A review of the literature concerning learning disability, challenging behaviour and social work.

Dr Elizabeth Tilley
Dr Sue Ledger
Janet Bardsley
Open University

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This literature review outlines the key findings and ‘headlines’ from the empirical research, contextualised within significant policy developments. We have structured this review according to the topic areas agreed with TCSW during the research period. Please note that for ease of reading, not every reference cited in the sections that follow is included in the lists of ‘key references’; instead we have fully referenced important empirical studies and policy documents of particular significance. However, all citations can be found in the full reference list at the end of this report.

**Explaining our use of the term ‘challenging behaviour’**

This literature review uses the term ‘challenging behaviour’ as described in the Mansell report (DH, 2007) where the label ‘challenging behaviour’ is used to refer to people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. Within the review we include behaviour that is attributable to mental health problems. When the term ‘challenging behaviour’ was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate and in this literature review the term is used in the original sense. Some people prefer to use the term ‘people who services label as challenging’ to make this point about placing the responsibility with services rather than the individual (NDTi, 2010 p.8).
## Contents:

Section 1: Research on value base and best practice in supporting people with learning disabilities ................................................................. 4  
Section 2: Research on best practice in mental health in relation to people whose behaviour is labelled as challenging and including links with mainstream mental health services .... 9  
Section 3: Research on supporting people with Autistic Spectrum Disorders (ASDs) and Challenging Behaviour ................................................................. 16  
Section 4: Research on engaging with the perspectives of and understanding the experiences of people with challenging behaviour .............................................. 19  
Section 5: Research on the experiences of family carers of people with challenging behaviour .................................................................................................. 23  
Section 6: Person-centred planning with people with challenging behaviour ............ 27  
Section 7: Self-directed support (SDS) and challenging behaviour ........................... 32  
Section 8: Research into the practice of out-of-area placements and returning people to their local area .................................................................................. 36  
Section 9: Research on transition and learning disability ........................................ 40  
Section 10: Research into the organisational context for social workers in supporting people with learning disabilities and challenging behaviour .............................. 43  
Section 11: Research on quality of life, wellbeing and learning disability ............... 46  
Section 12: Building community capacity for inclusion of people with challenging behaviour .................................................................................................. 49  
Section 13: Good practice guidance prepared by other professional bodies of relevance to the social work role with people with challenging behaviour .......................... 53  
Appendix 1: Summary of literature review process and criteria ................................. 56  
Reference list ........................................................................................................... 57
Section 1: Research on value base and best practice in supporting people with learning disabilities

A Unified Approach sets out multidisciplinary guidance for supporting people with challenging behaviour. Produced by the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists in 2007, the content is highly relevant to social work practice. This guidance defines behaviour as challenging ‘when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion’ (p.10). Although people with severe or profound learning disabilities are more likely to display challenging behaviour, such behaviours can still be a major factor in referrals for social work support in relation to people with mild and moderate learning disabilities and their families.

Pitonyak (2005) emphasises that ‘difficult behaviours are messages which can tell us important things about a person and the quality of his or her life’ (p.2). Yet all too often, as highlighted by a series of recent inquiries (Cooper, 2012), service responses to challenging behaviour result in restraint, seclusion, medication and locked doors. Research evidence to date indicates that effective support requires a highly individualised response with multidisciplinary practitioners, managers and commissioners committed to investing time in carefully listening to the needs of individuals and their families, skilled to design and deliver effective local support, and able to recognise and take action immediately if poor practice arises. A human rights-based approach may offer a unifying model for linking together different concepts identified as good practice with the legal foundation of Human Rights Act legislation arguably offering an increasingly robust framework to support interventions.

- The human rights-based approach (HRBA) to challenging behaviour and risk (Bailey et al, 2010) provides a model for advancing ethical practice. Key considerations are working in partnership with individuals, proportionality, identifying which human rights principles apply and how to work proactively.

- In order to achieve the best possible outcomes for individuals labelled as challenging, building good relationships with family carers is vital (Challenging


- Best practice also emphasises the importance of preventative, early intervention approaches with robust local systems that can skilfully respond to periods of crisis (DH, 2007; DH, 2010).

- Active support, Positive Behavioural Support (PBS), Functional Assessments and a range of enhanced communication approaches have been shown to be effective in reducing the severity of challenging behaviour and in enabling people to lead more fulfilling lives (DH, 2007; Emerson and Einfeld, 2011; LaVigna and Willis, 2012; Association for Supported Living, 2010; RCSLT, 2013).

- A central idea within PBS is ‘wraparound’ (Toogood et al, 2011 p.19). The logic of wraparound is that if an individual’s needs are met, his or her quality of life will improve and problem behaviour will decrease. To accomplish wraparound, support services must invest time in organising the social context of home and community life around the individuals they serve.

- Successful support services for people with complex needs require sustained effort. People with challenging behaviour and their families need ongoing access to skilled support including local support in a crisis (DH, 2007; NDTi, 2010).

- Appropriate training, supervision and management are essential (Mansell and Beadle-Brown, 2012). Training and skills development will be dictated in part by the role the individual is expected to play in the workforce.

- Guidance from the Challenging Behaviour Foundation emphasises the socially constructed nature of challenging behaviour and that challenging behaviour is the product of an interaction between the individual and their environment. Assessment, advocacy and intervention must therefore address
the person, the environment and the interaction between the two (RCN/BPS/RCSLT, 2007).

- The underlying cause/causes of challenging behaviour are multiple and in almost all cases they will include psychological, biological and social/environmental factors which interact together (Baker, 2011). Challenging behaviour may be associated with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), mental health problems and certain genetic and/or organic disorders. Physical disorders, particularly those causing pain, can result in challenging behaviours (Mencap, 2012). Challenging behaviour can also be a response to an environment, an indication of poor quality support or abuse (Flynn, 2014). In essence, challenging behaviour is a sign that there is something going wrong that needs to be analysed and addressed, not that there is a person doing something wrong who needs to be stopped (Scope, 2014).

- In the light of this complex pattern of potential causal factors it is most constructive to regard challenging behaviour as a form of communication (DH, 2007; Cooper, 2011). People with learning disabilities often find it difficult to communicate what is important in their lives. Social workers may need to develop skills in communicating and building relationships with people labelled as challenging and in evaluating whether services are effectively supporting their communication needs. RCSLT have produced specific guidance in this area (RCSLT, 2013).

- Care managers or social workers who conduct reviews of people placed out of area do not necessarily have expertise in managing challenging behaviour and so may not be able to recognise poor practice. Evers and Pilling (2012) describe how a good practice standards checklist was effective in enabling social workers to recognise a good standard of placement.

- Wright (2013), exploring available evidence to prevent another Winterbourne View, reviewed the literature on precipitants of physical and psychological abuse. She highlighted that staff confidence in working with people with challenging behaviour is influenced by their knowledge and level of
experience. Wright identifies gaps in the current research evidence concerning preventative approaches.

- Parrott (2013) stresses the major financial pressures on social care funding for people with learning disabilities. The need to promote independence and prevent the need for expensive reliance on social care is urgent. Emerson et al (2011) highlight that empirical evidence of the benefits and costs of prevention of social care for people with a learning disability is underdeveloped.

- The Local Authority Circular Transforming Care highlighted that ‘personalisation, early intervention and efficiency are not contradictory but will need to be more strongly aligned in the future’ (DH, 2008 p.7). However, findings from a recent study (Lingard et al, 2014) identified that the main barrier to personalisation for people with challenging behaviour was the volume of, and priority given to, safeguarding referrals by frontline commissioning social care workers. This reduced capacity for a proactive approach to support planning. Workers who participated in this research appreciated the expertise and support of a project team who could provide skilled guidance and the opportunity to reflect on their work. A major project limitation was the lack of time for commissioning workers and managers to engage with a project aimed at personalising and improving support for people with challenging behaviour.

- Emerson et al (2011) conducted a scoping review on prevention and social care for adults with learning disabilities. These authors conclude that while a plausible case can be made for preventative approaches in general, remarkably little high quality empirical research has been undertaken to evaluate the impact of early intervention and preventative approaches.

