

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

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Chris Bean
Project Lead

“Equality and diversity are at the heart of the NHS strategy. Due regard to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it, has been given throughout the development of the policies and processes cited in this document.”

Foreword



The aim of this Core Principles Commissioning Tool, and the project that developed it, is to support commissioners to improve the lives of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges through better informed local commissioning. This tool builds on the findings of the Department of Health's Review into events at Winterbourne View Hospital, and restates a model of care which is known to represent best practice.

While it is right that we do not inadvertently create unwarranted dependency on support services for any individual, there is clearly a need to look at an individual's whole life and commission services in a way that is personalised and local. Too often the experience for the individual and their family is multiple services working in isolation, working at cross purposes and avoiding responsibility, not wrapping around in the best interests of the individual. It is also frequently reported that emerging problems were predictable and could-have been prevented had co-ordinated, multiagency pro-active care been provided.

This document is for use by commissioners of education, health and social care (local authorities and clinical commissioning groups) and prescribed specialised services (NHS England). It is imperative that they work together and in partnership with the individual and their family when implementing it. A relentless person-centred focus on outcomes is paramount; all decisions should be based on the best interests of the individual with full recognition that family carers are most often those who know what the 'best interests' of the individual are. We believe the result of using this tool, with integrity; will be

improved quality of life for individuals and their carers; reductions in prevalence and incidence of behaviour that challenges; reduction of inappropriate placements; and reduction in inappropriate psychoactive medication, restraint and seclusion. What are we waiting for?

The transformation described within 'Transforming Care: A national response to Winterbourne View Hospital', needs to be considered alongside a wide range of other sector improvement programmes and policies. In particular: the introduction of Education, Health and Care Plans for all under 25-year-olds identified with special educational needs or disabilities (SEND); transition to adult services, which is the focus of the Preparing for Adulthood Programme; personal health budgets which will be available to those in receipt of Continuing Healthcare from October; National Market Development Forum tools and guidance on commissioning best practice and integration of services pioneer sites.

We urge commissioners to make full use of this tool in developing their service specifications, engaging meaningfully and in a coproductive way with local individuals and families, and using the learning to continuously improve local decision making and investment plans. The Winterbourne View Improvement Team and our partners welcome feedback and look forward to hearing about the progress you are making.

A handwritten signature in black ink, appearing to read 'Bill Mumford'. The signature is written in a cursive, flowing style.

Bill Mumford

Programme Director, Winterbourne View Joint Improvement Programme

Introduction

What is this document?

The aim of this Core Principles Commissioning Tool is to support the commissioning of high quality and safe services which meet the needs of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges, together with the needs of their families, throughout the life course.

This document describes the core principles that should be present across **all education, health and social care services** being accessed by children, young people, adults and older people with learning disabilities and or / autism who either display or are at risk of displaying behaviour that challenges.

Application of the Core Principles Commissioning Tool should result in:

- improved quality of life for children, young people, adults and older people who have learning disabilities and / or autism and their families through improved services which meet their needs
- reductions in the prevalence and incidence of behaviour that challenges amongst children, young people, adults and older people who have learning disabilities and / or autism
- reductions in the number of individuals placed in more restrictive settings which are inappropriate for their needs (for example, specialist hospitals and assessment and treatment (A&T) units, 52-week school/ college placements or residential care homes), especially those that are out of

area. The emphasis should always be on the provision of support in the least restrictive setting possible. Where, in a reduced number of cases, provision such as A&T services are required for a short period of time, the principles within this document will remain essential for supporting those who display behaviours that challenge

- reductions in the inappropriate use of psychoactive medication, restraint, and seclusion to manage behaviour that challenges.

Who is this document for?

This Core Principles Commissioning Tool is primarily for commissioners of education, health and social care (local authorities and clinical commissioning groups) and prescribed specialised health services (NHS England) in England. It has been produced in support of the shared commitment to ensure better life experiences and improved outcomes for this group of individuals, as well as delivering service quality and value for money, as outlined in *Transforming care: A national response to Winterbourne View Hospital* (Department of Health, 2012). It also supports a number of the provisions (subject to parliamentary approval) in the Children and Families Bill (2013) which aim to transform the system for children and young people with special educational needs and disabilities (SEND), including those who have learning/developmental disabilities.

