Tizard Learning Disability R

Care pathways for people with intellectual disabilities who present with behaviours that challenge

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Introduction

It is vital that people with intellectual disabilities, their families and carers who rely upon NHS and social care services have clear expectations as to the nature and purpose of such provision in order to successfully engage with these services. Yet provision for people with intellectual disability varies widely across the UK, resulting in ambiguity and the potential for less than optimal engagement. Care pathways are being increasingly used in the NHS to outline an anticipated programme of care in relation to a particular condition, illness or set of symptoms. The primary purpose is to inform the service user of what they might expect within what time frame. A care-pathway approach, providing an outline of care linked to evidence-based interventions and clear time frames, could reduce unacceptable variations in the quality of care and minimise the risk of the so-called 'postcode lottery'. Although care pathways have been developed and used in mental health services for people with intellectual disabilities for some time, they seem to vary widely in quality. There is also some confusion about what should be included in a care pathway and how that could be used to improve the quality of care (Royal College of Psychiatrists, 2014). In an impact assessment of care pathways for people with learning disabilities hearing impairment, epilepsy and challenging behaviour, Ahmad *et al*., (2007) reported that performance in key parameters can be improved without an increase in funding. In addition, Cocquyt (2018) also demonstrated benefits of a multidisciplinary care pathway with severe and profound disabilities especially with regard to staff training, delivery of care and links with primary care.

Challenging behaviours are commonly presented by individuals with intellectual disabilities (Bowring *et al*., 2017) and are one of the most common reasons for referral to Community Learning Disability teams (Lowe *et al*, 1995). Challenging behaviour is of course not an illness or clinical diagnosis; rather it is a single or series of events involving an individual that may occur for a variety of often complex and inter-related reasons. Frequently, the behaviour will be attempts by the individual to either directly meet their immediate needs or to communicate these needs to others. Given this, challenging behaviour cannot be cured or treated in conventional ways. Every individual who has engaged in challenging behaviour has the potential to behave again in similar conditions to those pervading at the time of the original occurrence. Thus, challenging behaviour can be a life-long phenomenon, with the language of treatment and cure being inappropriate and terms such as support, management and amelioration being a better fit.

Background

Challenging behaviour is not an issue just for the NHS, as people with intellectual disabilities who present with challenging behaviour use a variety of services and live in a variety of settings. Indeed, the NHS Commissioning Board (2013) require commissioners to '*take new and innovative approaches, working across organisational boundaries and focussing more strongly on outcomes and on quality of whole care pathways, particularly for people with long term conditions'.* This presents the additional complexity of integration across health with its multiple organisational divisions and

specialties (Learning Disabilities, Adult & Child Mental Health, Forensic Services), Social Care, Education and the Criminal Justice System. There are added complexities of geographical boundaries that are not always co-terminus, with different eligibility criteria, and ages at which specific services will and will not be available. For the majority of adults whose behaviour is challenging, their patterns of behaviour will have developed in childhood and the responses of children's services will have shaped how they are supported in adulthood. However, services in the UK are invariably organised into Child/Adolescent and Adult services with poorly developed transitions across the age groups. Pathways from childhood into adulthood are rarely coordinated in ways that support people effectively.

These complexities highlight the need to create clarity of what people with intellectual disabilities and their families can expect from services and quality standards in relation to delivery of services to them. This should be informed by evidence-based practice and the experience of those that use these services. The significance of the problem of working across organisational boundaries has been recognised in other areas by the adoption of the term Integrated Care Pathways (ICP) (Allen *et al*., (2009). These pathways also need to reflect the complex and multi-facetted nature of the phenomena of challenging behaviour, and a model of diagnosis – treat – discharge is clearly unsuitable and any pathway needs to accommodate the different permutations of circumstances that may prevail.

Challenging Behaviour- A Unified Approach update (Royal College of Psychiatrists and British Psychological Society, 2016) recognised that challenging behaviour is not a medical diagnosis, but rather a product of interaction between individual and environment and that any response needed to address both factors and the interactional effect. Whilst not using the term care pathway the report highlighted the components that would be essential in a care pathway including the need for comprehensive assessment addressing functional assessment of behaviour, underlying medical and organic factors, psychological/psychiatric factors, communication, and social/environmental factors leading to a clear formulation of the problem. This should inform intervention delivered in a person-centred context, and a framework of Positive Behaviour Support (PBS) with routine evaluation. More recent guidance has stressed the key role that PBS plays and has explicitly called for local specialist services to demonstrate clear PBS pathways (Local Government Association, 2014). With Positive & Proactive Care (DoH 2014) endorsing PBS as an evidence-based approach that can enhance quality of life and also reduce behaviours that challenge and again highlighting the importance of developing care pathways for people using services. These principles were enshrined within the national plan for learning disability services (LGA *et al*., 2015). NICE (2015) published guidance for people with learning disabilities of all ages highlighting the importance of understanding the cause of behaviour that challenges, and performing thorough assessments so that steps could be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers. An update of this guideline emphasised the need to take a lifespan approach and use prevention and early interventions to reduce the need for hospital admissions (Nice, 2018).