- Viv Cooper (2012), Chief Executive of the Challenging Behaviour Foundation and parent of a child with challenging behaviour, argues that we already know a huge amount about how to effectively support difficult behaviour – the challenge is to effectively translate this knowledge and evidence into practice on the ground that leads to better outcomes for people.
Key references

Cooper V. (2012) Support and services for individuals with intellectual disabilities whose behaviour is described as challenging, and the impact of recent inquiries. Advances in Mental Health and Intellectual Disabilities, vol.6, no.5, pp.229-235


Royal College of Speech and Language Therapists (2013) Five Good Communication Standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. London: RCSLT


Section 2: Research on best practice in mental health in relation to people whose behaviour is labelled as challenging and including links with mainstream mental health services

The prevalence of mental illness in individuals with learning disabilities is thought to be greater than in the general population. A number of studies have established that mental illness can co-occur with challenging behaviour. Making an accurate diagnosis of mental illness in an individual presenting with challenging behaviour can be difficult for clinicians due to communication impairments, side effects from existing medication and diagnostic overshadowing, among other factors. People with learning disabilities and their families report difficulty in accessing mental health support. The literature provides examples of a number of multidisciplinary service models, including social work, which have successfully supported people through periods of mental illness. The emphasis is on effective multi-agency work that engages closely with the individual and their family so expertise from a number of areas is utilised across community and inpatient services.

- *Valuing People* (DH, 2001; 2009) emphasises that all people with learning disabilities should be able to access mainstream mental health services when needed. The progressive closure of long-stay hospitals (Hall et al, 2006) and drive to reduce of out-of-area placements (DH, 1993; 2007; 2009; 2012a) has resulted in increased pressure on health and social care services to directly support higher numbers of people with challenging behaviour. This has brought to the fore issues of access to mental health and challenging behaviour support (Emerson et al, 2008; Jones, 2013). In many areas, previous reliance on out-of-area placements means that new service models and infrastructures are now required (Hall et al, 2006; DH, 2007).

- The national mental health framework ‘No Health without Mental Health’ (DH, 2011; 2012b) emphasises a need for preventative work and early intervention: this policy applies equally to people with learning disabilities whose behaviour is labelled as challenging. The 2012 Health and Social Care Act introduced a commitment that equal value should be accorded to physical and mental health. Hollins (2014) emphasises this must now be recognised for the whole population, including people with learning disabilities.
• The prevalence of mental illness in people with learning disabilities is generally estimated to be greater than the prevalence in the general population (Hemmings et al, 2013). Holden and Gitlesen (2009) found significant overlap in symptoms rated by carers as mental illness and those rated as challenging behaviour by carers and it is important that social workers engaged in supporting people with challenging behaviour are aware of the possibility of that in some circumstances behaviour described as ‘challenging’ may indicate the presence of mental illness, particularly in those with more severe learning disabilities (Thakker et al, 2012). Clearly not all individuals with challenging behaviour will have a mental illness and similarly mental illness may present without challenging behaviour. However, challenging behaviour and mental illness may co-exist in people with learning disabilities.

• Emerson (2001) provides clear examples of ways in which mental illness can be associated with challenging behaviour. For example, self-injurious behaviours, compulsions and ‘stereotypies’ may be an atypical presentation of an obsessive–compulsive disorder, and an unwillingness to participate in social activities may be associated with a depressive disorder, where symptoms of social withdrawal and low mood may occur. In addition, medication for the treatment of psychiatric disorder may result in challenging behaviour (e.g. akathisia – a feeling of restlessness – may be caused by antipsychotic medication and disinhibition by benzodiazepines).

• Thakker et al (2012) highlight that it is also important to consider that one of the consequences of challenging behaviour is exclusion from day and social activities, and that this in turn may lead to mental health problems such as depression.

• Hemmings et al (2013) reviewed UK-based research into mental disorder in people with learning disabilities during the last two decades. The paper considers research developments into the epidemiology of mental disorder and problem behaviours, psychopharmacology, psychosocial interventions, and services. The authors draw attention to the considerable complexities of diagnosing mental illness and ‘the fact that the most important difficulty in
diagnosis is the reduced or lack of ability of many people with a learning
disability to verbally report symptoms’ (p.129). The previous labelling of
challenging behaviour as so-called behavioural equivalents of psychiatric
symptoms is not supported by the evidence and the notion has aroused
opposition veering on hostility, especially if it is perceived as potentially
leading to more people with learning disabilities and challenging behaviour
being prescribed medication inappropriately. These authors conclude that one
example of the translation of research into clinical practice has been growing
recognition that medication should not be prescribed as a first-line response to
people who present with problem behaviours when there is no clear
diagnosable mental illness.

- Difficulties in the diagnosis of mental health conditions among people with
challenging behaviours have raised concerns about the use of medications in
the management of challenging behaviour in the absence of a diagnosed
mental illness (Valuing People DH, 2001; Deb et al, 2006; Deb and Unwin,
2007). In response to this, Deb et al (2006) produced an accessible guide to
the use of medication to manage behaviour problems among adults with a
learning disability, including good practice in relation to the prescribing of
medication to treat mental illness.

- Thakker et al (2012) reviewed the current evidence base for understanding
the relationship between mental health and challenging behaviour. They state
that the relationship between challenging behaviour and psychiatric disorder is
complex and not yet fully understood. However, they emphasise that
challenging behaviour is socially constructed (Mansell, 2011) and, as such,
should not be considered as a problem associated with an individual but
should instead be regarded as the product of an interaction between the
individual and their environment. Challenging behaviour may be an attempt by
an individual, consciously or unconsciously, to communicate that their needs
are not being met, that they are ill or have been hurt. It then follows that the
frequency of challenging behaviour can be reduced by provision of flexible,
proactive strategies of support (Jones, 2013). The fact that a person shows
challenging behaviour therefore carries no implication that they have a mental
health problem.
- In contrast, the essential feature of any mental illness is a clinically recognisable set of symptoms or behaviours, usually associated with distress and interference in personal functioning (Moss, 2012). The reference to a ‘set of symptoms’ is a key part of the definition as mental illnesses tend to have characteristic patterns of symptoms. Identifying the particular pattern exhibited by an individual is a central part of making a diagnosis.

- Thakker et al (2012) highlight that it is important for professionals working with people with learning disabilities to understand the complex relationship between mental illness and challenging behaviour. Anxiety disorders, depression and mania are all more prevalent in people with learning disabilities who display severe challenging behaviour than in the general population. Hemmings et al (2013) conclude that most researchers would now consider the prevalence of mental health problems overall to be increased in more severe levels of learning disability (Cooper et al, 2007) but caution that this conclusion is always complicated by the questionable validity of unmodified diagnostic classification systems and rating instruments for people with more severe disabilities.

- Children and adults with learning disabilities may not be able to recognise that they have a mental health problem, or seek treatment themselves (Burke, 2014). For this reason it is crucial that families and staff notice significant behavioural change, are aware of the signs of mental illness and seek mental health advice quickly when necessary. The PAS-ADD Checklist is a mental health questionnaire to help staff and carers collect information on symptoms of mental health problems, and to decide whether further assessment of an individual's mental health may be helpful.

- Many factors increase the chance of a person developing a mental health problem. These include: poor social support, isolation, low self-esteem, having little control over one’s life, not having anything to do and poor coping skills. People with learning disabilities, and perhaps in particular people labelled as challenging, are more likely to experience all the above: many do not have a partner or children, many have little control over their lives; others have experienced early parental rejection or long periods of institutional care. A
combination of these factors can mean that people are very vulnerable to mental illness (Moss, 2012).

- Although prevalence data confirms people with learning disabilities have a higher incidence of mental illness (Public Health Observatory, 2012), research shows that access to specialist mental health support continues to be problematic (Chaplin et al, 2009; Hall et al, 2006; Burke, 2014). Chaplin et al (2009) highlight that within mainstream mental health services staff often express reluctance and lack of confidence, believing that they do not have the skills or training to offer the range of assessments and interventions needed to treat the more complex needs of someone with learning disabilities. A label of challenging behaviour (Burke, 2014) can lead to diagnostic overshadowing where mental health symptoms are regarded as ‘part of the learning disability’ or ‘behavioural problem’.