This Core Principles Commissioning Tool is also of relevance to wider stakeholders (family carers, professionals, self-advocacy groups, family carer forums, researchers and providers) who support children, young people, adults and older people with learning disabilities and or / autism to enable them to advocate for and support high quality service transformations.

How should this document be used?

The 14 core principles in this document provide a foundation for commissioners to use to review services and develop more detailed local plans and specifications for future service delivery. Commissioners should also draw upon other specific and related guidance regarding support for children, young people, adults and older adults with learning disabilities and/or autism. **This is particularly true for those individuals who have autism and do not have a learning disability and for those individuals who have mental health difficulties who may or may not display behaviour that challenges.**

Associated guidance

This guidance should be read in conjunction with the forthcoming Department of Health (DH) guidance on the use of Positive Behaviour Support (PBS) and the minimisation or restrictive practices, and the Skills for Care and Skills for Health guidance on the commissioning of training in the use of PBS and restrictive practices. Both these documents will apply to all adults receiving health and social care services and are not focused on learning disability services. The Department of Health is also reviewing and updating the Mental Health Act Code of Practice, which provides guidance on the use of restrictive practices for individuals covered by the Mental Health Act 1983.

NHS Protect has also produced guidance on managing behaviour that challenges and the National Institute of Clinical Excellence (NICE) is also currently developing guidance regarding support for people who display behaviour that challenges, including children and young people which is due to be published in 2015.

Links and references are listed in the 'Resources and further reading' section at the end of this document. The Department of Health, Skills for Care and Skills for Health guidance which is yet to be published will be available via www.gov.uk later this year.

Definitions

Learning disabilities

As set out in Valuing People (HM Government, 2001, p. 14), individuals with learning disabilities (internationally referred to as individuals with intellectual disabilities) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
 - a reduced ability to cope independently (impaired social functioning)
 - which started before adulthood with a lasting effect on development.

Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability and those who have not received an IQ test or who have been found to score in the borderline range should not be automatically excluded from the scope of this guidance or services that are commissioned.

In early childhood (that is, under five years) it can also be difficult to determine whether or not a child with delays in development has a learning disability. During these years a label of Global Developmental Delay is often used. Children and young people with this diagnosis are therefore also considered within the scope of this guidance.

Autism

As described by the NICE Guidelines, autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities. Individuals with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

This Core Principles Commissioning Tool recognises that individuals and groups may prefer a variety of other terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. For clarity and consistency, in this document the term 'autism' is used throughout, in keeping with the use of 'autism' as described in 'Fulfilling and rewarding lives: the strategy for adults with autism in England' (DH, 2010).

Some individuals with autism also have a learning disability but many do not (that is, those with high functioning autism or Asperger's Syndrome). As previously indicated, further guidance needs to be drawn upon in addition to this document to ensure commissioners meet their specific needs.

Life course

'Life course' encompasses all age groups from pregnancy and birth through childhood, adulthood and older-adulthood (to the point of death).

Behaviour that challenges

As set out in *Challenging Behaviour: A Unified Approach* (Royal College of Psychiatrists, et al, 2007, p.14) challenging behaviour is behaviour "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 is likely to lead to responses that are restrictive, aversive or result in exclusion".

Risk factors

Not all children, young people, adults and older people who have learning disabilities and / or autism will display behaviour that challenges. A variety of factors are likely to contribute towards the development, maintenance and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical health difficulties, communication difficulties, mental health difficulties, neurological difficulties, quality of support, and exposure to adversities.

