provide special education?

Yes ☐
No (please go to Question 39) ☐

38. How many pupils does the special school have?

39. How many of the pupils

Live in the institution:
Live with their families:

40. Does the organisation have a support service?

Yes ☐
No ☐

41. Do residents have individual development plans?

Yes ☐
Some of them ☐
No ☐

42. Are residents involved in individual planning?

Yes, all of them ☐
Yes, some of them ☐
No ☐

43. How often are these reviewed?

Every 6 months ☐
Once a year ☐
Less than once a year ☐
Never ☐

44. Do residents have an individual timetable of activities?

Yes ☐
No ☐

Some of them ☐

45. Are residents involved in choosing the activities they do?

Yes, all of them ☐
Some of them ☐
No ☐

46. Number of residents under guardianship:

Medication and the treatment of challenging behaviour

47. Number of residents on regular medication:

48. Number of residents taking regular medication in these categories:

Antiepileptics:
Psycholeptics:
Psychoanaleptics:
Contraceptives:

49. Who prescribes the medicines?

50. Are there any difficulties in getting the prescribed medications?

Yes ☐
No ☐

If your answer is **<u>YES</u>**, please explain briefly why:

51. Are medications used to control residents' behaviour?

Yes ☐
No ☐

52. Restraint

Please indicate the measures that are used in the facility to control challenging behaviour *(tick all that applies):*

Sedation ☐
Seclusion ☐
Physical restraint ☐
Mechanical restraint☐

No restraint ☐

53. Are there written procedures for using restraint?

Yes ☐
No ☐

54. Do staff receive training in restraint?
Yes ☐
No ☐

55. Does the facility use cage beds?
Yes ☐
No ☐

56. Does the facility have a seclusion room?
Yes ☐
No ☐

57. Additional comments

If you have any additional comments or you would like to continue your answers to any of the questions, please use this space:

End of Service Questionnaire

THANK YOU!

MANAGEMENT PRACTICES INTERVIEW

(ALL questions asked as open question and coded according to answer.)

What time did residents get up yesterday?

Do the residents get up at the same time at weekends as they do during the week?

☐ Different times for everybody on both Saturdays and Sundays
☐ Different times for some, or on 1 day only
☐ Same time

What time was breakfast?

Is it always at that time?

☐ 2 Always
☐ 1 Different on specified days:
☐ 0 Different on weekends

Where is breakfast eaten? Is this the same for all meals? Is this the same for everybody?

What do residents do between dressing and breakfast? Can they go and have breakfast without having to wait for others?

☐ 2 They are occupied
☐ 1 Some wait doing nothing
☐ 0 Everybody waits doing nothing

Did anyone **leave the building** yesterday to go out to school or work? How many went, what time did they leave and what time did they return?

What did people who were left in the institution do during the day?

☐ Showering and toileting
☐ Watching TV
☐ Table activities
☐ Sitting about
☐ Seeing professionals (for therapy)
☐ Seeing parents
☐ Going for walks
☐ Games/reading/listen to radio
☐ Sleeping
☐ Other.

How did residents get to work/school?

☐ Private bus
☐ Public transport
☐ Walk
☐ Other:

Do residents travel together?

- ☐ 2 All in one group
- ☐ 1 Mixed pattern
- ☐ 0 No more than 3 in a group

How many residents work or attend a day programme in the institution?

What happened after people returned and before dinner?

What time was dinner?

Is it always at that time?

- ☐ 2 Always
- ☐ 1 Different on specified days:
- ☐ 0 Different on weekends

What happened after dinner yesterday?

How many residents had a bath yesterday?

Are there set times when the residents have their baths?

- ☐ 2 Yes all scheduled
- ☐ 1 Some scheduled
- ☐ 0 individual choice

How do staff assist residents at showering/bath times?

- ☐ *0 One staff member for each resident*
- ☐ *1 Mixed pattern*
- ☐ *2 Conveyor belt system*

What time did residents go to bed last night? Between

Do they always go to bed at that time?

- ☐ 2 Always
- ☐ 1 Different on specified days:
- ☐ 0 Different on weekends
- ☐ Other

Are the residents wakened for toileting at night?

- ☐ 2 All residents
- ☐ 1 Some residents
- ☐ 0 None

20. What rules are there about quiet times (e.g. use of TV etc)?

- ☐ 2 Strictly scheduled
- ☐ 1 Some time rules
- ☐ 0 Residents' own discretion

What is the curfew time for residents to be in the house at night?

Is it the same every night?

- ☐ 2 Yes
- ☐ 1 Yes, except specified nights
- ☐ 0 None

Is it the same for all residents?

- ☐ 2 Yes all
- ☐ 1 Yes, except for specified people
- ☐ 0 No, or none

Is the house door ever locked?

If yes, how many residents have their own keys?

- ☐ 2 None
- ☐ 1 Some
- ☐ 0 All

Are there set times when visitors can come?

- ☐ 2 Certain days only
- ☐ 1 Any day, but set times
- ☐ 0 Any time

When can friends visit the residence? Probe: opposite-sex friends

- ☐ 2 Certain days only
- ☐ 1 Any day, but set times
- ☐ 0 Any time

What rules are there concerning dating?

- ☐ 2 No dating allowed
- ☐ 1 Allowed under specified conditions, times (probe: rooms restricted, supervision, times)
- ☐ 0 no restrictions

When may residents use their bedrooms?

- ☐ 2 Only at bedtime or to change
- ☐ 1 Under specified conditions
- ☐ 0 Any time

30. When may residents use the kitchen?

- ☐ 2 Not at all
- ☐ 1 Under supervision, specified times
- ☐ 0 Any time

Are there restrictions on the use of any other area of the residence? Please explain what areas are restricted.

- ☐ 2 Certain areas restricted always
- ☐ 1 Certain areas restricted certain times
- ☐ 0 No restrictions

Where do the residents keep their clothes?
- ☐ 2 Communal storage
- ☐ 1 Shared storage
- ☐ 0 Private storage

How many of the residents have personal possessions other than clothes of their own, e.g. books, radio, games?
- ☐ 2 None
- ☐ 1 Some
- ☐ 0 All

What is done with these items?
- ☐ 2 Kept but now allowed to use
- ☐ 1 Used but become communal
- ☐ 0 Used and shared at owner's discretion

How many of the residents have clothes of their own?
- ☐ 2 None
- ☐ 1 Some
- ☐ 0 All

What is done with the clothing a resident brings into the institution?
- ☐ *0 Kept and used by residents*
- ☐ *1 Used only on visits or special occasions*
- ☐ *2 Not used or not allowed*

Are residents allowed pictures, photographs, posters or religious icons in their rooms?
- ☐ *0 Yes, in all rooms*
- ☐ *1 In some rooms*
- ☐ *2 No*

Who shops for residents' clothing and personal articles?
- ☐ 2 Staff only
- ☐ 1 Staff and certain residents
- ☐ 0 Residents only (with support)

How many residents have bank accounts?

How is the banking handled?
- ☐ 2 Staff only for all
- ☐ 1 Staff and certain residents
- ☐ 0 Residents only
- ☐ Other

How are meals planned at the residence?
- ☐ 2 Staff only
- ☐ 1 Staff and certain residents
- ☐ 0 Residents only Instead: All residents with staff support

☐ Other

Who shops for food?

☐ 2 Staff only or delivery
☐ 1 Staff and certain residents
☐ 0 Residents only

Do residents participate in household chores?

☐ 2 None
☐ 1 Some
☐ 0 All

How are the household chores allocated (e.g. beds, vacuuming etc.)?

☐ 2 Staff decide who will do what
☐ 1 Staff and certain residents
☐ 0 Residents decide

How often are parties or social events held in the residence?

Who organises parties?

☐ 2 Staff only
☐ 1 Staff and certain residents
☐ 0 Residents only

Do staff invite their friends and relatives to parties too? How often do friends and relatives of staff visit?

☐ 2 Rarely
☐ 1 Sometimes
☐ 0 Frequently

Do staff have a chance to eat with residents at meals?

☐ 2 Seldom, usually supervise during meals
☐ 1 Some staff, sit but don't eat
☐ 0 All staff frequently

How are tables laid for meals?