- The Foundation for People with Learning Disabilities (Burke, 2014) worked with a reference group of people with learning disabilities to conduct a literature review of the mental health needs of people with learning disabilities and a national survey to gather data on access to mental health services. Key findings were that people with learning disabilities said that they were not listened to, supported or believed when they ‘felt down’, that professionals concentrated on the learning disability rather than their problem and that they wanted to have more control of their mental health. Families reported difficulty in accessing mental health support, particularly in getting GPs to understand concerns and refer to a specialist. Families also experienced long waits to see a specialist, during which time their family member often deteriorated. Families reported that once psychological support was received it was very valuable. Interviews with people with learning disabilities who had experienced mental illness revealed that it was important for them to have materials that could help them understand about mental health and wellbeing and help them explain that they were feeling unwell to their GP. The group have published resources for this purpose: www.learningdisabilities.org.uk/mental health
• Hall et al (2006) describe how they set up a ‘virtual team’ comprising psychiatrists, psychologists, occupational therapists (OTs), nurses, pharmacists, care managers and community support workers. The team worked with the whole range of people with learning disabilities. The work of the team is described as reactive to mental health problems when they arise but also anticipating problems and undertaking preventative and early intervention work. A significant part of the team’s work has been to support and promote access to mainstream services and they have been successful in doing this with local crisis intervention teams, who provide an out of hours service not available from learning disability services.

• Hall et al (2006) emphasise that for community based mental health support to be successful it is important that care managers are closely involved when a person with learning disabilities is admitted to hospital to ensure that everyone works together during their inpatient period to plan their future discharge and support.

• Chaplin et al (2009) suggest that in looking to provide appropriate services for people with learning disabilities we need to move away from the concept of mainstream adult mental health versus specialist learning disability mental health – with services either provided by one or the other. The challenge is to look at care according to clinical and social need rather than fitting into existing service configurations by complementing and developing both mainstream and specialist services.

• Agrawal et al (2008) propose a ‘hub and spoke’ model. This model can be delivered in a variety of ways with a regional hub providing the clinical service linked to an academic centre for research evaluation. The spoke(s) then reach out and both support and complement existing mental health services. Similarly Bouras et al (2003) advocated that the gold standard is for multi-agency working to bring about effective liaison and integration between services so expertise from a number of areas is utilised across community and inpatient services.
Key references


Section 3: Research on supporting people with Autistic Spectrum Disorders (ASDs) and Challenging Behaviour

The empirical research shows that early intervention with children with ASDs and their families, in conjunction with a joined-up approach between different agencies, can prevent the development of severely challenging behaviour. Positive behavioural support (PBS) has been shown to reduce incidents of challenging behaviour, but social workers’ knowledge of and engagement with PBS is currently under-researched.

- Research has shown that a high proportion of children with autism with severe speech impairments use challenging behaviour as a form of expressive communication in their school environments (Chiang, 2008). Early intervention with children with learning disabilities and ASDs can prevent the development of severely challenging behaviour (Emerson, 1996).

- In the context of interventions at home, research has demonstrated that intensive early behavioural intervention programmes are most successful when families receive sufficient resource and support from professionals (Trudgeon and Carr, 2007).

- Other useful interventions include short break services to families with children with ASDs. Although provision is patchy and some families find it more difficult than others to access such services, Northamptonshire County Council has experienced high satisfaction rates among families. Key factors in the success of their services have been the development of a unified approach, with consistency between education and social care services and investment in staff training (Preece, 2009).

- Research has shown that casework for professionals (particularly social workers) who support families with disabled children with ASDs can be ‘emotionally highly charged’ and can leave professionals feeling that it is ‘almost impossible to get things right’ (Hingley-Jones, 2005 p.116). Drawing on psychoanalytic theory, Hingley-Jones argues that professionals and parents can become involved in a cycle of blame and pity, and that it is
essential for professionals to continue to engage in reflective practice to enable them to work with families to explore positive interventions.

- Staff training designed to increase awareness of autism-specific interventions has been shown to reduce challenging behaviour in adults with ASD. In one UK study, training that focused on environmental support; communication strategies; behavioural approaches; and person-centred approaches led to a marked decrease in service users’ challenging behaviour and a significant increase in staff knowledge (Jackson and Duperouzel, 2012).

- Positive behaviour support (PBS) has been shown to lead to a reduction in challenging behaviour among adults with autism. In one Irish-based study, PBS interventions were introduced and monitored over a three-year period, and were linked to significant reductions in challenging behaviours, along with incremental improvement in mental health scores and quality-of-life scores (McClean and Grey, 2012). Most empirical research on the use of PBS has been with health professionals or social care workers. There is a gap in the literature regarding social workers’ knowledge of and engagement with PBS.

- In health contexts, research has shown the importance of robust hospital admissions pre-planning among young people with a label of learning disability, ASD, and challenging behaviour. Pre-planning incorporates detailed awareness of a child/young person’s communication needs and behaviours, and can significantly reduce distress and improve the patient experience (Pratt et al, 2012). This is likely to be relevant for other contexts.

**Key references**


Preece D. (2009) Effective short break services for children with ASDs: how one local authority in the UK is working to meet the challenge. Practice: Social Work in Action, 21(3), September 2009, pp.159-174

Section 4: Research on engaging with the perspectives of and understanding the experiences of people with challenging behaviour

Relatively little attention has been given to the perspective of people with challenging behaviour who receive services and support. In the aftermath of Winterbourne View it is particularly important that the voices of potentially very vulnerable individuals are not lost when developing policies and services to support individuals and their families. An ‘insider perspective’ may allow factors associated with the onset and after effects of a challenging behaviour episode to be more clearly understood. Research findings suggest this (largely absent) perspective would make a valuable contribution to the development of policy and practice.

- Evidence from research establishes that effective support for people with challenging behaviour requires a person-centred, individualised approach (Mansell and Beadle-Brown, 2012). Pitonyak (2005) emphasises that person-centred approaches require an understanding of meanings and communication when working with people with challenging behaviour. This rests in developing sound relationships with people and taking time to reflect on their communication and different possible meanings linked to behaviours. It also means concentrating on working with the person and getting to know them as a person, rather than focusing solely on the behaviour.

- Many people with learning disabilities with behaviours described as challenging are dependent on others for good communication (RCSLT, 2013). Developing skills in listening to and communicating with people labelled as challenging is key to social workers engaged in improving services and support (Bigby and Frawley, 2010).

- Relatively little attention has been given to the personal experiences of people with challenging behaviour who receive services and interventions for challenging behaviour, although these can include controversial restrictive practices such as seclusion, physical and chemical restraint, and rapid tranquilisation (Matson and Boisjoli, 2009). In addition, many children and adults labelled as challenging continue to be moved away from their families and local communities to receive services (Emerson et al, 2008; Chinn, 2011).
Griffith et al (2013) argue that the opinions of individuals with challenging behaviour are often overlooked in research, policy making and decisions regarding their treatment.

Many people labelled as challenging do not communicate verbally. Pitonyak (2005) and Meininger (2006) emphasise the importance of taking time to understand the life story of a person with challenging behaviour as opposed to relying on the disability focused case histories commonly found in services. These authors provide examples of how previously absent life story information can assist in understanding behaviour that may be labelled as challenging. People with learning disabilities, including individuals labelled as challenging, (Thorne, 2005; DH, 2013) have provided feedback that recording their story was important and helpful in enabling them to explain their past to staff.

Griffith et al (2013) reviewed the literature on the experiences of individuals with challenging behaviour in relation to received supports and interventions. The authors identified four themes emerging from people with learning disabilities: imbalance of power; causal attributions of challenging behaviour; experiences of restrictive interventions; and opportunities for improvements. People with learning disabilities identified the stress of living in a residential unit and the impersonal attitudes of support staff as major contributory factors in triggering outbursts of challenging behaviour.