Behaviour that challenges:

- is generally considered as learned behaviour that serves important functions for the person who displays it (it helps the individual to cope better or exert some control over their immediate environment) and is not a deliberate attempt (including if a phenotype) to upset or harm others
 - is not a diagnosis, mental health or physical health condition (though mental and physical health conditions can be contributing factors)
 - is influenced by a variety of factors including the individual needs and abilities of the person who displays it, the adversities to which they have been exposed and the behaviour of others who support them
 - usually begins in childhood or young adulthood and without effective intervention is highly persistent; around 30 per cent of young children with learning disabilities (aged 0 to three) display behaviour difficulties (Emerson & Enfield, 2011)
 - puts individuals who display the behaviour at increased risk of exclusion, physical injury, abuse, and harsh restrictive management approaches such as physical restraint
 - is associated with high rates of stress and other emotional difficulties amongst family carers and others who support children, young people, adults and older people with learning disabilities and / or autism.
- is displayed by 10 to 15 per cent of adults who have a learning disability (see Emerson & Enfield, 2011)
 - occurs in many forms (for example, aggression, self-injury, property damage, etc) but is defined by the impact it has on the wellbeing and quality of life of the person who displays it and others who support them

Core principles

1. Positive Behavioural Support

Positive Behavioural Support (PBS) is built on the strongest evidence base for supporting individuals with behaviour that challenges.

PBS is not a single intervention or therapy. It is a multi-component framework for delivering a range of evidence based supports to increase quality of life and **reduce the occurrence, severity or impact of behaviours that challenge**.

PBS is not a 'one-size fits all approach'. It is underpinned by person-centred values and demands flexibility and tailoring that responds to the individual needs, complexities and circumstances of children, young people, adults and older people with learning disabilities and / or autism, together with their families, throughout the life course. A holistic assessment of need underpins the planning and delivery of appropriate support for each individual.

The core principles for commissioning and specifying services outlined below stem from PBS. They are applied here across the life course and settings that cover generic and specialist education, health and social care services commissioned and/or delivered locally, regionally and nationally for individuals who either display or are at risk of displaying behaviour that challenges; as well as prescribed specialised health services. For a comprehensive account of PBS see the essential reading listed at the end of this document.

2. A whole systems life course approach

Behaviour that challenges can be displayed at multiple points during the life course of individuals with learning disabilities and / or autism. It also occurs in multiple settings and is influenced by multiple factors. Commissioners should therefore ensure that:

- The individual is at the centre of planning and commissioning. Services are flexible and adjust to changes in need over the life course.
- Individuals and their families are aware that they can have a personal budget or personal health budget, including the option of a direct payment. Adults and older people receiving NHS Continuing Healthcare and children and young people receiving Continuing Healthcare will have the right to have a personal health budget from October 2014.
- Local specialist challenging behaviour services for individuals with learning disabilities and / or autism are routinely provided to meet the needs of children, young people, adults and older people.
- Wider services (such as those providing physical health care, housing, dental care or leisure activities) should make reasonable adjustments to ensure smooth access and effective support for children, young people, adults and older adults with learning disabilities and / or autism.
- A wide range of mental health services including those provided by general practitioners (GPs), mainstream mental health and forensic services, and specialist

learning disability services are accessible to individuals with learning disabilities and/or autism of all ages who display or are at risk of displaying behaviours that challenge.

- Particular attention should be paid to times of transition both between and within services which are focused on the needs of children and young people and those which are focused on the needs of adults and older adults. Services focusing on each age group need to work closely, well in advance of a transition to support individuals and families effectively.
- At all ages, education, health and social care services should work in partnership to deliver the kind of consistent and holistic support that is required to meet the needs of individuals with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges together with their families.