The wide variation in and/or complete absence of ICPs creates major difficulties in evaluating services, users experience and outcomes. This can result in individuals, their families and those who support them having no clear expectation of the options available to them. It also creates a situation whereby less than optimal service provision persists, such as the reliance on reactive management &

out of area placements. A framework for care pathways for people with intellectual disabilities who present challenging behaviour is presented below. These care pathways need to be locally agreed with those responsible for actions and expected time frames made clear.

Insert figure 1 here:

Evidence

It is vital that all elements of the care pathway are evidenced based. This should be based upon an underpinning theory regarding the nature and causation of challenging behaviour in people with learning disabilities and include the methodologies for assessment as well as the interventions (Hastings *et al*., 2013)**.** Gore *et al*., (2013) summarise the components of Positive Behaviour Support (PBS) and provide evidence of the benefits of adopting it as a framework for understanding and managing challenging behaviour. Skills in using PBS were regarded as essential to deliver the new national service model highlighted in Building the Right Support (LGA *et al*., 2015).

Acknowledgement that transition has been a difficult process for children and young people to navigate led to the publication of NICE guidelines (2016). This was then followed by the publication of a Competency Framework specifically concerned with Learning Disability Transition (HEE 2016)

Recommendations

Any pathway needs to accommodate the different circumstances that individuals might find themselves in that could necessitate support from services. These might include:

- Childhood – where the individual child is or is at risk of acquiring/demonstrating challenging behaviours with early screening and smooth diagnostic pathways;
- Recent onset in adulthood;
- Ongoing provision to maintain and review existing supports, taking into consideration the needs, wishes, abilities and resources of those families and carers directly responsible for the care of these individuals;
- Times of change and/or crisis, including transition between services.

Figure 2 here:

What is clear is that it is in the interest of all parties that individuals should have early access to services, i.e. they should not have to pass a threshold of distress or go into crisis before services are offered.

NICE pathways (2019) provide the core of the integrated approach towards challenging behaviour. They describe a series of steps that are part of a coordinated and timely response to people who present challenging behaviour, their families and carers. Previously, local initiatives (Pitts et al 2002) have had little impact in terms of overall service development on account of the multi-agency nature of input required and lack of a national service model. The national service model now clarifies the key principles which provide quality standards for the full range of services including those for people who present challenging behaviour. Intensive Support Teams have been established

nationally for adults and children with learning disabilities. These teams have a key role in working with community teams and inpatient services to reduce the need for inpatient care and reduce lengths of stay. Local initiatives can then proceed and current ICPs should be reviewed or amended to fit this national framework. Commissioners should consider this an essential part of the offer from providers supporting people who present challenging. It should be possible in every local area to access the pathway based on this framework and the principles on which it is based.

Framework for Integrated Challenging Behaviour Care Pathways

Integrated care pathways can enable local services to be accessed easily and ensure that appropriate expertise is available to look at prevention or early intervention of challenging behaviour. The common components of key services should be configured as shown in Figure 2 and provide person centred support to enable persons with challenging behaviour to lead a fulfilling life within their local communities.

Figure 3 here:

Identification – pre-assessment

Any care pathway needs to identify an entry point; this could either be through referral or some other notification process whereby the individual is made known to services (Survey, audit, register). This differs from many standard NHS care pathways in that most often a third party will ask for help in relation to the individual or that the person's behaviour is in some way noticed by the statutory authorities (NHS, Education, Social Services, and Criminal justice System). The person in question is commonly referred into services and does not refer themselves. They may also commonly lack capacity to consent to referral, assessment and/or intervention. This has obvious implications for the appropriate use of the Mental Capacity Act and/or Mental Health Act.

From the earliest possible point, it is essential that the individual and their family have an identified person who acts to coordinate the responses from services. It should also be considered good practice that, as far as is possible, this person remains involved over time.

A critical part of this early identification phase is to highlight when obvious urgent needs are directly contributing to the distress experienced by the individual. There should be an expectation that these should be addressed immediately rather than waiting for further, more formal assessment procedures to be completed. The outcomes of early identification/pre-assessment might include highlighting health problems leading to treatment, identifying recent life events and addressing their sequelae, noting any environmental deficits and organising social care intervention. Critically this phase should ask the question for whom is the behaviour a problem? If the response is anything else other than for the individual in question, this should shift the focus of intervention away from the individual to where the problem actually resides. If for example, inappropriate provision is the issue, this should be the focus. In addition, this pre-assessment may well identify immediate risks that need to be managed without delay; this should not only include risk to the person but also risk associated with the impact of their behaviour on others, for example physical safety, stress and burn out in families and carers.