Griffith et al (2013) noted that in the research reviewed there was a clear sense of participants’ disempowerment, along with reports that they are often treated unfairly and unkindly by support staff. People who recognised they had acted aggressively or self-harmed reported that they did not like engaging in these behaviours and wanted to learn techniques to help them cope with these situations. Good relationships with staff were emphasised as very important in improving services. The authors emphasise that the views of people with challenging behaviour are key to informing the development of service provision and support.
MacDonald et al (2011) highlight that the experiences of people who have been subject to restrictive physical interventions are largely unreported in the literature. The authors interviewed people with learning disabilities who had either directly experienced or had witnessed restrictive physical interventions. Their findings suggest that service users experience restrictive physical interventions as painful, emotionally distressing, and as indistinguishable from abuse, or from general violence in the environment. Service users attributed mixed motivations to staff and did not feel that restrictive physical interventions were justified; they also made practical suggestions for more positive alternatives. This study adds to a growing literature pointing to the adverse effects of restrictive physical interventions. Practitioners should seek to reduce the need for the use of such interventions through greater emphasis on preventative strategies (Pitonyak, 2005) and the broader application of proactive approaches such as PBS.

Some studies have interviewed people with learning disabilities labelled as challenging about their experiences of being placed out of area to receive care (Chinn, 2011; Mencap, 2012). Chinn et al (2011) interviewed 17 people with learning disabilities about their experiences of living in out-of-area psychiatric units. Their findings highlighted that the distance from home affected contact with family and friends.

Biswas (2009), a psychiatrist supporting people with challenging behaviour, argues that the participation of people labelled as challenging and their family carers in training doctors is essential to increase understanding of their perspective on services, to improve future practice and to progress genuine partnership working.

Key references


Royal College of Speech and Language Therapists (2013) Five Good Communication Standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. London: RCSLT
Section 5: Research on the experiences of family carers of people with challenging behaviour

This section reviews the literature on the experiences of family carers supporting a person labelled as challenging at home. Studies confirm the strong commitment of family members, particularly mothers, to keeping their relative at home. Research highlights that many family carers wish to avoid admission to boarding school or residential care, but would welcome improved information, a more preventative approach, reliable local support, skilled professional advice, better working partnerships with professionals and easy access to short break support that is close to home. Families report that support is difficult to access unless there is a crisis. It should be noted that little research has focused on the perspectives of families caring for someone with severe or profound intellectual disabilities and challenging behaviour.

- Hubert (2010) interviewed and observed 20 families, mainly mothers, who were caring for a son or daughter with severe learning disabilities and challenging behaviour over a two-year period. Most were socially isolated, even from close kin. Hubert found negative attitudes to institutions and fears for the safety and wellbeing of their children led to a determination not to put them into long-term care. Mothers struggled to care for the young people at home, in spite of difficulties, family tensions and social isolation. Lack of effective services, especially around transition to adulthood, increased parents’ protectiveness. Hubert’s findings emphasised the strength of the bonds established between the carers and their child with challenging behaviour and the strong commitment of many mothers to continuing to support their child.

- A study by Wodehouse and McGill (2009) explored carer perceptions of the ways in which support is unhelpful and how it could be more helpful. Thirteen mothers caring for a child with learning disabilities and challenging behaviour were interviewed. Parents reported problems with generic disability services including accessing good services, obtaining relevant information, working relationships with professionals and issues with respite provision. Concerns were also expressed about challenging behaviour-specific provision, including
ineffective strategies being suggested, an apparent lack of expertise, insufficient input and their child’s exclusion from services. Although a small sample, findings indicate a need for more preventative approaches, more widespread adoption of effective behaviour management and improved partnership between professionals and families.

- The risks involved in not working more preventatively with families are high, given that decisions are often made to place children in residential provision in response to a crisis (Mental Health Foundation, 1997 p.35), and that currently many children and young adults end up in residential placements far from their family home (e.g. McGill et al 2006a). Within the 13 families interviewed by Wodehouse and McGill (2009) the authors highlighted four children who were either already attending, or about to begin, residential education because of behaviour concerns.

- McGill et al (2006a, b) found that between a quarter and a third of families reported that their child was excluded from respite, with challenging behaviour often being a key factor in this. Mansell (2010) confirmed that access to short breaks was also a problem for families supporting adults.

- Challenging behaviour is associated with a range of family difficulties, including high stress levels (Hastings, 2002) and quality of life restrictions (Emerson, 2001). Such difficulties, combined with inadequate family support and inadequate access to short breaks, contribute to children being placed in residential schools (McGill et al, 2006a) and young adults in out-of-home placements (McIntyre et al, 2002).

- Specialist short break services aim to provide enhanced support to family carers as a means of preventing children whose behaviours severely challenge from being placed in full-time residential care. McConkey et al (2013) randomly selected 17 children from 123 who were currently receiving services or had done so in the past two years from three specialist short break and community support services. For each child, interviews were conducted with a parent, the child’s key worker within the service and the professional (mostly social workers) who had referred families to the services. Five core
themes captured the informants' common experiences: the complexities underlying the provision of services; the negotiations required to implement, maintain and adjust service packages; the relationships forged by the services; and the benefits they brought to children and families. The researchers conclude that specialist short break services can make a vital contribution to retaining children within their families, but under some important conditions which this study has identified: notably, the management of complexity, the formation of trusted relationships and the creation of tangible benefits for the family and for the child.

- McGill et al (2010) conducted a scoping exercise to develop better commissioning for individuals with behaviour that challenges services. In-depth consultations were undertaken with the families of six individuals with behaviour that challenges services. This study aimed to provide an up-to-date picture of the outcomes of services for individuals and their families. Families reported a lack of expertise and capability in understanding and responding to challenging behaviour in local services. This was seen as an important factor in the use of out-of-area placements. Access to services was reported by families to be extremely difficult other than at times of crisis and as a result opportunities for early intervention and crisis prevention were missed; families reported a lack of support and training in their roles as carers, with detrimental effects on physical and mental health; a lack of information and training restricted the extent to which families could plan realistically, and hopefully, for the future; families consistently reported not being included as essential partners in planning for their relatives.

- McGill et al (2010) observed that all of the experiences reported by families have been commonly reported in the past and are well documented in the professional and academic literature.
Key references


Section 6: Person-centred planning with people with challenging behaviour

The first Mansell report (DH, 1993) stressed that services for people with challenging behaviour must be commissioned on an individualised basis and should seek to promote inclusive lifestyles. *Valuing People* identified a person-centred approach (PCP) as essential to deliver real change in the lives of people with learning disabilities and advocated PCP as a tool to provide a single, multi-agency mechanism for achieving this. Research evidence specifically in relation to PCP has generated little evidence of success with people with challenging behaviour and raises concerns that people with behavioural problems, mental health needs or autism are less likely to receive a plan and less likely to benefit if they do receive a plan. There is however increasing empirical evidence for the effectiveness of specific closely related person-centred or individualised approaches such as person-centred active support and positive behavioural support (PBS).

- Person centred planning is defined by Sanderson and Routledge (2014) as ‘a process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends’ (http://www.helensandersonassociates.co.uk/what-we-do/how/person-centred-planning.aspx accessed 6.7.2014).

- Sanderson and Routledge (2014) highlight that within services, person-centred planning has been influenced and stimulated by best practice in social work assessments which emphasised the assessor’s expertise in negotiation, problem solving and imaginatively designing solutions using available service and community resources.

- Person-centred planning gained momentum in the 1980s and 1990s (see, for example, O’Brien 1987; Mount, 1995; Smull, 1997; Sanderson et al, 1997; Sanderson, 2000) and was heavily promoted in subsequent Valuing People policy (DH, 2001; 2009). In terms of support for people with challenging behaviour this movement represented a call for services designed around the social networks (King’s Fund, 1988) and hopes and dreams of individuals (Dowson, 1991), as opposed to people being slotted into services that may or may not exist (Dowson, 1998). Person-centred planning tools such as
PATHS\(^1\) provided frameworks for people and their families and supporters to engage with services to make plans for the future in their local areas.