3. Prevention and early intervention

Behaviour that challenges often (though not always) begins in childhood or young adulthood. There are a number of risk factors that can be used to predict which individuals with learning disabilities and / or autism are most likely to develop behaviour that challenges both at an early stage and in later life. The early detection of risk factors and systematic assessments of behaviour is the key to prevention of behaviour difficulties and the basis of early intervention. A major aim of PBS is to reduce the likelihood of behaviour that challenges by providing supports at an early stage to proactively address these risk factors. This should include:

- early screening and clear, smooth diagnostic pathways for children and young people suspected of having a learning disability and / or autism
- proactive prevention via the identification of additional risk factors for development

of behaviour that challenges across all age groups of people with learning disabilities and / or autism. This should include those with rare genetic syndromes (for example, Cornelia de Lange syndrome or Lesch-Nyhan syndrome) associated with behaviour that challenges; those with significant communication impairments; those with additional mental health, physical health or sensory needs; and those who are exposed to high rates of environmental adversity (for example, poverty, abuse, harsh or inconsistent parenting)

- recognition that children, young people, adults and older people with learning disabilities and / or autism are at increased risk of displaying psychiatric disorders; consequently services should ensure support for behavioural problems includes an assessment of possible psychiatric co-morbidities
- early intervention supports to meet the needs of children and young people with learning disabilities and / or autism together with their families at the point of identification; with further specialist supports provided, when additional risk factors have been identified and / or early forms of behaviour that challenges have been highlighted. Consideration should be given to commissioning parenting support programmes that have been shown to be cost effective in reducing behaviour that challenges (see the Department for Education's parenting programme commissioning toolkit)
- recognition that children, young people, adults and older people with learning disabilities and / or autism who are not currently displaying behaviour that challenges may still be at risk of doing so if adequate supports that prevent this behaviour are not in place, or have been removed following a reduction in behaviour that challenges
- recognition that additional risk factors for development of behaviour that challenges may emerge in later stages, including during

adulthood, which need to be predicted, identified and supported proactively (this should include development of dementia amongst older people with learning disabilities and / or autism)

- provision of environments that are suited to the needs of children, young people, adults and older people with learning disabilities and / or autism (this should include a consideration of how predictable the environment is; levels of stimulation, and the quality and frequency of interactions with other people).

4. Family carer and stakeholder partnerships

Whilst the focus on the rights and needs of the individual is paramount, working in partnership with family carers and other stakeholders (ie siblings, professionals, advocates, service providers) who directly support children, young people, adults and older people with learning disabilities and / or autism is an essential aspect of PBS. This does not mean that family carers should be made responsible for implementing or coordinating all supports and interventions unaided; this should remain a partnership with their key worker. Working in partnership should include:

- supporting family members to be parents, siblings and relatives first and foremost, which means supporting the families of individuals with learning disabilities and / or autism to lead a full family life and to maintain their physical and emotional resilience
- close involvement of family carers and other stakeholders throughout assessment, planning and intervention pathways to support children, young people, adults and older people with behaviour that challenges
- specific training and support programmes that empower family carers and other stakeholders to most effectively support children, young people, adults and older

people with learning disabilities and / or autism, particularly in relation to behaviour that challenges.

- support for the emotional wellbeing and resilience of family carers (including parents and siblings) and paid carers in recognition of the high rates of stress and other emotional difficulties found amongst those who support individuals with behaviour that challenges.
- support for children, young people, adults and older people with learning disabilities and / or autism who display behaviour that challenges to access short break and respite services (the difficulties to families arising from supporting a relative with behaviour that challenges should not be under-estimated and providing short break and respite services proactively is therefore essential for families to cope over time and lead a full family life)
- recognising the importance of the key worker role and the skills and expertise required to fulfil it within job descriptions.

5. Function based holistic assessment

Within a PBS framework, interventions to support children, young people, adults and older people who display behaviour that challenges should be preceded by a thorough, holistic assessment facilitated by a suitably trained person or group of people. This is generally referred to as a Functional Assessment, the main features of which should:

- ensure individualisation and tailoring of assessment procedures and arrangements with close involvement of family carers and stakeholders
- follow a systematic and data-driven process
- consider the individual's physical environment and consider how other people behave towards the individual and respond

to behaviour that challenges

- consider the broader context that may influence how and why the individual displays behaviour that challenges (including mental health and physical health factors; communication and sensory needs and relationships and social inclusion)
- consideration of underlying biological/genetic factors (certain rare genetic syndromes have a behavioural phenotype which is associated with specific behaviour that challenges)
- provide an understanding of when and why the individual is displaying behaviour that challenges by helping to identify the function of that behaviour (in other words, how it helps the individual to cope better or exert some control over their immediate environment).