☐ *0 Tables laid for all residents*
☐ *1 Tables laid for some residents*
☐ *2 Not laid, food and cutlery handed out by staff*

Do residents watch TV as a group in the evenings? Do staff get a chance and watch shows with them?

☐ 2 Seldom, usually supervise only
☐ 1 Someone sometimes does
☐ 0 Someone usually does

How are birthdays celebrated?

☐ 2 Joint parties/no recognition
☐ 1 Mixed pattern
☐ 0 individual parties, presents

Can a resident have a pet?

- ☐ 2 None allowed
- ☐ 1 Common only
- ☐ 0 Individual pets allowed

What hobbies, crafts etc. do the residents enjoy?

How much time do the residents have each day (on average) for hobbies or other leisure pursuits they choose themselves?

- ☐ 0 At least 30 minutes a day
- ☐ 1 At least 15 minutes a day
- ☐ 2 None

Do the staff work on these with them sometimes?

- ☐ 2 Rarely
- ☐ 1 Someone sometime does
- ☐ 0 someone usually does with at least some residents

Residents' rights

1. Is there a User Council in the institution? (*If answer is NO, jump to question 7*)

2. How are its members elected?

3. How often do they meet?

4. What support do they get from staff?

5. What issues do they discuss?

6. Are they regularly consulted by the Management? If yes, please give an example.

7. How were the "House Rules" drafted?

8. How are residents informed about their rights and the house rules?

9. Does the User Rights Representative visit regularly? What does he/she do in the institution?

10. Are there policies/mechanisms to detect and report abuse or neglect? Are they written?

11. Is there a complaint procedure for residents?

The Observable Indicators of Nursing Home Care Quality Instrument

1. Were the conversations between staff and residents friendly?
    - ☐ 1 Most were not
    - ☐ 2 A few were
    - ☐ 3 Some were
    - ☐ 4 Many were
    - ☐ 5 Most were

2. When staff talked to residents, did they call them by name?
    - ☐ 1 Most did not
    - ☐ 2 A few did
    - ☐ 3 Some did
    - ☐ 4 Many did
    - ☐ 5 Most did

3. Did residents and staff acknowledge each other and seem comfortable with each other (for example, smile, eye contact, touch, etc.)?
    - ☐ 1 Most did not
    - ☐ 2 A few did
    - ☐ 3 Some did
    - ☐ 4 Many did
    - ☐ 5 Most did

4. Did residents and staff interact with each other in positive ways (for example, conversation, humour, touch, eye contact, etc.)?
    - ☐ 1 Most did not
    - ☐ 2 A few did
    - ☐ 3 Some did
    - ☐ 4 Many did
    - ☐ 5 Most did

5. Did staff appear caring (compassionate, warm, kind)?
    - ☐ 1 Most did not
    - ☐ 2 A few did
    - ☐ 3 Some did
    - ☐ 4 Many did
    - ☐ 5 Most did

6. Did staff treat residents as individuals with dignity and respect?
    - ☐ 1 Most did not
    - ☐ 2 A few did
    - ☐ 3 Some did
    - ☐ 4 Many did
    - ☐ 5 Most did

COMMUNICATION SUB-TOTAL: ☐

7. Were registered nurses (RNs) visible? (Look at name badges of staff to identify RNs. May need to ask staff.)
    - ☐ 1 Rarely seen
    - ☐ 2 Occasionally
    - ☐ 3 Sometimes
    - ☐ 4 Often
    - ☐ 5 Very often

8. Did registered nurses (RNs) seem to know the residents so that they are able to direct their care? (May need to ask staff)
    - ☐ 1 Did not seem to
    - ☐ 2 Occasionally
    - ☐ 3 Sometimes
    - ☐ 4 Often
    - ☐ 5 Very often

9. Did staff help residents with food or fluids?
    - ☐ 1 Rarely seen
    - ☐ 2 Occasionally
    - ☐ 3 Sometimes
    - ☐ 4 Often
    - ☐ 5 Very often

10. Were residents walking or independently moving about the facility with or without assistive devices such as canes, walkers, wheelchairs?

- ☐ 1 Rarely seen
- ☐ 2 Occasionally
- ☐ 3 Sometimes
- ☐ 4 Often
- ☐ 5 Very often

11. Were staff helping some residents walk or move about the facility?

- ☐ 1 Rarely seen
- ☐ 2 Occasionally
- ☐ 3 Sometimes
- ☐ 4 Often
- ☐ 5 Very often

12. Did staff communicate with confused residents in positive ways (for example, talk, touch, sit with, etc.)?

- ☐ 1 Rarely seen
- ☐ 2 Occasionally
- ☐ 3 Sometimes
- ☐ 4 Often
- ☐ 5 Very often

CARE DELIVERY SUB-TOTAL:

13. Were residents dressed and clean?

- ☐ 1 Most were not
- ☐ 2 Some were
- ☐ 3 Many were
- ☐ 4 Most were
- ☐ 5 All were

14. Were residents well groomed (shaved, hair combed, nails clean and trimmed)?

- ☐ 1 Most were not
- ☐ 2 Some were
- ☐ 3 Many were
- ☐ 4 Most were
- ☐ 5 All were

GROOMING SUBTOTAL:

15. Were odours of urine or faeces noticeable in the facility?

- ☐ 1 Pervasive throughout
- ☐ 2 In most areas
- ☐ 3 Occasionally
- ☐ 4 Hardly at all
- ☐ 5 Not at all

16. Were other unpleasant odours noticeable in the facility?

- ☐ 1 Pervasive throughout
- ☐ 2 In most areas
- ☐ 3 Occasionally
- ☐ 4 Hardly at all
- ☐ 5 Not at all

ODOURS SUBTOTAL:

17. Were hallways and common areas uncluttered?

- ☐ 1 Very cluttered
- ☐ 2 Frequently cluttered
- ☐ 3 Somewhat cluttered
- ☐ 4 Neat and uncluttered
- ☐ 5 Very neat and uncluttered

18. Were resident rooms, hallways, and common areas clean?

☐ 1 No apparent access
☐ 2 Occasional access with assistance
☐ 3 Some access with assistance
☐ 4 Frequent access
☐ 5 Access any time

19. Were buildings, grounds, and furniture in good condition?

☐ 1 Very poor condition
☐ 2 Poor condition
☐ 3 Fairly good condition
☐ 4 Good condition
☐ 5 Very good condition

20. Were the hallways well lighted?

☐ 1 Poorly lighted
☐ 2 Some light but not enough
☐ 3 Moderately lighted
☐ 4 Well lighted
☐ 5 Exceptionally well lighted

21. Were resident rooms well lighted?

☐ 1 Poorly lighted
☐ 2 Some light but not enough
☐ 3 Moderately lighted
☐ 4 Well lighted
☐ 5 Exceptionally well lighted

ENVIRONMENT BASICS SUBTOTAL:

22. Did confused residents have a safe place to wander indoors? (May need to ask staff.)

- ☐ 1 No apparent safe place
- ☐ 2 Very small
- ☐ 3 Small
- ☐ 4 Moderate
- ☐ 5 Large safe place

23. Did confused residents have a safe place to wander outdoors? (May need to ask staff.)

- ☐ 1 No apparent safe place
- ☐ 2 Very small
- ☐ 3 Small
- ☐ 4 Moderate
- ☐ 5 Large safe place

24. Did confused residents have access to outdoor space? (May need to ask staff.)

- ☐ 1 No apparent access
- ☐ 2 Occasional access with assistance
- ☐ 3 Some access with assistance
- ☐ 4 Frequent access
- ☐ 5 Access any time

25. Did other residents have access to outdoor spaces? (May need to ask staff.)

- ☐ 1 No apparent access
- ☐ 2 Occasional access with assistance
- ☐ 3 Some access with assistance
- ☐ 4 Frequent access
- ☐ 5 Access any time

ENVIRONMENT ACCESS SUBTOTAL:

26. Were residents' rooms personalized with furniture, pictures?

- ☐ 1 Most were not
- ☐ 2 A few were
- ☐ 3 Some were
- ☐ 4 Many were
- ☐ 5 Most were