- Person-centred planning (PCP) can be seen as both a philosophy and a set of techniques (Robertson et al, 2005). At the heart of it is a shift away from conventional social care services (Dowling et al, 2006) towards a future that seeks to recognise the potential in every individual. This includes recognition that all people with learning disabilities have the capability to determine how they want to live their lives (Bigby and Frawley, 2010). In the UK, PCP is a key component of social care (DH, 2001). Person-centred approaches were introduced as a means of ensuring support is tailored to the needs and aspirations of the individual. Such planning is also closely associated with the personalisation agenda and the allocation of individual budgets to provide self-directed support (see section 7).

- Initial evidence shows that people with challenging behaviour may not be benefiting from PCP. Robertson et al (2007a; 2007b) found that people with behavioural problems, mental health needs or autism were less likely to receive a plan and less likely to benefit if they did receive a plan. Similarly, recent research conducted by the Challenging Behaviour Foundation into personalisation highlighted little evidence of person-centred planning in relation to the futures of people referred to the project (Lingard, 2012). A lack of adequate time was identified as significant barrier to PCP. Researchers highlighted that to develop individualised support for people with more complex needs staff may need greater expertise in communication and specialist support (Mansell and Beadle-Brown, 2004).

- Many people with challenging behaviour have communication difficulties that make dialogue among family, friends, advocates and professionals more difficult. Bigby and Frawley (2010) emphasise that social workers must use careful observation to become aware of communication methods used by people who are non-verbal. This may take investment of social work time which managers, in turn, may find hard to accept.

\(^1\) PATH is a tool that focuses on an identified dream for the person and works back from a positive and possible future, mapping out concrete actions required to realise this in practice (Sanderson et al, 1997 p.90).
• Taylor and Taylor (2013) reviewed the evidence base for PCP. They concluded that while the potential of PCP values to bring about positive change continues to be widely accepted (Mansell and Beadle-Brown, 2004; Jones, 2013), empirical evidence of its effectiveness is lacking. Therefore as a practice it still lends itself open to question in terms of its efficacy and implementation.

• Mansell (2011) emphasised that person-centred approaches – not just person-centred planning but person-centred ways of working – are absolutely central to successful support: ‘Services we design for people whose behaviour presents a challenge need to be tailored to each individual’ (Mansell, 2011, SCIE online).

• While establishing empirical evidence for the effectiveness of PCP has proved problematic, there is growing empirical evidence for the effectiveness of related person-centred approaches such as person-centred active support (Beadle-Brown et al, 2012) and positive behavioural support (PBS) (Jones, 2013; Allen, 2009, 2011; Giraud-Saunders, 2014) in increasing positive activity, contact and reducing challenging behaviour. Recent research has also highlighted the value of a person-centred outcomes-based approach to safeguarding (LGA, 2013) which can enhance social work practice at no cost. With regard to transitions, Hudson (2006) suggests a person-centred approach is likely to be a more effective one in relation to the difficulties of inter-agency collaboration than central guidance on good practice. There is also evidence from good practice guidance on commissioning (NDTi, 2010) about the need for clear outcome measures that can only come from PCP.

• Jones (2013) emphasises that a good person-centred plan is an ideal partner to PBS. He asserts that PBS is best understood as a toolkit of person-centred action that many authors have called for if person-centred planning is to achieve real differences in people’s lives (Mansell and Beadle-Brown, 2004; Emerson and Stancliffe, 2004). In short, to develop competent services for people with challenging behaviour the task of specialist teams is to assist mainstream services to understand and implement these procedures in person-centred ways (Department of Health, 2007).
Jones (2013), supporting the view of Mansell (cited in SCIE, 2011) asserts that the evidence for individualised support is clear – in terms of a) its benefit for improving the lives of people with challenging behaviour, and b) the potential these approaches hold to reduce long-term support costs. ‘The evidence of what works best is clear; it now urgently needs to be implemented. We need people to actually develop individual services. If we started doing that, several things would happen. Individuals would have a better life; we’d begin to build expertise about how to do this and how to sustain it. And we’d stop wasting so much money on poor quality placements that aren’t really part of the solution.’ (Mansell, 2011, SCIE online)

Key references


Section 7: Self-directed support (SDS) and challenging behaviour

Limited research evidence to evaluate the impact of self-directed support (SDS) suggests that individual budgets (IBs) are effective for some people with complex needs where carers reported flexibility, control, choice and independence as the main benefits of SDS. Research identifies a number of barriers to SDS including: lack of accessible information, professional concern about placing vulnerable adults at risk and a lack of awareness among social workers of the availability and possible benefits of SDS.

- Self-directed support (SDS) policies have been adopted by both Scottish and Westminster governments to move forward the agenda of personalisation in health and social care. *Putting People First* (DH, 2007) stated that adult social care was to be guided by person-centred planning, SDS and personal budgets for all who were eligible. With SDS, people assessed as having social care needs are offered a funding package instead of directly provided services to meet those needs. SDS should be available to all people with challenging behaviour and their families.

- SDS can be delivered in several ways, ranging from Direct Payments (DPs) to the person to notional budgets managed by the council through council-commissioned services (SCIE, 2012). Data for 2012/13 reported by Hatton (2014) suggests a rapid increase in the number of working age (18-64) adults with learning disabilities receiving SDS and DPs, largely accounted for by an increase in the numbers of people receiving SDS in the form of council-managed personal budgets. These figures indicate that in the region of 60% of adults with learning disabilities are receiving some form of DP or SDS. Hatton raises concerns that although these statistics suggest rapid progress, wide geographical variation, the possibility that councils may be re-labelling existing DPs as SDS, a need for more information about how council-managed SDS budgets are benefiting people, and a relatively static number of people with learning disabilities on DPs suggest that policy objectives concerning the provision of meaningful SDS have yet to be achieved in ways that are meaningful to people with learning disabilities and their families.
Harkes et al (2014) reviewed the evidence base underpinning SDS. The systematic review revealed little robust evidence to demonstrate that a clear government strategy underpinned DPs or the promotion of SDS for people with learning disabilities. Harkes et al (2014) reported that few studies had specifically examined the impact of SDS on people with learning disabilities.

Existing research provides limited evidence that IBs are effective for some people with learning disabilities (Donnelly and Brooke-Mawson, 2008; Chapman, 2008; Hatton and Waters, 2007; Glendinning et al, 2008). This includes two small-scale studies that looked specifically at IBs with people with complex support needs (Homer and Gilder, 2008; Henwood and Hudson, 2009). In studies with people with complex support needs, interviews were mostly with carers who reported flexibility, control, choice and independence as the main benefits of SDS despite significant challenges of negotiating for and managing a care package. Henwood and Hudson (2009) highlighted that ongoing support from family was essential in making SDS work.

Hall (2009) argues that people with physical disabilities, and those with mild to moderate learning disabilities with existing support, have been best placed to take advantage of personal budgets. Henwood and Hudson (2009) found that not all councils in England included people with complex needs in the move to SDS. Manthorpe et al (2011) and Lingard (2012) reported that staff often doubted whether the model of SDS was applicable to those with severe learning disabilities. Nevertheless, Davey et al (2007) concluded that DPs were believed to be of most benefit to users with high-level complex needs.

From the literature, it is evident that SDS is not as yet available to everyone with a learning disability; however, some of those who used it reported an improvement in their quality of life and the control they had over it.

The Challenging Behaviour Foundation has raised concerns about reports from families finding it difficult to access SDS. Their recent research into personalisation (Lingard, 2012) highlighted barriers to SDS encountered by participants with challenging behaviour including a lack of care management time to invest in setting up IBs and a lack of understanding on the part of care
managers of the possible application of SDS and its potential benefit to people with challenging needs.

- Research evidence identifies a number of barriers to SDS including: lack of access to accessible information (Manthorpe et al, 2011; Roulstone and Morgan, 2009); professional concern about placing vulnerable adults at risk; and a lack of awareness among social workers of the availability and possible benefits of SDS (Glendinning et al, 2008; Homer and Gilder, 2008; Manthorpe et al, 2011). For those in receipt of an IB there were concerns about the volume and complexity of paperwork, and the difficulty in recruiting good staff and integrating the various funding streams (Glendinning et al, 2008; Henwood and Hudson, 2007; Homer and Gilder, 2008; Manthorpe et al, 2011). Henwood and Hudson (2007) identified particular difficulties for people with complex needs with a range of different, often interrelated, needs that were likely to require support from different services, for example, social, health and housing services.