6. Behaviour that challenges is reduced by better meeting needs and increasing quality of life

Supports and interventions for children, young people, adults and older people who display behaviour that challenges should be based on a functional understanding of that behaviour following function based holistic assessment. Within a PBS framework the vast majority of supports should focus on better meeting an individual's needs and increasing their quality of life in a way that reduces the likelihood of behaviour that challenges occurring in the future.

Best practice supports should include:

- provision of an environment appropriate to the individual that is less challenging and ensures helpful support arrangements from others (in other words, how others communicate with and proactively meet the needs of an individual to reduce the likelihood of behaviour that challenges)
- strategies that develop the individual's

competencies to ensure that their capacity to influence the world is less restricted; this is likely to include support to develop communication or other skills that can serve the same functions as those that relate to behaviour that challenges

- support to address broader needs identified during assessment that relate to why the individual displays behaviour that challenges, including physical health and mental health, communication and sensory difficulties, and relationships and social inclusion
- support to better address the needs of family carers and other stakeholders when these have been found to influence why the individual displays behaviour that challenges
- a set of (reactive) strategies to safely support an individual and others when it has not been possible to prevent an instance of behaviour that challenges
- active avoidance of restrictive and punitive approaches to managing behaviour that challenges at all times
- clear arrangements to support implementation and on-going monitoring of their effectiveness.

7. Support for communication

A high proportion of children, young people, adults and older people with learning disabilities and / or autism have communication difficulties. Communication impairment and insufficient adjustments from other people to support communication increases the likelihood that individuals with learning disabilities and / or autism will display behaviour that challenges. It is important for commissioners and providers to read and implement the Royal College of Speech and Language Therapists' recently published Five good communication standards, produced to meet Action 12 of the Winterbourne View Concordat. Consistent with a PBS framework, services should support communication needs across the life course by:

- providing ongoing support to individuals with learning disabilities and / or autism to develop functional forms of communication together with support to families and paid carers to adjust their own communication appropriately (these supports should be evidence-based and provided as an early-intervention/preventative measure irrespective of whether behaviour that challenges has developed or is currently being displayed and there should be a detailed description of how best to communicate with individuals)
- ensuring additional communication supports are provided as part of a package of interventions to support those who are either currently displaying or are at increased risk of displaying behaviour that challenges
- developing choice-making abilities and ensuring frequent opportunities to make choices that are effectively supported by others, or demonstrating how they support individuals with communication needs to be involved with decisions about their care and their services
- supporting the development and maintenance of positive social relationships, and creating opportunities, relationships and opportunities that make individuals want to communicate.
- effective systems to ensure the physical health needs of children, young people, adults and older people with learning disabilities and / or autism are identified and supported effectively through partnership working between GPs, acute services and specialist learning disability teams to ensure that physical health problems detected through annual health checks, screening, physical examinations and investigations are acted on and the outcomes monitored
- support for children, young people, adults and older people with learning disabilities and / or autism to understand and express their needs in relation to their health and wellbeing, and to access health-based information together with support and opportunities to lead healthy lifestyles
- support and training for family carers, paid carers and professionals to recognise how the child, young person, adult or older person with learning disabilities and / or autism that they support reacts to and communicates pain and discomfort from a range of conditions which may or may not be known to them
- support for individuals with learning disabilities and / or autism to communicate when they are experiencing pain, discomfort or other symptoms of physical illness.