27. Were there pets (dogs, cats, birds, etc.) and/or live plants in the facility?

- ☐ 1 None or rarely seen
- ☐ 2 Occasionally
- ☐ 3 Sometimes
- ☐ 4 Often
- ☐ 5 Very often

28. Were the pets and/or live plants in good condition?

- ☐ 1 None seen or very poor condition
- ☐ 2 Fair condition
- ☐ 3 Average
- ☐ 4 Good
- ☐ 5 Very good condition

29. Was there a home-like appearance about the facility?

- ☐ 1 Not at all home-like
- ☐ 2 Somewhat
- ☐ 3 Moderately
- ☐ 4 Quite home-like
- ☐ 5 Very home-like

30. Were visitors visible in the facility (family members, volunteers, community members, etc.)?

- ☐ 1 Rarely seen
- ☐ 2 Occasionally
- ☐ 3 Sometimes
- ☐ 4 Often
- ☐ 5 Very often

ENVIRONMENT HOMELIKE SUBTOTAL:

DOMAIN	**BELOW Range**	**MEAN Range**	**ABOVE Range**
Communication	7-22	23-28	29-30
Care Delivery	6-17	18-25	26-30
Grooming	2-6	7-8	9-10
Odour	2-6	7-8	9-10
Environment-Basics	10-18	19-21	22-25
Environment- Access	4-12	13-16	17-20
Environment-Homelike	6-14	15-21	22-25
TOTAL SCORE	56-103	104-127	128-148
PROCESS Questions 1-14, 22-30	37-76	77-97	98-114
STRUCTURE Questions 15-21	14-26	27-30	31-35

INTERPRETATION:
A SCORE EQUAL TO OR ABOVE 128 SUGGESTS A QUALITY NURSING HOME.

A SCORE EQUAL TO OR BELOW 103 SUGGESTS A NURSING HOME WITH QUALITY ISSUES.

SCORES BETWEEN THESE NUMBERS ARE TYPICAL OF MOST NURSING HOMES.

Note: This Questionnaire is officially titled, “OBSERVABLE INDICATORS OF NURSING HOME CARE QUALITY” VERSION 10 (Revised - February, 2005) MU MDS and Quality Research Team © 1998, 1999, 2000, 2002, 2003, 2004, 2005

PHYSICAL ENVIRONMENT and HOMELIKENESS

Type of facility
- ☐ Institution
- ☐ Group home
- ☐ Campus-style group home

How old is the building?

Was it built specifically for this service?
- ☐ Yes
- ☐ No

Is the building located in:
- ☐ Separate road or cul-de-sac in an urban setting
- ☐ Separate road or cul-de-sac in a rural setting
- ☐ Ordinary road in an urban setting
- ☐ Ordinary road in a rural setting
- ☐ Outside any setting

Are there open areas adjacent to the building?
- ☐ Yes
- ☐ No

INSIDE THE LIVING UNIT/WARD

Eating areas

Is the dining room a central eating area for several living units? (If YES, go to question 15.)
- ☐ Yes
- ☐ No

Is the living unit dining room:
- ☐ Separate (a room specifically for eating meals)
- ☐ Kitchen/dining room combined
- ☐ Living/dining room combined

How homelike is the living unit dining room?

Very homelike				Non-homelike
1	2	3	4	5

Note:
Very Homelike would typically be a small dining area, like you might find in an ordinary family home, seating no more than 8 people. It would have family style furnishings and dishes. It would have a good material standard and the residents would eat family style.
Non-Homelike would typically be a large area, seating 25 or more people. There would be no subdivision of space. Complete meals would be taken to residents at the table, or there would be cafeteria style serving. Furniture and dishes would be for large numbers in a barren setting.

Orderliness/clutter

Messy & badly maintained				Neat & well maintained
0	1	2	3	4

Cleanliness of walls & floors

Dirty				Clean
0	1	2	3	4

Condition of furniture

Bad condition				Good condition
0	1	2	3	4

Window areas

Dirty				Clean
0	1	2	3	4

Odours

Bad smelling				Airy &Fresh
0	1	2	3	4

Living areas

How many living areas are there in the living unit/ward? ....

How many people use each living area? ....
....

How homelike is the main living area?

Very homelike				Non-homelike
1	2	3	4	5

Note:
Very Homelike would be like a typical family home. The furniture would be comfortable and like you would find in a family home. It would be of a good material standard, and there would be personal touches.
Non-Homelike would be large and poorly furnished. The furniture would be designed for use by large numbers. There would be no, or only a few, personal touches.

Do the living areas have:

- ☐ Occasional tables/coffee tables
- ☐ Armchairs
- ☐ Couch/settee
- ☐ Bookshelves
- ☐ Cupboards
- ☐ Television
- ☐ Radio
- ☐ Curtains/blinds
- ☐ Waste bins

Orderliness/clutter

Messy & badly maintained				Neat & well maintained
0	1	2	3	4

Cleanliness of walls & floors

Dirty				Clean
0	1	2	3	4

Condition of furniture

Bad condition				Good condition
0	1	2	3	4

Window areas

Dirty				Clean
0	1	2	3	4

Odours

Bad smelling				Airy &Fresh
0	1	2	3	4

Bathrooms

How many bathrooms are there in the living unit/ward? ....
....

How many bath tubs are there in the living unit/ward? ....
....

How many showers areas are there in the living unit/ward? ....
....

How homelike is a typical bathroom?

Very homelike				Non-homelike
1	2	3	4	5

Note:
Very Homelike would be typical of a bathroom found in a private home - including elements which are typical of a bathroom in the country of research (for example,

bath, sink, toilet etc.). Residents would have personal towels and toiletries. There would be personal touches such as plants etc.
Non-Homelike would be a large bathroom, for use by several people at the same time. There would be no provision for privacy, or personal storage for toothbrush, shampoo etc.

Are there waste bins in the bathroom/s?
- ☐ Yes
- ☐ No

If the living unit has a solarium, or any other 'extra' facilities, please note them here:

Do the showers have:
- ☐ No partitions or doors/curtains
- ☐ Partitions only
- ☐ Partitions and doors/curtains

Please tick here if there are no showers on the living unit/ward:
☐

Do the bathtubs have:
- ☐ No partitions or doors
- ☐ Partitions only
- ☐ Partitions and doors/curtains, or separate rooms

Please tick here if there are no bathtubs on the living unit/ward:
☐

Does/do the bathroom/s have the following:
- ☐ Sluicing slabs
- ☐ Hand basins
- ☐ Mirrors
- ☐ Toilet paper (if toilets in bathroom)
- ☐ Toilets

How many toilets are there in the living unit/ward? ....
....

Are the toilets separate from the bathrooms?
- ☐ Yes
- ☐ No

Do the toilets have:
☐ No partitions or doors

☐ Partitions only
☐ Partitions and doors

Do the toilets have toilet paper?
☐

Orderliness/clutter

Messy & badly maintained				Neat & well maintained
0	1	2	3	4

Cleanliness of walls & floors

Dirty				Clean
0	1	2	3	4

Condition of furniture

Bad condition				Good condition
0	1	2	3	4

Window areas

Dirty				Clean
0	1	2	3	4

Odours

Bad smelling				Airy &Fresh
0	1	2	3	4

Bedrooms/Sleeping areas

How many bedrooms/sleeping areas are there in the living unit/ward?

How many beds are there in each bedroom/sleeping area?

Min: .... – Max: ....

How homelike is a typical bedroom/sleeping area?

Very homelike				Non-homelike
1	2	3	4	5

Note:
Very Homelike would be no more than one adult per room. There would be private cupboards. The room would be of good material standard and have personal touches. Floors/floor coverings would be like those found in a private home. There would be evidence of activities other than sleeping -for example, books, desk, comfortable chair.
Non-Homelike would mean four or more adults per room. There would be minimal furnishings, with furniture designed for use by large groups. The room would be crowded, with no personal cupboards, or just a locker. There would be no, or few, personal possessions. The room would just be used for sleeping.

Were the floors/floor coverings suitable for a sleeping area?
☐ Yes
☐ No

Did the bedrooms/sleeping areas have curtains/blinds?
☐ Yes
☐ No

Did the beds have suitable bedding?
☐ Yes
☐ No
Did the beds have bedspreads?
☐ Yes
☐ No

Were there personal photographs or paintings on the walls?
☐ Yes
☐ No

Were there posters or other non-resident art on the walls?