- Riddell et al (2006), in their UK-wide study, found that the North West of England had the highest number of people with learning disabilities using DPs, due in part to knowledgeable local support services and strong parental influence. Vick et al (2006) reported evidence of creative efforts to stimulate progress in relation to people with learning disabilities by using ‘Circles of Support’, ‘Person-centred Planning’, setting up ‘care funds’ and having contact with peer support groups. Davey et al (2007) suggested the need to invest in intensive, ongoing support such as user-controlled or family-led independent living trusts to increase the availability of DPs to people with learning disabilities.

- Several studies identified lack of social work staff awareness and experience of personal budgets as a barrier to obtaining SDS for people with learning disabilities who have more complex needs (Hall, 2009; Manthorpe et al, 2011; Lingard, 2012; Harkes et al, 2014).

- In conclusion, although challenges and barriers to using SDS have been identified, solutions have also been offered within the literature to suggest that
most could be overcome. The evidence that they will be effective is still to be found (Hall, 2009; Hatton, 2014).

**Key references**


Section 8: Research into the practice of out-of-area placements and returning people to their local area

Despite the closure of long-stay institutions research shows that people with challenging behaviour continue to be moved away from their family and local area in order to receive specialist support. Decisions to move people out of area are often made in response to crisis situations such as the breakdown of a local resource or family support and deplete investment in local resources for future generations. Recent case study material provides information about how some people with challenging behaviour have successfully returned to their local area.

- People with severe challenging behaviour remain vulnerable to exclusion from local services. Emerson et al (2008) showed that in 2006 one-third of people with learning disabilities aged 18-64, and in residential or nursing home accommodation commissioned by local authorities, were placed outside of their home authority area and that this proportion increased between 2003 and 2005. Predictors of out-of-area placement included: younger age, less severe learning disability, repeated self-injury, significant challenging behaviour, autistic spectrum disorder, mental health problems and having been detained under the Mental Health Act (Allen et al, 2007; Hassiotis et al, 2008).

- While a minority of out-of-area placements may be made for positive reasons, the majority are believed to stem from a failure of authorities to commission or provide adequate local support arrangements to meet people’s specialist needs, a belief accompanied by concerns about both the high costs and potentially poorer outcomes of such placements (Becker, 2006; Emerson et al, 2008).

- In a national practice survey, Emerson et al (2008) consulted with people with learning disabilities, families, advocacy organisations, commissioners and service providers on the subject of out-of-area placements. The research concluded that most people with learning disabilities, including people labelled as challenging, were not choosing to move away from their families, friends and local areas but instead decisions to move people out of area were often
made in response to crisis situations such as the breakdown of a local resource or family support (Beadle-Brown et al, 2005, 2006).

- A frequently reported consequence of moving people with challenging behaviour out of area is reduced contact with, and separation from, family and friends (Barron et al, 2011; Perry et al, 2007; Chinn et al, 2011).

- Research looking at the impact of out-of-area placements on quality of care or quality of life is limited. Concerns about the quality of out-of-area placements include low numbers with person-centred plans (Becker, 2006), low levels of access to healthcare, psychology, psychiatry and appropriate behavioural support (Becker, 2006; Allen et al, 2007). Pring (2004) and Goodman et al (2006) reported low levels of individual assessment and planning for people in out-of-area placements and raised concern over the extent to which monitoring oversight by the placing authorities was maintained in practice.

- The ethics of placing vulnerable people away from their home areas and families, through no choice of their own, is of serious concern (Emerson et al, 2008; Perry et al, 2013) and may contravene the rights of people with challenging behaviour to a family life (Bailey et al, 2010). Young people with learning disabilities who go to residential special schools and colleges are highly vulnerable, often living a long way from home (Abbott and Heslop, 2006).

- Perry et al (2013) compared the cost of out-of-area placements in one area with a matched sample of people from the same area who had remained in borough. Contrary to findings from other comparative studies (Hassiotis et al 2006; Pritchard and Roy, 2006) these authors found the overall cost of out-of-area placement cheaper, but concluded that although additional resources may be required, government policy to provide comprehensively for those who want to live locally, irrespective of their needs, appears to be attainable.

- Perry et al (2007) highlight that every person who moves out of a geographical area effectively depletes the local resources for others with similar needs. In relation to challenging behaviour the migration of people out
of area prevents the development of local skills in supporting complex distressed behaviour (Wood and Cooper, 2011).

- Recently a range of case study material has been reported giving information about how some people with challenging behaviour have successfully returned to their local area. These accounts evidence how effective and local specialist behavioural support has enabled people to progress to leading happier and more independent lives (Association for Supported Living, 2011; Toogood et al, 2011).

- Toogood et al (2011) provide a detailed account of work undertaken over a 10-year period to successfully support the return of a man with very distressed behaviour to his local area after an out-of-area provider terminated their support. This case study demonstrates how, with focused and skilled local input, extremely difficult behaviour can change and remain changed. The authors state that in the case study concerned, commissioners, specialist and mainstream services connected in ways that were helpful to him. Reviewing progress over a 10-year period, Toogood et al (2011) report that at the end of this period the individual is not cured of challenging behaviour and that it remains likely that he will always need the support of a capable environment where early intervention can be provided if signs of distress re-occur. However, the authors provide a detailed account of how this individual has successfully remained in his local area, established daily routines of his choice, developed hobbies and interests, and is continuing to enjoy a good level of community involvement.

- One of the key policy objectives set out in Valuing People Now (DH, 2009) is that people should have ‘…an informed choice about where, and with whom, they live’ (p.21). The capacity to provide comprehensive local services is a prerequisite for this, because it is only then that a decision to move out of area would not be enforced by an absence of suitable local provision.

- Good multidisciplinary support, including skilled social work input (IDeA, 2008; Baker, 2011; Cooper, 2011) is an essential part of supporting people with challenging behaviour to return to their local area.
Key references


Association for Supported Living (2011) There is an Alternative. Loughton: ASL


Section 9: Research on transition and learning disability

There is a considerable body of literature exploring the transition from children to adult services for children with a range of health, behavioural and learning needs. The evidence suggests that challenges of collaboration across agency and professional boundaries mean that good practice guidelines continue to remain unheeded for most of these young people, including young people with challenging behaviour. The suggestions and feedback from young people and carers about good practice centre on good information, forward planning, outcome-based plans and named key professionals in adult services.

- Transition in this context is largely a bureaucratically driven change for young people with learning disabilities concerning the move from childhood to adult support services. The literature also notes the changes in meaning and identity associated with adulthood both for young people and their carers. There have been two major literature reviews and associated research studies to provide guidance on good practice. SCIE commissioned an exploration of the information needs of young people and families at transition called the ‘The Road Ahead’ (2004). Deb et al (2006) provided guidelines for ‘Services for Young People (14-25 years) with Learning Difficulties/Disabilities and Mental Health problems/Challenging Behaviours’ in the form of a quick reference guide. Central guidelines for the management of transition for young people also exist (DH, 2006).

- ‘The Road Ahead’ (SCIE, 2004) and more recently ‘From the Pond into the Sea’ (CQC, 2014) showed that transition remained a period of confusion and stress for young people and their carers. It did not often meet aspirations for ‘adult status of work or financial independence, living away from home, social and sexual relationships’ (Beresford, 2004 p.583). Alborez (2003) noted that people with learning disabilities and challenging behaviour rarely moved from the family home as part of the ‘normative’ family life cycle and the majority of such moves were a result of problems in the family, behaviour resulting in forensic/police contact or service deficits.

- The negative messages about the experience of transition persist in more recent research suggesting continuing difficulties in forward planning, co-
ordination and negotiation of responsibilities, and lack of involvement of young people themselves or their carers (Heslop and Abbott 2009; Raghavan and Pawson, 2013; CQC, 2014).