8. Physical health support

Children, young people, adults and older people with learning disabilities and / or autism are at increased risk of experiencing physical health difficulties. Whilst behaviour that challenges is not a physical health diagnosis, experiencing difficulties in this area may be associated with why some individuals display behaviour that challenges. As part of the broad framework of supports for children, young people, adults and older people who display or are at risk of displaying behaviour that challenges there should be:

9. Mental health support

Children, young people, adults and older people with learning disabilities and / or autism are at increased risk, relative to the general population, of experiencing mental health difficulties. Whilst behaviour that challenges is not a mental health diagnosis, experiencing difficulties in this area may be associated with why some individuals display behaviour that challenges. Mental health difficulties, learning disability, autism, behaviours that challenge, and offending behaviour can coexist and be difficult to distinguish especially with coexisting communication difficulties (JCPMH 2013). As part of the broad framework of supports

for children, young people, adults and older people who display or are at risk of displaying behaviour that challenges there should be:

- effective identification of mental health and other emotional difficulties amongst children, young people, adults and older people with learning disabilities and / or autism and active recognition that symptoms of mental health difficulty, such as depression or psychosis, may be presented differently amongst individuals who have learning disabilities and / or autism compared to those who do not
- appropriate use of evidence-based therapeutic interventions and medication to support children, young people, adults and older people with learning disabilities and / or autism who have been identified as having a mental health difficulty, either in the context of a function-based holistic assessment or at a time when they are not displaying behaviour that challenges
- access to appropriately-trained mental health professionals, who have knowledge, expertise and skills in learning disabilities and autism; mental health professionals should not deny access to services (Child and Adolescent Mental Health Services (CAMHS) and adult/older people's mental health services) on the basis of learning disability and / or autism
- strong partnership working between mainstream mental health services and learning disability services and local autism services to ensure that individuals with learning disability and/or autism have access to the full range of support
- support available in the least restrictive setting possible that is therapeutic and safe for children, young people, adults and older people, and safe for their family members, carers and professionals.

10. Support for additional needs

Children, young people, adults and older people with learning disabilities and / or autism are likely to present with a number of other areas of need that if not adequately supported may increase the likelihood of behaviour that displays as challenging developing. As part of a preventative PBS strategy the following areas should be addressed:

- A high proportion of children, young people, adults and older people with learning disabilities and / or autism experience sleep difficulties. This has a negative impact on their wellbeing and impacts on the wellbeing of family carers. Both of these factors may increase the likelihood of behaviour that challenges. Sleep difficulties should be actively screened for and evidence-based sleep programmes, with medication to support where appropriate, should be implemented routinely and appropriately by services supporting individuals across the life course.
- Young People with learning disabilities and/or autism may have coexisting Attention Deficit Hyperactivity Disorder (ADHD) that is either undiagnosed or overlooked during transition to adult services. The appropriate treatment and support needs to be made available from childhood into adulthood.
- High numbers of children, young people, adults and older people with learning disabilities and / or autism experience sensory difficulties. This includes sensory impairments (in other words, hearing difficulties and visual difficulties) and increased sensitivity across a number of areas (for example, tactile sensitivity). These should be addressed as part of a package of intervention supports through provision of equipment/devices, communication methods, therapeutic work and appropriate structuring of an individual's environment.
- Children, young people, adults and older

people with learning disabilities and / or autism often require support to engage in stimulating and meaningful activities. When deprived of activity and appropriate levels of stimulation there is an increased likelihood that individuals will display behaviour that challenges. Family carers and paid staff require training and support to help those children, young people, adults and older people they support to live full and active lives in the community. In addition (in line with wider equality and diversity agendas) increased support is required to raise public awareness of the needs of individuals with learning disability and or/autism and their families.

11. Specialist local services

Local specialist services that focus on the needs of individuals with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges need to be routinely available for children, young people, adults, older people and their families. These services should:

- demonstrate a clear PBS pathway and local policy that reflects all principles covered in this document and embodies the highest level of expertise in this approach
- support other services for children, young people, adults and older people with learning disabilities and / or autism and generic services (in other words, non-specialist physical health services) to use the principles outlined in this document.

Further guidance for the design and delivery of these services produced by McGill (2013) is provided as an appendix.