- ☐ Yes
- ☐ No

Were there murals?

- ☐ Yes
- ☐ No

Orderliness/clutter

Messy & badly maintained				Neat & well maintained
0	1	2	3	4

Cleanliness of walls & floors

Dirty				Clean
0	1	2	3	4

Other areas in the living unit/ward

Does the living unit/ward have the following:

- ☐ Rooms for storing residents' clothing?
- ☐ A laundry?
- ☐ A kitchen?

IF YES, does the kitchen have the following?

- ☐ Washing machine
- ☐ Dryer
- ☐ Cabinets to store dishes
- ☐ Refrigerator
- ☐ Stove/Cooker
- ☐ Hotplate
- ☐ Dishwasher
- ☐ Drinking fountain

Orderliness/clutter

Messy & badly maintained				Neat & well maintained
0	1	2	3	4

Condition of furniture

Bad condition				Good condition
0	1	2	3	4

Window areas

Dirty				Clean
0	1	2	3	4

Odours

Bad smelling				Airy &Fresh
0	1	2	3	4

Cleanliness of walls & floors

Dirty				Clean
0	1	2	3	4

Condition of furniture

Bad condition				Good condition
0	1	2	3	4

Window areas

Dirty				Clean
0	1	2	3	4

Odours

Bad smelling				Airy &Fresh
0	1	2	3	4

Did the living unit have an office?

- ☐ Yes
- ☐ No

Other rooms or facilities?

- ☐ Yes
- ☐ No

OUTSIDE THE LIVING UNIT/WARD

Garden or yard attached to the living unit/ward

Does the living unit/ward have a yard or garden for the residents/patients?

- ☐ Yes
- ☐ No

Is there a shared yard/garden/grounds, which residents of this living unit can access?

- ☐ Yes
- ☐ No

If the living unit has a yard or garden, is the yard/garden enclosed?

- ☐ Yes
- ☐ No

How homelike is the yard/garden?

Very homelike				Non-homelike
1	2	3	4	5

Note:

Very Homelike would be well landscaped, with flowers, shrubs and trees. There would be garden furniture/equipment available, appropriate to the age of the residents/patients.

Non-Homelike would have no landscaping, grass or concrete only. There would be no outdoor furniture or equipment, or it would be inappropriate for the age of the residents. The yard/garden would be poorly maintained.

MANAGER QUESTIONNAIRE

This questionnaire is intended to explore your opinion about the institution, the challenges of your daily work and your attitudes towards community living.

1. How long have you been managing this facility?

2. What was your previous post?

3. What is your qualification?

4. How would you describe the physical conditions of the institution?
   Good ☐
   Acceptable/Average ☐
   Poor ☐

5. How would you describe the quality of care/service you provide?
   Above average ☐
   Acceptable/average ☐
   Below average ☐

6. Which statement describes best the financial situation of your institution?

Bad, hardly enough to cover running and staff costs, no money left for service development (including minor renovations, staff training etc.).
☐

Acceptable, revenue covers running and staff costs but no money left for service development.
☐

Good, revenue covers expenditure and there is funding available for development.
☐

7. What do you think are the 3 most important factors in providing quality services for PWID. *(Mark in order of preference, 3=most important, 1=less important)*

Factor	Rank (1-3)
Staff commitment	
Staff qualification	
Enough funding	
Good relationship with the community	
Good location	
Good physical conditions	
Organisation/management	
Other	

8. What do you think are the biggest challenges in your everyday work? *(Mark in order of preference, 3=most important; 1=less important)*

Issue	**Rank (1-3)**
Keeping up with administrative and reporting requirements towards authorities	
Dealing with authorities	
Recruiting or keeping staff	
Dealing with internal conflicts among staff	
Managing staff	
Ensuring the everyday operation of the institution (financial problems)	
Dealing with relatives	
Reforming current provision	
Dealing with problems/conflicts among residents	
Other	

9. How satisfied are you with the following factors:

	Very satisfied	**Somewhat satisfied**	**Not satisfied nor dissatisfied**	**Somewhat dissatisfied**	**Very dissatisfied**
Regulations					
Funding arrangements					
Amount of funding					
Resources for human/capital investment					
Inspection arrangements					
Methodological support					

10. If you could change two things in the environment, what would they be?

1: ☐ 2: ☐

11. How do you see the role of the following organisations?

Organisation	**Irrelevant**	**Negative (hinders work)**	**Neutral**	**Positive (helps work)**
Ministry of Social Affairs and Labour				
County council				
Local council				
Methodological Institution				

12. Please define here what you understand by the term “normalisation”? (Max 1-2 sentences)

☐

13. Please read the following statements and tick the appropriate box:

	Strongly agree	**Slightly Agree**	**Slightly disagree**	**Strongly Disagree**
Institutions are an adequate form or provision for PWID.				
All PWID are capable of living in the community.				
PWID should be given the opportunity to make decisions on where and with whom they want to live.				
PWID are better off in the institutions than in the community.				
PWID have the right to live like everyone else in the community.				
PWID usually like living in an institution.				
Only people with mild intellectual disability are capable to live in the community, therefore there will always be a need for institutions.				

End of Manager Questionnaire
THANK YOU!

QUESTIONNAIRE ON SERVICE USER NEEDS, CHARACTERISTICS AND INVOLVEMENT

The following booklet contains three **sections**. This questionnaire should be completed for **each resident** who has been selected and has **given their consent** to take part in the study. There will be a **maximum of six** such residents in each group home, or a maximum of 12 such residents in institutions.

If you have any questions, please contact Agnes Kozma on 06306583888

Please read each question carefully and follow the instructions regarding how many options to tick.

- ***Section one*** gathers information about the needs and characteristics of the resident including a challenging behaviour scale and questions on health and lifestyle.
- ***Section two*** is a questionnaire called the *Index of Community Involvement*
- ***Section three*** is a brief questionnaire on participation in daily life and choice making.

To make sure that results are comparable I need to use the same questionnaire in group homes and institutions as well. Therefore some of the questions might seem less relevant. However, it is essential that you complete the full questionnaire and do not skip questions.

The information you provide in this questionnaire is completely confidential and will only be used for academic purposes. Where the information from the questionnaire is included in a report or published paper, it will be done in a way that preserves the anonymity of all concerned.

One member of staff should complete this questionnaire about the resident. I need your name so that I can come back to you if I have any questions. I will not store or use your name for any other purpose.

Informants name:

Date completed:

From now on the information we ask you for is about the resident

Date of birth (YYYY/MM/DD):

Place of birth: (if you don’t know it, please leave it blank)

Gender:
- ☐ Female
- ☐ Male

Additional Impairment (tick all that apply)
- ☐ Physical disability
- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ Speech impairment
- ☐ Mental health impairment
- ☐ Autism
- ☐ Epilepsy
- ☐ Other (please specify): ....

Please list all the services this person uses in the facility or organised by the service:

Section 1: User needs and characteristics

Understanding the people that services support is important and has many implications for the skills and knowledge staff need to develop and for the level and type of support services should provide to meet those needs and provide a good quality of life. It is also important to know whether people who have taken part in this research are like other people living in services and to find out whether things are different for people with different characteristics.

Please read the information on the following page carefully and then complete Section 1.

Instructions:

Please note the following general rules:
1. Items that specify "with help" or "with assistance" for completion of the task refer to direct physical assistance.

2. Give credit for an item if verbal prompting or reminding is needed to complete the task, unless the item definitely states "without prompting" or "without reminder".

These questions are about what the person can do rather than what they want to do or have the opportunity to do.

There are **five types of questions in the questionnaire**:

The **first** asks you to tick only the highest level shown by the person concerned. For example:

Q11 Eating in public*(Tick highest level)*

- ☐ Orders complete meal in restaurants
- ☐ Orders simple meals like hamburgers or fish and chips
- ☐ Orders single items e.g. soft drinks, ice cream etc. at a stall or canteen.
- ☐ Does not order in public eating places

Tick the ***one*** statement that best describes the most difficult task /activity the person can usually manage.