Where the situation that leads to the person's challenging behaviour is complex or unclear, this should indicate a need for more formal assessment and intervention. Any subsequent support needs

should be derived from this assessment, be commensurate with the problem identified, taking into consideration the capacity and sensitivity of the situation the person is in. This may well involve a tiered approach with a range of options based on the above. This is especially the case when the person in question is still living with their family, as intervention can easily be considered intrusive and burdensome. A range of resources need to be available to manage this risk in each locality including access to 24 hours a day 7 days a week assessment of risk along with the provision of short breaks or emergency respite.

Comprehensive assessment

A full functional assessment should focus on the immediate and historical context in which the behaviour occurs and has occurred. It should be an analysis of the immediate triggers, settings and responses to the behaviour and this should be interpreted with consideration to the less immediate individual and environmental factors that may set the context for the behaviour. Individual factors should include the impact of the intellectual disability, physical and mental health, communication and sensory issues.

This assessment should be joined up, synthesised and coordinated to arrive at a working formulation that will serve to provide a logical set of interventions that are predicted to address the situation, but which will be revised based upon new information. The expected outcome of this assessment should be a written formulation explaining the factors that are thought to be influential in the manifestation of the individual's challenging behaviour. Any such explanation is likely to identify multiple factors and it should detail the interactional effects that may be occurring. There should be an expectation that this formulation should be useful, in that it clearly highlights the matters that need to be addressed in order to bring about an improvement in the quality of life and a reduction in the distress and consequent challenging behaviour presented by the individual. It is anticipated that this assessment and the subsequent formulation should be of the individual within the context that they are living. The initial pre-assessment risk management should deal with issues of immediate safety. Only in very exceptional circumstances should inpatient provision in assessment and treatment units be considered. These units should be local to the individual and their family, with the expectation during the course of a short inpatient stay of continued and active involvement of the local community learning disability team and care managers.

Support/Intervention

The assessment should highlight the support/intervention needs of the person. This needs to include the particular strengths and weaknesses of the supports that surround the person. For each individual person there should be in place a written person-centred behaviour support plan that highlights the elements required to sustain or increase their quality of life, reduce the challenging behaviour and manage any risk. This plan should be comprehensive and, where needed, integrate input from multiple agencies across all areas of the individual life. It should include social care and educational provision with where the person lives and how they spend their time (in the case of children where they go to school) determined by the formal assessment.

Evaluation

It is important that the intervention is regularly evaluated against the outcomes identified above, i.e., maintenance or increase in quality of life, reduction in challenging behaviour, reduction in medication, reduction in restrictive practices & the management of risk

Review

Based on this evaluation the formulation should be amended accordingly and adjustments made to the behaviour support plan.

Adjustment of level of support

It is likely that many people will have a lifelong need for support so discharge from all clinical services should be a rare occurrence, with the likelihood being a continued need for some sort of support. Reductions in a person's challenging behaviour are likely to be a consequence of changes that have been made to the person's environment and supports. Therefore, any reductions in the level or type of support that the person receives may lead to an escalation of the behaviour again.

Standards

In summary, the following should be in place:

- Every person whose behaviour is identified as being challenging should have, from childhood, a detailed plan that is informed by how we understand their behaviour to have developed and to be maintained, with a description of what is needed to reduce the likelihood of its occurrence, and a support plan to reduce risk;
- A longer term life plan should be developed with the person and family as well as services;
- Child and adult services should ensure there are seamless pathways at transition to adulthood. There should be absolute clarity about which services are responsible for planning and delivering their support. There should be a named senior person in each authority that has clear accountability for the transition process;
- There should be standards for local pathways against a national template- regularly audited and reported to Health and Wellbeing Board or Transformation Board;
- For each person there should be a clear set of outcomes that the pathway aims to deliver;
- At the heart of the pathway should be the aim to support the person to live as part of a local community, with a quality of life that reflects what is important for the person.