12. Safeguarding and advocacy

The whole system has responsibility to work with families to safeguard the safety and wellbeing of children, young people, adults and older people with learning disabilities and / or autism: those without positive family involvement are likely to require additional support. The provision of independent advocacy at these times is central to safeguarding vulnerable people across the life course and needs to be tailored accordingly to take into consideration mental and physical capacity. At all times commissioners should:

- identify clearly and transparently (both within and across geographical areas) the responsibilities of different parts of the whole system for safeguarding children, young people, adults and older people with learning disabilities and / or autism
- ensure the availability of independent advocates especially for those whose situations are at increased risk (for example, because of limited family involvement or placement far from home)
- have policies and procedures for supporting whistleblowing and other activities that may prevent or lead to the early detection of abuse or inappropriate treatment and should also ensure that providers have clear whistleblowing policies and procedures, and a means of assuring themselves that these are adequate and understood by staff within provider settings
- ensure that a range of stakeholders (family carers, professionals, researchers, partnership boards, and providers) are made aware of the use of specialist services (including residential schools and out of area placements) and the use of restrictive treatment (including physical restraint, seclusion and excessive/inappropriate medication) via transparent data reporting approaches.

13. Workforce

The constitution of the workforce will be partly dependent upon the specific service commissioned. It is likely that a range of different professionals, working together in a multi-disciplinary and multi-agency team/network will be required to provide the kind of holistic support outlined in this Core Principles Commissioning Tool. Further guidance on the roles of particular professionals is described in the 'Challenging Behaviour Foundation Pamphlets for Commissioners' referenced at the end of this document.

Children, young people, adults and older people with learning disabilities and / or autism need a workforce that know and value how to provide safe high quality services. Those who are providing educational, health or social services should demonstrate they are managing their workforce to achieve this by:

- involving children, young people, adults and older people with learning disabilities and / or autism and their family and carers in the recruitment process, especially interview panels, for all staff
- providing accredited training to keep up to date with best practice and maintain professional development in PBS and other related areas
- involving, wherever appropriate, family and carers in the delivery and review of training sessions/programmes
- supporting staff to value and use competently the best approaches to communication with each individual they support
- ensuring their staff have a good understanding of the symptoms/signs of co-morbid conditions (for example, Mental Health and ADHD) which can be associated with behaviours that challenge
- ensuring all staff receive regular supervision, appraisal and support
- ensuring staff understand the Mental Capacity Act to a level that is applicable to their role and the environment in which they work

Capacity Act to a level that is applicable to their role and the environment in which they work

- having a clear process for raising and discussing concerns
- actively encouraging innovation and creativity, especially in relation to reasonable adjustments
- supporting the development of a competencies framework to monitor quality of PBS provision.

14. Monitoring quality

Commissioners and providers need to work collaboratively to specify and deliver services that are safe and of a high quality. These should be informed by the key principles and outcomes described in the 'model of care' contained within Transforming care: A national response to Winterbourne View Hospital. The focus of assurance systems should include:

- the experiences of children, young people, adults and older people with learning disabilities and / or autism and their families
- timely and regular review and audit of services and care plans to ensure they are safe, meeting needs and delivering outcomes
- local quality requirements, including initiatives to make marked improvements (eg, Commissioning for Quality and Innovation (CQUIN))
- national quality requirements, (for example, Ofsted and Care Quality Commission)
- early warning and learning from complaints and serious incidents
- involvement of children, young people, adults and older people with learning disabilities and /or autism; and their family and carers as Experts by Experience

- clear understanding of monitoring and reporting arrangements, including through to local Partnership Boards and Health and Wellbeing Boards.

Mechanisms are also required to monitor the quality of commissioning procedures and should form part of the Joint Strategy as per Action 57 of the 'Concordat: Programme of Action' (DH, 2012). This should be assessed by measuring outcomes for individuals with learning disabilities and / or autism and other stakeholders and should include:

- the satisfaction of individuals and families regarding service provision
- positive increases in quality of life for individuals and families
- population level changes in prevalence of behaviour that challenges
- reduced numbers of individuals with learning disabilities and / or autism in residential school/out of area placements.