The **second** type of question asks you to read each statement and tick each activity/task the person can usually do. For example:

Q21 Other Domestic Activities*(tick all that apply)*

- ☐ Washes dishes well
- ☐ Makes bed neatly
- ☐ Helps with household tasks when asked
- ☐ Does household tasks routinely
- ☐ Can load and use the dishwasher
- ☐ Can use small electrical kitchen appliances

For these questions, tick **as many boxes** that apply to person on whom you are focusing.

The **third type** of question is Question 30, **Possible Problem Behaviour**. Here you are asked to rate the person's behaviour for the last **FOUR WEEKS**. For each item, decide whether the behaviour is a problem and tick the appropriate box:

None = not a problem at all
Slight = the behaviour is a problem but slight in degree
Mod = the problem is moderately serious
Severe = the problem is severe in degree

When rating this person's behaviour, please keep the following points in mind:
a) Take relative *frequency* into account for each behaviour. For example, if the person averages more temper outbursts than most other service

users you know, it is probably moderately serious or severe even if these occur only once or twice a week. Other behaviours such as "refuses to co-operate" would probably have to occur more frequently to merit an extreme rating.

b) If you have access to this information, consider the experiences of other care providers. If the person has problems with others but not with you, try to take the whole picture into account.

c) Try to consider whether a given behaviour interferes with the person's development, functioning, or relationships. For example, body rocking or social withdrawal may not disrupt others, but it most certainly hinders individual development or functioning.

The fourth type of question is a simple multiple-choice question where your are required to tick the answer that applies to the person. For example:

NNN. How often does this person take exercise?

- ☐ Several times a week
- ☐ Weekly
- ☐ Less than weekly but more than once a month
- ☐ Less often than monthly
- ☐ Never
- ☐ Not applicable (e.g. service user is bedfast)

The **fifth type** of question is open-ended and you need to answer it with your own words. The answer is usually short, a few words. For example:

NNN. Please list the names of medication he/she takes regularly:

Do not spend too much time on each item - your first reaction is usually the right one.

Q1 Communication: Use of verbal language (*Tick highest level*)

- ☐ Verbal
- ☐ Partially verbal
- ☐ Minimally verbal
- ☐ Non-verbal

Q2 Use of signs *(tick highest level)*

Please record sign method used: ……………………………………………………

- ☐ Uses 20 + signs
- ☐ Uses 5-20 signs
- ☐ Uses 1-5 signs
- ☐ Does not use signs to communicate

Q3 Use of symbols *(tick highest level)*
Please record method
used: ....

☐ Uses 20 + symbols
☐ Uses between 5 and 20 symbols
☐ Uses between 1 and 5 symbols
☐ Does not use symbols to communicate

Q4 Other means of communication *(tick all that apply)*

☐ Objects of reference
☐ Facilitated communication
☐ Writing
☐ Reading
☐ Pictures
☐ Photographs
☐ Body movements
☐ Manipulation
☐ Eye contact
☐ Gesture
☐ Point-eye contact
☐ Manual aid Type of manual aid: ....
☐ Electronic aid Type of electronic aid: ....

Q5 Use of table utensils (*Tick highest level*)

☐ Uses table knife for cutting or spreading
☐ Feeds self accurately with spoon and fork
☐ Feeds self causing considerable spilling with spoon and fork
☐ Feeds self with spoon without spilling
☐ Feeds self with a spoon causing considerable spilling
☐ Feeds self with fingers
☐ Does not feed self or must be fed

Q6 Self-care (***tick all that apply***)

☐ Lowers appropriate clothing at the toilet without help
☐ Sits on toilet seat without help
☐ Uses toilet tissue appropriately
☐ Flushes toilet after use
☐ Puts clothes back on without help
☐ Washes hands without help

Q7 Bathing (***Tick highest level***)

☐ Prepares and completes bathing independently
☐ Washes and dries self independently
☐ Washes and dries with verbal prompting
☐ Washes and dries self with physical assistance
☐ Attempts to soap and wash self
☐ Participates when being washed and dried by others

- ☐ Needs total support to be washed and dried

Q8 Dressing (***Tick highest level***)

- ☐ Dresses self independently
- ☐ Dresses self with verbal prompting only
- ☐ Dresses self by pulling or putting on all clothes with verbal prompting and help with fastenings e.g. zips, buttons, velcro.
- ☐ Participates in dressing self by pulling or putting on most clothes and fastening them
- ☐ Participates when being dressed by extending arms or legs.
- ☐ Needs total assistance when dressing

Q9 Shoes (***tick all that apply***)

- ☐ Puts on shoes correctly without assistance
- ☐ Ties shoelaces without assistance
- ☐ Unties shoelaces without assistance
- ☐ Removes shoes without assistance
- ☐ Attaches or detaches Velcro on shoes

Q10 Walking and running (***tick all that apply***)

If person manages to perform activity alone but with aid of equipment, tick as alone

- ☐ Walks alone
- ☐ Walks up and down stairs alone
- ☐ Walks down stairs by alternating feet
- ☐ Runs without often falling
- ☐ Hops, skips or jumps

Q11 Eating in public (***tick highest level***)

- ☐ Orders complete meal in restaurants
- ☐ Orders simple meals like hamburgers or fish and chips[98]
- ☐ Orders single items e.g. soft drinks, ice cream etc. at a stall or canteen.
- ☐ Does not order in public eating places

Q12 Care of clothing (***tick all that apply***)

- ☐ Wipes and cleans shoes when needed
- ☐ Puts clothes in drawer, chest or cupboard
- ☐ Hangs up clothes without prompting
- ☐ Calls attention to missing buttons and holes and/or repairs clothing

Q13 Miscellaneous (***tick all that apply***)

- ☐ Has regular control of appetite, eats moderately
- ☐ Knows postage rates, buys stamps from post office
- ☐ Looks after personal health e.g. changes out of wet clothing
- ☐ Deals with simple injuries e.g. cuts and burns
- ☐ Knows how and where to obtain a doctor's or dentist's help

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[98] In the Hungarian translation: „hamburger and pizza”

☐ Knows about benefit services in the community
☐ Knows own address

Q14 Safety at home (***Tick highest level***)
☐ Asks whether an unfamiliar object is safe to touch or consume
☐ Is careful about dangers of electrical outlets and sockets
☐ Is careful about danger of hot foods and beverages or hot dishes or pans
☐ Is unaware of possible dangers

Q15 Money handling (***Tick highest level***)
☐ Takes care of own money
☐ Calculates change correctly but does not use banking facilities
☐ Add coins of various denominations, up to one pound[99]
☐ Uses money but does not calculate change correctly
☐ Does not use money

Q16 Purchasing (***Tick highest level***)
☐ Buys own clothing
☐ Buys own clothing accessories
☐ Makes minor purchases without help (sweets, soft drinks etc.)
☐ Does shopping with minimum support
☐ Does shopping with full support
☐ Does not participate in shopping

Q17 Sentences (***Tick highest level)***
☐ Sometimes uses complex sentences containing "because", "but" etc.
☐ Asks questions using words such as "why", "how", "what". etc
☐ Speaks in simple sentences
☐ Communicates with sounds or is non-verbal

Q18 Understanding of spoken information (***Tick highest level***)
☐ Understands complex information involving a decision e.g. If X do Y, but if not, do Z"
☐ Understands information involving a series of steps, e.g. "First do X, then do Z".
☐ Answers simple questions such as "What is your name?" or "What are you doing?"
☐ Responds correctly to simple phrases e.g "Sit down", "stop", "come here"
☐ Is unable to understand even very simple verbal communications

Q19 Numbers (***Tick highest level***)
☐ Can complete division and multiplication problems
☐ Does simple addition and subtraction
☐ Counts ten or more objects

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[99] In the Hungarian translation: Recognises coins and notes of various denominations.