- Informal care was key to achieving employment outcomes (Beyer, 2008). Barron et al (2013), in a study of a cohort of young people with challenging behaviour, noted the high contribution of informal care and the higher provision of full-time education to this group. Costs of care were associated with levels of disability rather than levels of challenge young people presented.

- A need for information is identified as essential both by parents (Attfield, 2009) and young people themselves (Tartleton and Ward 2005). Heslop and Abbott (2007, p.491) also noted that parents valued four key elements as helpful: ‘being well connected with other parents or with key professionals; being proactive; having sufficient information; and good forward planning’. There are differences in perceptions of transition between parents, young people and professionals. Smart (2004, p.130) noted parents’ desire for ‘atmosphere and environment’ in considering future options for their children, whereas professionals prioritised ‘educational and employment opportunities’. Pascall and Hendy (2004) noted the key role articulate parents had played in achieving independence. Deb et al (2007), in their review, note the perception of parents in conflict with professionals, particularly in adult services. This was supported in further focus group discussions with parents (Unwin et al, 2008). Professional preoccupation with ‘transition processes’ rather than outcomes reinforces ideas of difference in approach to transition (Kaehne and Beyer, 2009).

- Hudson (2006) provides an analysis of the apparent failure of collaborative requirements of transition planning as being a result of: competing priorities in learning disability services; short- versus long-term perspectives; organisational complexity and environmental turbulence; visible and invisible transition; and transition as ‘everybody’s distant relative’. He suggests that further central guidance to frame good practice is unlikely to be effective and that organisations can best respond to such complexity by individual mapping
of a person-centred approach. Williams and Heslop (2006) found young people better able to express their preferred outcomes in the process of transition through the emotional support of friendship groups.

**Key references**

CQC (2014) From the Pond into the Sea: Children’s Transition to adult health services


DH (2006) Transition: Getting it Right for Young People, Improving the Transition of Young People with Long-Term Conditions from Children’s to Adult Health Services. Child Health and Maternity Services Branch


Section 10: Research into the organisational context for social workers in supporting people with learning disabilities and challenging behaviour

The evaluations of practice centre on multi-agency approaches to supporting people and their families and do not identify the specific contribution of social work. Within this context there is evidence of social work practitioners having difficulty committing to long-term planning. Resource constraints requiring safeguarding concerns to be prioritised, an increased use of agency and temporary staff, and the generic nature of some social work settings are suggested as factors in hindering practice and provide a context for the evidence that social workers do not always feel confident and informed in their specific roles of either supporting individuals and families, or to challenge poor practice in reviews. The management and strategic commitment to develop a collaborative culture for commissioning and operational support to social workers is often not present.

- The literature on social workers specifically working with people with learning disabilities and/or challenging behaviour in the implementation of personalised social care services is limited. Examples of the contribution of social care have to be inferred as part of evaluations of multi-agency approaches (Sims and Gukyurtlu, 2013; Hill, 2007; Carnaby et al, 2010). However, there is some evidence and good practice guidance generated more generally for other groups that could be considered relevant (Henwood and Hudson 2009; Newbronner et al, 2011).

- This lack of direct evidence reflects a lack of clarity about the social work role within present multi-agency policy contexts, although there is also evidence of some ambivalence to personalisation for people with learning disabilities among social workers (Sim and Gukyurtlu, 2013; Henwood and Hudson, 2009). However, recent analysis does suggest a trend towards an increasing use of personal budgets for people with learning disabilities (Hatton, 2014).

- Social workers in a generic context are under pressure to prioritise other work, such as safeguarding, rather than investment in time on collaborative individual planning for people who are challenging (Lingard et al, 2014) or visits to out-of-area placements (Beadle-Brown et al, 2006; Becker, 2006).
There is a suggested lack of overall expertise and confidence among social workers about the development of person-centred plans for people with challenging behaviour (Giraud-Saunders, 2014; Lingard et al, 2014). The research evidence suggests that this is also experienced by parents and carers seeking advice (McGill et al, 2010; Wodehouse and McGill, 2009). The use of temporary employment agency staff to maintain adult social care services also contributes to lack of expertise within the service (Cornes et al, 2010).

The absence of clear person-centred planning leads to a lack of positive outcome measures that could contribute to the review and evaluation of packages of support options for individuals (Beadle-Brown et al, 2006; Lingard et al, 2014) and/or the defence of potentially expensive packages of support for commissioners (NDTi, 2010; McGill et al, 2010).

Collaborative and partnership working with other agencies is enhanced by the development of a ‘shared vision’ and attention to different professional identities and organisational concerns of those involved (Dixon, 2000; Hill, 2007; Giraud-Saunders, 2014).

Evaluations and good practice guidance note that within the present policy context, a strategic and management commitment to shared practice and values, service development, and commissioning and funding is needed to ensure frontline clarity for those working directly with people who challenge services (Emerson et al, 2008; NDTi, 2010).

Key references


Section 11: Research on quality of life, wellbeing and learning disability

Research on quality of life for people with learning disabilities has focused increasingly on subjective and person-centred approaches, alongside a growing emphasis on the impact of the environment on people's wellbeing. Research to date has shown that smaller, less institutionalised settings do support greater choice and self-determination for learning disabled service users. However, as yet, no systematic link between smaller/less institutionalised settings and a reduction in challenging behaviour has been identified, suggesting that more research is needed into the impact of staff management practices and staff/service user interactions in these settings. In addition, there are growing calls to promote greater awareness of wellbeing (subjective and environmental) in social work education, in recognition of the potential for social workers to influence wider structural concerns.

- The trend towards using ‘quality of life’ (QoL) indicators for evaluation and researching learning disability services, and for assessing and evaluating personal outcomes, has been shaped by the conceptual problem of from whose perspective notions of ‘quality’ are determined (Northway and Jenkins, 2003). In the context of learning disability (drawing on the wider QoL and wellbeing literature), these indicators have generally covered areas such as: independence, life satisfaction, emotional and physical wellbeing, employment, community activities, social networks and relationships, civic participation/social inclusion, choice and self-determination, material changes, and personal skills (Schalock, 2004; Walsh et al, 2010).

- In recent years, there has been a definite shift from objective measures towards more subjective and person-centred approaches, including life story work that actively engages with people with learning disabilities (Beadle-Brown, 2006; Walsh et al, 2010). This has been accompanied by a growing emphasis on ‘wellbeing’, which includes a greater emphasis on environmental factors alongside subjective indicators.

- A systematic review of the literature on quality of life, learning disability and supported accommodation found consistent evidence that greater choice and self-determination is available in smaller less institutional settings, and that
these settings led to some developments in personal skills, and greater participation in community-based activities. However, there was considerable evidence of no systematic association between de-institutionalisation and emotional wellbeing, mental health or challenging behaviour in less institutionalised settings (Walsh et al, 2010). The authors call for more research to explore the apparent failures of these settings to improve residents’ wellbeing. They suggest future studies need to pay closer attention to the impact of staff management practices, social climate, working methods, and staff activities on service user wellbeing outcomes. This is corroborated by a study that highlighted the relationship between staff/service user interactions and service user choice, control and participation in daily activities (Clement and Bigby, 2010).

- In addition, there have been calls for more research on the impact of structural issues such as poverty, rurality, neighbourhood deprivation and social capital on learning disabled people’s quality of life and wellbeing, particularly in light of the findings from the 2005 National Survey on learning disability (Walsh et al, 2010; Emerson et al, 2005).

- More recently there has been a call to incorporate wellbeing (subjective and environmental) as a critical tool for practice in social work and social work education (Dominelli and Hackett, 2010). Simpson argues that a ‘justification for its inclusion is the focus upon holistic models of practice…a whole person approach, which acknowledges vulnerability and also seeks affirmation from a strengths-based perspective’ (2012, p.626). This, he argues, attends to the social work concern with the person and society, and could serve to shift the balance from an over-emphasis on ‘choice’ (and the associated cost-cutting agenda associated with personalisation) to greater consideration of community integration and social relationships.