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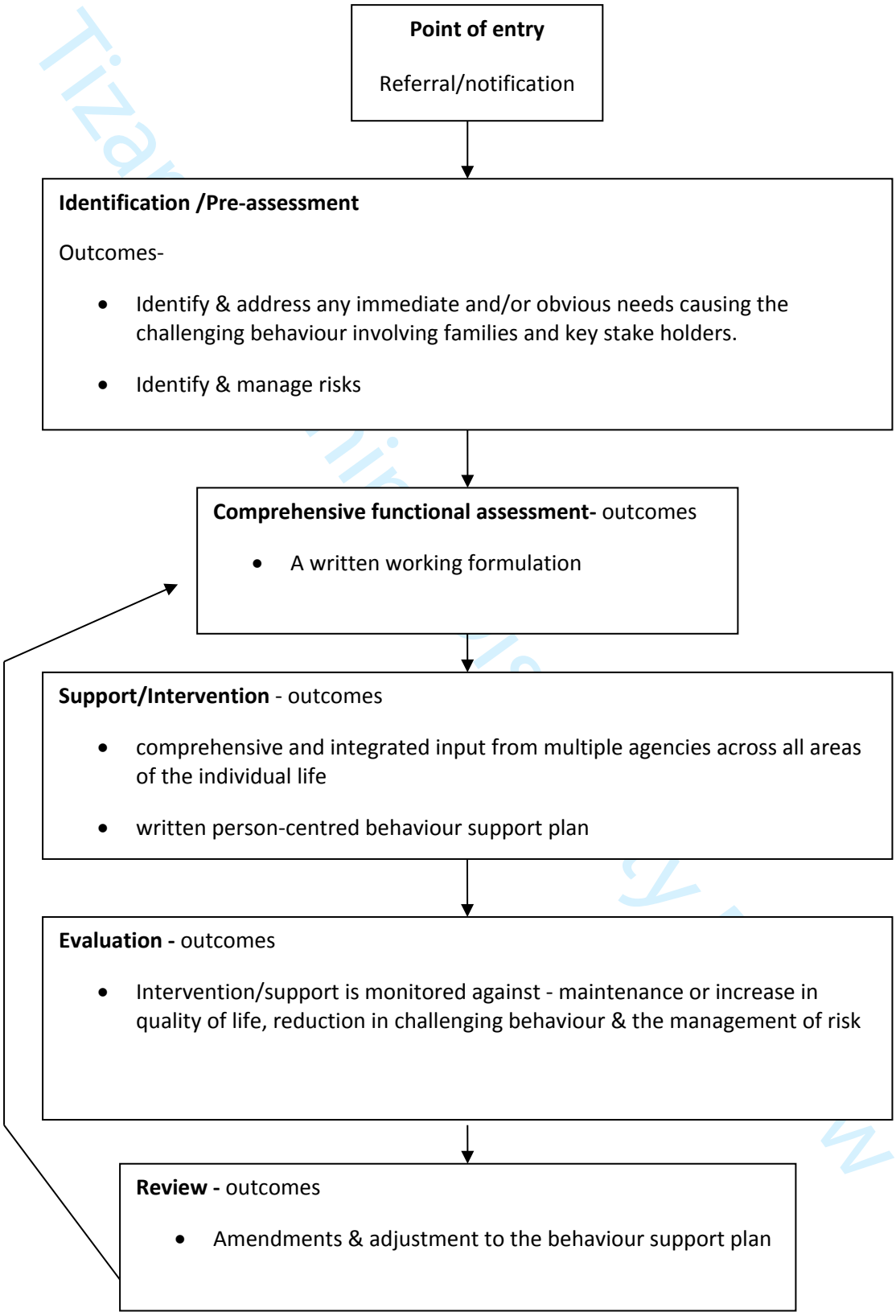
Figure 1 Care pathway framework for people with intellectual disabilities who present with behaviours that challenge



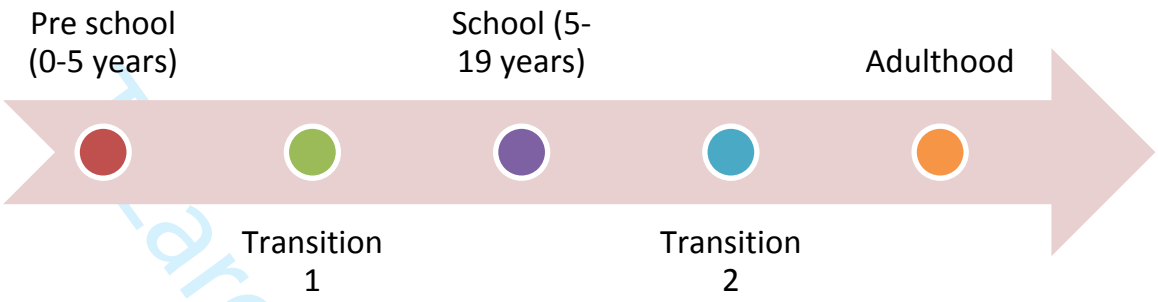


Figure 2 Lifespan scope of challenging behaviour pathways for people with learning disabilities

Figure 3 Configuration of Challenging behaviour services