- ☐ Rote counts to ten
- ☐ Counts two objects by saying "one ... two"
- ☐ Discriminates between "one" and "many" or "a lot"
- ☐ Has no understanding of numbers

Q20 Food preparation (***Tick highest level***)

- ☐ Can use microwave correctly to prepare a meal
- ☐ Prepares an adequate and complete meal (may use tinned or frozen food)
- ☐ Mixes and cooks simple food e.g. fries eggs, cooks TV dinners etc.
- ☐ Prepares simple foods requiring no mixing or cooking e.g. sandwiches, cold cereal, etc.)
- ☐ Does not prepare food

Q21 Other domestic activities (***tick all that apply***)

- ☐ Washes dishes well
- ☐ Makes bed neatly
- ☐ Helps with household tasks when asked
- ☐ Does household tasks routinely
- ☐ Can load and use the dishwasher[100]
- ☐ Can use small electrical kitchen appliances

Q22 Encouragement and motivation (***tick all that apply***)

If the person is fully reliant on others tick all boxes and go to next question.

- ☐ Needs constant encouragement to complete task
- ☐ Has to be made to do things
- ☐ Does not appear to be interested in setting and achieving goals
- ☐ Does not appear to be interested in activities
- ☐ Finishes task last because of wasted time
- ☐ Is unnecessarily dependent on others for help
- ☐ Movement is slow and sluggish

Q23 Determination (***tick all that apply***)

If the person is fully reliant on others to organise activities tick all boxes and go to next question.

- ☐ Cannot organise activity/task
- ☐ Becomes easily discouraged
- ☐ Fails to carry out tasks
- ☐ Jumps from one activity to another
- ☐ Requires ongoing encouragement to complete an activity or task.

Q24 Leisure activities (***Tick highest level***)

- ☐ Organises own leisure time activities on a fairly complex level, e.g. going fishing, arranging to play snooker etc.

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[100] In the Hungarian translation: „washing machine"

☐ Has an active interest in hobbies, e.g. painting, embroidery, collecting.
☐ Participates in organised leisure activities when arranged for him or her
☐ Engages in simple leisure activities e.g. watching TV, listening to the radio
☐ Does not arrange leisure activities

Q25 General responsibility(***Tick highest level***)
☐ Very conscientious and assumes much responsibility -always completes activities and/or tasks which have been agreed.
☐ Usually dependable, makes an effort to carry out responsibilities –generally completes activities and/or tasks which have been agreed
☐ Variable, often forgets responsibilities - often does not complete activities and/or tasks which have been agreed.
☐ The person is not currently given responsibility for activities and/or tasks

Q26 Personal responsibility **(*tick all that apply*)**
☐ Usually maintains control of own emotions, desires etc.
☐ Understands concept of being on time
☐ Seeks and accepts help on instructions
☐ Says (e.g. to staff) if there is a problem

Q27 Consideration of others **(*tick all that apply*)**
☐ Shows interest in the affairs of others
☐ Takes care of others' belongings
☐ Directs or manages other people's affairs when needed.
☐ Shows consideration of other peoples' feelings

Q28 Awareness of others **(*tick all that apply*)**
☐ Recognises own family
☐ Recognises people other than family
☐ Has information about others, e.g. job, address, relation to self.
☐ Knows names of people close to him or her, e.g. neighbours, co-workers
☐ Knows the names of people not regularly encountered e.g. doctor.

Q29 Social interaction (*Tick highest level*)

Thinking about the person's everyday social interaction with peers (not staff, parents or other caregivers) tick the statement below that best describes the person's general social interaction.

☐ Generally does not interact with others - appears distant and unresponsive
☐ Generally does not interact with others but will interact to obtain needs (e.g. to get food or drink)
☐ Responds to and may initiate physical contact such as chasing, tickling, cuddling etc.

- ☐ Generally does not initiate interactions with others but responds to social, not just physical, contact if others, including peers, make approaches. Joins in passively in social situations. Tries to copy others but with little understanding. Shows some pleasure in passive role.
- ☐ Makes social approaches actively, but these are usually out of place, naive, unusual and one sided. The person cannot change their behaviour to match the needs, interests and responses of the other person.
- ☐ Shy but social contact with well-known people, including peers, is appropriate to individuals support needs.
- ☐ Social contact with children and adults is appropriate to the individuals support needs. The person looks up with interest and smiles when approached. Responds to ideas and interests of people with similar abilities and contributes to the interaction.

Q30 Possible problem behaviour

Rate person's behaviour over last month. ***Tick one box for each item,*** *rating the behaviour as not a problem, a slight problem, a moderately serious problem, or a severe problem*

		Non	**Slight**	**Mod**	**Severe**
1	Excessively active				
2	Injures self				
3	Lacks energy, slow-moving, inactive				
4	Aggressive to others				
5	Seeks isolation from others				
6	Inappropriately noisy and rough				
7	Meaningless recurring body movements				
8	Screams inappropriately				
9	Talks excessively				
10	Temper tantrums				

		Non	**Slight**	**Mod**	**Severe**
11	Stereotyped, repetitive movements				
12	Preoccupied, stares into space				
13	Impulsive (acts without thinking)				
14	Irritable				
15	Restless and unable to sit still				
16	Withdrawn, prefers solitary activities				
17	Odd, bizarre behaviour				
18	Non-compliant, difficult to control				
19	Yells at inappropriate times				

20	Fixed facial expression; does not show emotional reactions				

		Non	Slight	Mod	Severe
21	Disturbs others				
22	Repetitive speech				
23	Does nothing but sit and watches others				
24	Uncooperative				
25	Depressed mood				
26	Resists any physical contact				
27	Moves or rolls head back and forth				
28	Does not attend to instructions				
29	Demands must be met immediately				
30	Isolates self from others				

		Non	Slight	Mod	Severe
31	Disrupts group activities				
32	Sits/stands in one position for a long time				
33	Talks loudly to self				
34	Cries over minor things				
35	Repetitive hand, body or head movements				
36	Mood changes quickly				
37	Unresponsive to structured activities.				
38	Does not stay in seat during structured activities				
39	Will not sit for any length of time				
40	Is difficult to reach or contact				

		Non	Slight	Mod	Severe
41	Cries or screams for no apparent reason				
42	Prefers to be alone				
43	Does not try to communicate by gestures				
44	Easily distracted				
45	Waves or shakes hands or feet repeatedly				
46	Repeats a word or phrase over and over				
47	Stamps feet while banging objects				
48	Constantly runs or jumps around the room				
49	Rocks body back and forth				
50	Deliberately hurts self				

		Non	Slight	Mod	Severe
51	Does not pay attention when spoken to				
52	Does physical violence to self				
53	Never moves spontaneously				
54	Tends to be excessively active				
55	Responds negatively to affection				
56	Deliberately ignores directions				
57	Has temper outbursts				
58	Shows few social reactions to others				

Questions on Lifestyle and Health

31. What is this person's height? ☐ cm
32. What is this person's weight? ☐ kg

33. Does this person smoke?

Yes ☐ Please indicate daily quantity: ☐ cigarettes
No ☐

34. Does this person consume alcohol?

Yes, excessively ☐
Yes, moderately ☐
Not at all ☐

35. Does this person drink coffee?

Yes, regularly ☐
Yes, occasionally ☐
Not at all ☐

36. How often does this person take exercise? *(By this we mean exercise for the purpose of keeping fit and/or maintaining or improving health, such as gentle exercise, swimming, aerobics, horse riding etc)*

Several times a week ☐
Weekly ☐
Less than weekly but more than once a month ☐
Less often than monthly ☐
Never ☐
Not applicable (e.g. service user is bedfast) ☐

37. Does this person suffer from any long-term illness or health condition?

Yes ☐ Please specify what: ☐ ☐
No ☐

38. Is this person on regular medication?

Yes ☐ Please answer question 9.
No ☐ Please go to question 10.

39. Please list the names of medication he/she takes regularly:

40. How many times has this person seen their GP in the past 3 months?

times

41. How many times has this person seen any other health professional in the past 3 months?

times

42. Has this person been in hospital as an inpatient, overnight or longer during the past 12 months?

Yes ☐
No ☐

43. If your answer was yes, please explain briefly the reason of hospitalisation:

44. Is this person in a relationship?

☐ Yes (please answer questions 45-46)
☐ No

45. Does the relationship involve sexuality?

☐ Yes
☐ No

46. Has she/he received sexual education, including information on family-planning, STD and abuse?

☐ Yes please describe briefly:

☐ No

Thank you for completing section one. Please now turn over to section 2 on community involvement.