- Simpson described a social work teaching model that was developed, which focused on three specific elements of wellbeing: friendships and relationships; community engagement; and the structural context. This, he argues, served to ‘develop a more critical engagement with the current narrow focus of the
personalisation agenda, whilst promoting the ‘needs’ of this service user group’ (2012, p.633).

**Key references**


Section 12: Building community capacity for inclusion of people with challenging behaviour

Our research returned very few articles that explicitly addressed the question of community responses/reactions/networks/social inclusion for people with challenging behaviour. Indeed, in 2012, Christine Bigby (the internationally renowned researcher in learning disability) published a systematic review of the literature concerning social inclusion and people labelled as having behaviour that challenges. She identified a paucity of research in this field, arguing that there is a ‘complete absence of research beyond the level of the individual that considers, for example, the inclusive nature of localities or locally based clubs or organisations’ (p. 369). There are a few examples of the importance of functional assessment and multi-behavioural support plans to help improve outcomes for people with challenging behaviour living in the community, covered elsewhere in the review (LaVigna and Willis, 2005; MacDonald et al, 2010; Toogood et al, 2011) but very little about people’s networks and interactions in the community.

Nevertheless, we have opened the search as widely as possible and report the findings below:

- Bates (2010) catalogued strategies for engaging members of the public in offering support to disabled people. The Inclusion Web Resource Pack is a practical resource for organisations and groups supporting people with challenging behaviour to increase their community inclusion and help demonstrate service effectiveness (Bates, 2010).

- Bates et al (2012) discuss the value of ‘subtle’ (p. 156) support and contrast it with more overt, visible and inappropriate ways to support community participation and inclusion. While this paper makes no specific reference to challenging behaviour the messages are of relevance. The authors argue that getting support for inclusion right from the start forms a secure foundation for the person to move into genuine engagement with other participants in the community. Bates et al (2012) argue that support with community inclusion must be person centred, as what works for one person may not work for another. Therefore plans must clearly specify how the person wishes to be supported in each setting, how other participants will become involved, and
how things will change over time. When done well, it enables some of the support to transfer from the worker to informal community members, and so the person merges into the general community and acquires friends.

- To do this, frontline staff need to develop skills in person-centred planning, community mapping (Bates, 2010), capacity building, subtle support and problem resolution. Advocates need to recognise the value as well as the hazards of engaging with the wider community; and employers need to support these activities in their confidentiality procedures, culture of risk management and opportunity support, and understanding of professional boundaries.

- Mabel Cooper, a self-advocate with learning disabilities, and her supporter Jane Abraham undertook an innovative project to promote the social inclusion of people with complex needs within local communities. Cooper visited primary and secondary schools in London to talk to children about her life story, including her experience of being sent away to a long-stay learning disability hospital as a child. The aim of the presentations was to support a shift in attitude away from the view of people as dependent and ‘ineducable’ to a more inclusive society where people with learning difficulties, including those with challenging behaviours, are accepted, valued and welcomed within their local schools and communities. Mabel Cooper’s story challenged the limitations and negative stereotypes often associated with the label of learning disability. The aim of sharing her story with young children was to contribute to breaking down attitudinal barriers to accommodating people within local communities and to provide children with the opportunity to engage directly with a person with learning disabilities. The project was not formally evaluated but initial feedback from children and teaching staff was very positive. Further funding is now being sought to develop similar local projects (Cooper and Abraham, 2005; DH, 2013; Abraham et al, 2014).

- Think Local Act Personal Building Community Capacity
  http://www.thinklocalactpersonal.org.uk/BCC/Learning_network/Timebanking/?parent=9030&child=9543 (Greg’s story) provides a number of practical
examples of involvement in how involvement in schemes such as timebanks have supported community networking for people with challenging behaviour.

- The ‘Include Me In Research’ Project (TIMRT, 2012) provided independent evaluation of a large independent living project (ILP) carried out in Leeds between 2009 and 2011. The ILP project involved the relocation of over 300 people living across nine local authority learning disability and four mental health hostels to new supported independent living accommodation. The experiences of people described as having challenging behaviour or autism were included in this evaluation. A principal aim was to find out if the moves had an impact on social inclusion. The research explored the experiences of residents, support staff/managers and family carers before and after relocation. The main methods of data collection were one-to-one interviews, focus groups and a social inclusion questionnaire completed with residents. Creative methods were also used with residents. Overall responses showed little difference in social inclusion after a move to independent living. While some learning disabled residents talked of accessing a varied a range of community facilities for leisure and social activities, researchers noted that a number of residents with higher support needs went out less than they did when living in the hostels. Responses indicated that community involvement for some relied heavily upon the availability of staff to accompany them. Family carers believed involvement was more about establishing meaningful ties and relationships with the community, which they felt was lacking. A key recommendation from this project is the need to build in consultation with local communities at an early stage. The research also highlights that volunteer involvement to facilitate community/activity participation and inclusion could be further considered.

**Key references:**


Section 13: Good practice guidance prepared by other professional bodies of relevance to the social work role with people with challenging behaviour

The following publications were identified as potentially relevant for informing future work on social work guidance:


- Department of Health (2012) No Health without Mental Health: Implementation Framework. Available online at:


- Hollins et al (Numerous dates and publications) Books Beyond Words (http://www.booksbeyondwords.co.uk/ produces books) Publications are available to support communication with people with learning disabilities about bereavement, dementia and mental health

- LGA/NHS England (2014) Ensuring quality services: Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges. London: LGA


• Royal College of Speech and Language Therapists (2013) Five Good Communication Standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. London: RCSLT

• The Think Local Act Personal (TLAP) homepage contains a link to a section on Building Community Capacity, which contains a helpful list of references and resources. http://www.thinklocalactpersonal.org.uk/BCC/


• Turner S and Bates P. (2013) Green Light Toolkit 2013: A guide to auditing and improving your mental health service so that it is effective in supporting people with autism and people with learning disabilities. London: NDTi

Forthcoming

NICE guidelines on learning disability and challenging behaviour due May 2015.
Appendix 1: Summary of literature review process and criteria

Search strategy
We conducted our literature review using three key databases (ASSIA, Community Care Inform and Social Care Online). Where necessary, we also drew on Medline and NHS Evidence.

When required, we also used snowballing techniques to identify additional literature of relevance.

Our focus was on the findings of empirical research projects.

We focused on peer reviewed journal articles and books, and consulted relevant grey literature where needed.

We targeted the search on studies published in the past 10 years, but drew on earlier seminal works where appropriate.

We focused on UK-based studies, but drew on international studies where appropriate.

Example of a search strategy: Topic of Quality of Life, Wellbeing and Learning Disability:

Database: Social Care Online

Search Terms: Social Work AND Quality of Life AND Learning Disability

Returned: (0)

Refined search terms: Quality of Life AND Learning Disability

Returned (31)

Of relevance: 1 (Simpson, 2012)

Database: ASSIA: Same search terms returned 13 and 60 respectively, but only 1 of relevance.

Therefore used snowballing, focused on Walsh et al (2010) and Simpson (2012).
Reference list


Association for Supported Living (2011) There is an Alternative. Loughton: ASL.


Bering S. (2010) Facing the commissioning challenge: responding effectively to people whose behaviour is challenging. Advances in Mental Health and Intellectual Disabilities, vol.4, iss.2, pp.4-12


Care Quality Commission (2014) From the Pond into the Sea: Children’s Transition to Adult Health Services. London: CQC


Cooper V. (2012) Support and services for individuals with intellectual disabilities whose behaviour is described as challenging, and the impact of recent inquiries. Advances in Mental Health and Intellectual Disabilities, vol.6, no.5, pp.229-235


Preece D. (2009) Effective short break services for children with ASDs: how one local authority in the UK is working to meet the challenge. Practice: Social Work in Action, 21(3), September 2009, pp.159-174


Royal College of Speech and Language Therapists (2013) Five Good Communication Standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. London: RCSLT


The Include Me In Research Team (2012) The Include Me In Research Project: An Evaluation of the Independent Living Project, Leeds