Section 2: The Index of Community Involvement

This is a short section of five questions about community involvement. For question 44 in the table below please tick the correct answer for each statement

47. ***Within the past month*** has the person named above **(please indicate yes or no by ticking the appropriate option below):**

	Yes (1-4 times)	Yes (5 or more times)	No
Been to a hairdressers?			
Had friends/family in for a meal?			
Been out for a meal with friends/family?			
Had guests to stay?			
Been on an overnight stay to family/friends?			
Been shopping?			
Been to a cinema?			
Been to a café?			
Been to a pub?			
Been to a place of worship?			
Been to a sports event?			
Been to a social club?			
Been to a concert or play?			
Has been on a bus?[101]			
Been to their bank?			
Been on an excursion/day trip?[102]			

48. In the past 12 months, has this person been on holiday

☐ Yes
☐ No

49. Does this person have regular contact with his or her family? **Please tick one box**

☐ Yes, Go to Q3
☐ No, Go to section 3

50. If yes, how often? **Please tick one box**

☐ More often than once a week
☐ Once a week
☐ Once a fortnight
☐ Once a month
☐ Less than once a month

51. Who, from the family, are they most in contact with?

☐ Mother
☐ Father

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[101] In the Hungarian translation: Has used public transport

[102] Item added

☐ Sibling
☐ Grandparent
☐ Aunt/Uncle
☐ Cousin
☐ Other, please
specify ....

Thank you for completing Section 2. Please now turn over to Section 3

Section 3: Participation in daily life and opportunities for choice

Question 52 requires you to indicate whether the person does each of the daily tasks on their own, with help or not at all. For questions 50 to 55 please indicate whether the service user is encouraged and helped to make choices in different situations, using the scale provided (no, some of the time, most of the time or yes all of the time). Questions 56-57 help me interpret some of the answers.

52 Index of participation in domestic tasks

	Yes	With help	no
shopping for food			
preparing meals			
setting table			
serving meals			
washing up			
cleaning kitchen			
cleaning living and dining room			
cleaning own bedroom			
cleaning bathroom & toilet			
shopping for supplies			
doing own washing			
doing own ironing			
looking after garden (if applicable)			

53 Food

	No	Some	Most	Yes
what foods to buy				
what for main meal				
what to eat/leave				
desserts and snacks				
choosing cafes				

54 House, room

	No	Some	Most	yes
Decorations to own room				
choosing to be alone				
Type of personal hygiene articles				
setting house or room temp				

55 Clothes

	No	**Some**	**Most**	**yes**
what clothes to buy				
what clothes to wear				
what to wear in bed				

56 Sleeping and Waking

	No	**Some**	**Most**	**Yes**
when to bed on weekdays				
when to bed on weekends				
when get up on weekends				
Naps, evenings and weekends				
Time and frequency of baths/showers				

57 Recreation

	No	**Some**	**Most**	**yes**
Choice of outings				
What to watch on TV				
Visiting friends				

58 Other

	No	**Some**	**Most**	**yes**
How to spend own money				
Choice taking medicines				
How/when show affection				
Use tobacco, alcohol, caffeine				

59 Does this person have a person centred-plan?

☐ Yes If yes, when was this last reviewed? ....

☐ No

60 Is this person under guardianship?

☐ Yes (Please answer questions 58-59)
☐ No

61 Please indicate what type of guardianship:
☐ Partial
☐ Complete

62 Who is the guardian?
☐ Parent
☐ Staff from the service
☐ Professional
☐ Other, please specify: ....

END OF SERVICE USER QUESTIONNAIRE
THANK YOU FOR ANSWERING THE QUESTIONS!

Annex 3 Description of services in the field work

Institution 101 is located in a small village with a population of around 1,700 people. The institution has 145 residents. The village is a "dead end": the road ends there which makes it difficult to access on road or by public transport. Unemployment is high, the institution is the main employer in the local area. People have to commute long distances for jobs (that have been affected by the economic downturn). Nevertheless the village has a fairly active community life and a good range of local facilities, including a nursery, a primary school, a library and a so-called "tele-house" providing access to the Internet, a GP surgery, and 3 churches. The institution is in the centre of the village, on the grounds of a large fenced[103] park that once belonged to a noble family. The main building was built in the late 1920 as a country house. The property was nationalised after the 2nd World War and opened as a long-stay hospital for children with disabilities in 1954. In less than 3 years nearly 320 children were moved there from overcrowded long-stay facilities all over the country. In 1962 a new wing was added to the building. In the early 1990s children were moved to institutions closer to their families or other, more modern facilities. The new residents who moved in from other institutions in the county were mainly adults with intellectual disabilities or mental health problems, and elderly people in need of nursing care. Around that time a so-called rehabilitation unit was established for young adults with mild learning disabilities in the institution. The total number of residents was 240. Facilities were poor, rooms were overcrowded and 30-50 residents had to share one washing and toileting facility. In 2000 new management took over the institution. The number of places was downsized to 150 – people were moved to other institutions in the local area – the existing buildings were refurbished and new facilities were added. At present the site consists of 5 buildings: the main building and the wing accommodate all residents and offices. In addition there is a laundry, a garage and a workshop on site.

Institution 102 and group home 301 are situated in a small town (population 7,200) in one of the poorest areas of the country. The town is relatively well connected to neighbouring cities and villages by road and rail. The area was very badly affected by the decline of heavy industry after the collapse of socialism. Unemployment soared in the early 1990s and remained high despite considerable government aid to the region. The level of unemployment was 17% in 2007 and has been rapidly increasing recently due to the closure of businesses in the area. Poverty is visible and striking in the town which has a very high rate of Roma population. Ethnic tensions are also noticeable. There are concerns regarding crime and safety. The institution was established in the 1966

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[103] In Hungary this is normal, most properties are fenced.

as one of the first rehabilitation institutions in Hungary. Currently it has four sites with a total of 202 residents. The main site with just over 140 residents is the original rehabilitation institution (service 102). It is located on the edge of the town by the main road on the grounds of former army barracks. It is a large site with a large residential building (120 residents), a smaller living unit in a converted stable, various office buildings, workshops and garages. The site is also used by the local bus company as a bus and coach park during the night because of the high rate of crime in the area (e.g. petrol stolen from the tanks of buses etc.). The institution moved to this site in 1990 from an old mansion in the centre of the town. The mansion has been empty since then and in bad repair. The second site is in the centre of the town on the main road. It accommodates 40 residents, mostly older people with intellectual disabilities and/or dementia. The building is an old merchant house that belonged to a Jewish family who were deported during the 2nd World War and most of them were killed (and those who survived never returned to Hungary). The property was nationalised after the war and opened as a mental health asylum in the 1950s. It became part of the institution in 1982. The institution has three group homes with a total of 21 residents. The group homes are in a quiet residential area within easy walking distance from the main site but not too close. Two group homes are in a semi-detached house (service 301) and the third one is in a large detached house. All three buildings are ordinary houses; they had been family homes before the institution purchased them in 1998 and in 2003. The institution also has an industrial site with a large workshop where most residents work during the day. This is located on the outskirts of the town in a rather deprived area. People are taken to work by bus from the main site.

Institution 103 and group home 302 are located in a small village with a population of 2,300 people. The institution is operated by the Municipality of Budapest for people with intellectual disabilities from Budapest. Controversially, it is more than 110 miles from the city with poor public transport links, particularly during the winter. It is difficult to go and return the same day, but accommodation is only available in neighbouring villages. Unemployment is high and the institution is the main employer in the local area. However, there are seasonal employment opportunities in and around the village. The institution has a total of 214 residents who live on one of the five sites in the village. It was established by the Municipal Government of Budapest for people with intellectual disabilities and mental health problems in the early 1950s. Originally it operated in a nationalised manor house a few kilometres from the village. However, that building partly burnt down during its renovation in 1986. Because it was so badly damaged and it was a listed building, the Government decided to reprovide the institution in alternative settings. The first group home was purchased in the village in 1989. It was an ordinary family home in the centre of the village that was refurbished to accommodate 14 people. This was followed by the purchase of other houses in the village that currently have 20-20 residents (service 302). In 1999 a new site on the outskirts of the village was added with 2 purpose-built homes for 20-20 people. Finally in 2006 the old institution closed and all remaining residents were moved to a new purpose-built campus-style setting in the village. The site consists of a main building with places for 65 residents, a central dining hall and administration. There are two smaller buildings with 30 people in each and a common room. In addition there are a number of workshops and sports facilities (gym, outdoors football pitch etc.) on site. The management of the institution originally wanted smaller buildings with 20 places and more communal areas however these plans were rejected claiming insufficient funding.

Institution 104 is in a small town with a population of 5,300 inhabitants on the Eastern border of Hungary. Similarly to the other institutions, it is the main employer in the area, unemployment is very high (16%) and poverty is visible. The institution is a new, purpose built complex on the edge of the town, by the main road. Residents moved in to the new setting in November 2008, just 2 months before my visit. Previously the institution was in an old farm a few kilometres outside the town. It was established in 1949 for people with intellectual disabilities and mental health problems. The old buildings were described as completely inadequate with poor facilities and overcrowding. The decision to reprovide the institution in a new setting was made by the county government and the management of the institution was not consulted regarding the plans. The idea of moving people to small homes and alternative settings did not emerge at all. The site consists of a main building accommodating 137 people, offices, a central dining hall and other facilities (e.g. therapy rooms, gym, laundry etc.). There are 4 smaller units on the site, right next to the main building. Each unit has 12 places, providing accommodation for a total of 48 residents. At the time of my visit these places, together with 37 places in the main building, were not filled, the institution was "recruiting" new residents. In addition there is a workshop and some green areas for sports, barbecues etc. There is a large car park in front of the building for staff and deliveries.

Service 105 is located near Budapest, on the outskirts of a village with a population just under 5,000 people. Although the institution was originally outside the village, now there are houses and services (a garage) in its close proximity. It is easily accessible; just a few minutes walk from the main road where buses to/from main towns and cities stop. It was founded in 1958, originally as a home for elderly people, later converted into an institution for adults with intellectual disabilities. The institution is located on the grounds of a former mansion house. It was completely renovated in 2006 and to reduce overcrowding in the main building four identical group homes were built in close proximity to the main building. These are named after the four seasons. The main building has 56 places and the four group homes have a total of 48 places. In addition, there is a block of 3 studio flats, each for 2 people. The buildings are surrounded by a large park and there are some facilities for outdoors activities (e.g. benches, barbecue, football, gardening etc.).

Service 201 is a group home in a suburban district of Budapest. It is a large detached house with a sizeable garden in an ordinary street in a residential area. Although the building is in style with the surrounding houses, but it is slightly larger. It is easily accessible by public transport and there are a number of community facilities in the close proximity. The home was founded by parents of children with learning disabilities who went together to the nearby special school. The local government provided the land and they received funding from the Nest Programme to build a home in 1999.

Service 202 is a group home run by a charity in a small rural town with a population of 11,000 inhabitants. It is located in one of the most disadvantaged areas of the country where unemployment is high (11.7%) and poverty is widespread – although this was less visible than in other deprived areas. The main site of the charity is situated in the centre of the town close to local amenities (shops, GP surgery, church etc.) on an ordinary road. The organisation purchased 3 old properties (house, barns, "summer kitchens", storage buildings and land) next to each other. The buildings were nicely renovated keeping their original features from the outside. There are 2 group homes, workshops, and a cafeteria in the site that provide sheltered employment for people with all types of disabilities, including the residents of the group homes. They keep animals on the site and cultivate the garden at the back of the property. The organisation also owns some land on the outskirts of the town where they grow vegetables for use in the cafeteria and sale. The site looks like a traditional large rural household and seems part of the local community with the gates always open and people coming and going.

Service 203 is in a town with a population of 17,000 people. The setting is located on the outskirts, however it is walking distance from the high street and close to amenities (e.g. supermarket). One side of the street is rather industrial with warehouses and garages, the other side, however is residential with detached houses. The property originally belonged to a wealthy family and it was built probably at the beginning of the 20th century. During the 1980s and early 1990s it belonged to the local government and was used as a nursery, however there are no signs of this now. It was closed due to the decline in the number of children and the organisation purchased it in 2000. The site stands out of the neighbourhood because it was built in an unusual style and has a fairly large garden. However, it took me a while to find it because there is no indication that it is a group home for people with intellectual disabilities. By mistake I tried to enter the property next door which looked more like a purpose-built group home but it was a private home.

Service 204 is located in a medium-sized town (population 25,000) in the central part of the country. The setting is in the old part of the town in a quiet street with listed buildings and many local shops. The group home is in an old converted town-house that once belonged to a wealthy family, however it was nationalised after the 2nd world war and used as a nursery. The organisation purchased the property in 2000 and completely renovated it, keeping only the outer walls and redesigning the interior to fit its new purpose. In 2005 they added a new building – a workshop – to the back of house. There is a small back-yard as well. The building does not stand out from its environment, it is in style with the surrounding buildings.

Service 205 is found in a small village (less than 2,500 inhabitants) near the capital. It is a wealthy area with many people from Budapest buying property here. The site is on the outskirts of the village next to a busy road. A footpath leads to the service from the centre of the village which was built recently by volunteers from a large company and service users, family members and staff of the service. Although the area is fenced, the gates are always open and anyone can enter (or leave) the site. The service occupies a large area with several buildings and farm land for agricultural use. There are three service settings on the site: a residential home for 16 children with profound and multiple disabilities. The care home for 11 adults with profound learning disabilities and the group home for 12 adults with moderate learning disabilities share the same building. There is a supported living setting in the village (an ordinary house) shared by 4 people (2 couples). The other buildings on the site include a house originally built for the caretaker of the farm. It is now being converted into a workshop and training rooms. There is also a small office building and a number of barns. The settings were built with financial support from Dutch organisations which is reflected in the appearance of the site. The complex is very modern looking and stands out of its surroundings (not in a negative way though).

Service 303 is in a medium-sized town near Budapest with a population of 35 thousand inhabitants, easily accessible by public transport and on the road. The institution is on the outskirts of the town on a busy road. It is a large, three-storey building, purpose built in the 1970s for people with intellectual disabilities who were considered “able to work”. Until recently the institution was the “national model institution” with an influential manager and funding directly from the central budget. Although the site stands out from its surroundings, it is not immediately obvious for the visitor that it is a care home; it could be a student hall, office building, hospital etc. In 2003 two group homes were built on the main site, right next to the main building. The institution has two other group homes in ordinary settings within easy walking distance from the main site. They are large detached houses with a garden that were purchased by the institution in 1990s.

Service 304 is in a small village (population 2,800) in one of the most disadvantaged areas of the country, with high unemployment and poverty. The area has a very high rate of Roma population and many of them live in extreme poverty. The area is difficult to access by public transport or road, due to the poor quality of infrastructure. The institution is in the centre of the village, surrounded by a big park. The park is well-kept by the residents of the institution with trees, shrubs, flower beds and various footpaths. It is open to members of the local community and it is a popular spot for wedding photos during the summer. The site consists of various units: the main building is a large concrete block, purpose built in the early 1980s. More recently a new wing was added to it with a central dining hall. There are a number of smaller buildings on the site, these are either workshops where people work during the day or storage units used by the maintenance unit. The group home is on the grounds of the institution, located just a few minutes walk away from the main building.

Service 305 is in a small town (population 6,000). It is one of the two group homes of an institution. The institution is on the outskirts of the town next to a busy road. It is a large fenced estate with a pleasant park. The gates are locked at all times and there is a gatekeeper in small cabin next to the entrance. The property originally belonged to a noble family who left the country in the 1930s. The mansion, which is currently the main building is over 100 years old. Until 1972 it was used as a pulmonary hospital (local residents still call the institution “lung centre”). Between 1973-75 it was briefly used as a mental health hospital and after that as an institution for people with intellectual disabilities. People who were considered “able to work” were moved here from other institutions in the area. In 1987 the building was partly renovated and a pavilion was added to alleviate overcrowding. Next to the main building there is a small single-storey office building and some makeshift sheds and garages.

The institution purchased its first group home in 2002. It is an ordinary detached house with a garden close to the centre of the town and local facilities. It is approximately 25-30 minutes walk from the institution. The other group home was purpose built in 2005. It is on the outskirts of the town, closer to the institution and the farm where most residents work.