Implementation

To effectively implement this Core Principles Commissioning Tool commissioners should:

- ensure they comprehend what it is describing; reading it alongside the documents highlighted in 'Resources and further reading' section. The information above, whilst updated in places, does not expand significantly on the 'model of care' published in the 2007 revision of 'The Mansell Report' (this point is made because it is important to remember that the DH's Review found there was a widespread failure to: design, commission and provide community-based services that meet the needs of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges)
- work through the commissioning cycle so that existing specifications are reviewed and revised and/or new ones are developed that are consistent with the model of care and established best practice including personal budgets and personal health budgets; it is important that this is done collaboratively across education, health and social care; and with involvement of providers and partnership boards, parent carer forums, and self-advocacy groups
- consider the full transformation programme set-out in Transforming care: A national response to 'Winterbourne View Hospital'; and the local response to the Stocktake; the findings from reviewing existing specifications should inform local Joint Strategies, which the Concordat requires to be in place by April 2014
- implement this guidance alongside their preparation to implement the provisions

(subject to Parliamentary approval) in the Children and Families Bill 2013, in particular the requirements to:

- provide a 'local offer' of services for children with Special Educational Needs (SEN) and their families
- replace statements with birth-to-25 education, health and care plans
- offer families personal budgets (which can include education, health and care)
- jointly commission services across education, health and care.

It is by following these stages that commissioners can support the realisation of the vision in Transforming care: A national response to Winterbourne View Hospital, which is to ensure all services across England are consistent with established best practice; and deliver good outcomes for all children, young people, adults, older people, and their families.

Resources and further reading

Resources

Children and Families Bill 2013. www.education.gov.uk/a00221161/

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Royal College of Psychiatrists (2012). *Enabling people with mild intellectual disability and mental health problems to access healthcare services*. www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr175.aspx

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HM Government. (2001). *Valuing people: a new strategy for learning disability for the 21st century*. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153

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Improving Health and Lives: Learning Disabilities Observatory, Royal College of General Practitioners, Royal College of Psychiatrists (2012). *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Groups*. [https://www.improvinghealthandlives.org.uk/publications/1213/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups_\(CCGs\)_-_revised](https://www.improvinghealthandlives.org.uk/publications/1213/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups_(CCGs)_-_revised)

Joint Commissioning Panel for Mental Health. (2013). *Guidance for commissioners of mental health services for people with learning disabilities*. www.jcpmh.info/resource/guidance-for-commissioners-of-mental-health-services-for-people-with-learning-disabilities/

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Royal College of Nursing. (In development). *Use of restrictive practices in health and adult social care and special schools*. www.rcn.org.uk/support/consultations/pages/use_of_restrictive_practices_in_health_and_adult_social_care_and_special_schools

Royal College of Speech and Language Therapists. (2013). *Five good communication standards*. www.rcslt.org/news/good_comm_standards

Skills for Care. (In development). *People whose behaviour challenges*. www.skillsforcare.org.uk/Skills/People-whose-behaviour-challenges/People-whose-behaviour-challenges.aspx

The Challenging Behaviour Foundation. (2009/13). *The challenging behaviour national strategy group charter*. www.challengingbehaviour.org.uk/strategy-group/charter.html

Further reading

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Denne, L.D., Noone, S.J. Gore, N.J., Toogood, S., Hughes, C.J., Hastings, R.P., Allen, D., Baker, P., & McGill, P. (2013). *Developing a core competencies framework for Positive Behaviour Support: Issues and recommendations*. *International Journal of Positive behavioural Support*

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Giraud-Saunders. A. and Turner, S. (2013) *Personal health budgets for people with learning disabilities*, Think Local, Act Personal Partnership.

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Hastings, R.P., Allen, D., Baker, P., Gore, N.J., Hughes, C.J., McGill, P., Noone, S.J., & Toogood, S. (2013). A conceptual framework for understanding why Challenging Behaviours occur in people with developmental disabilities. International Journal of Positive behavioural Support (in press)

Appendix

Detailed Pathway and Policy Specification (McGill, 2013)

Individuals

What needs to happen	Evidence that happening
<p>Behaviour support is based on a holistic assessment (incorporating functional assessment) of the context in which the person's behaviour occurs.</p>	<ul style="list-style-type: none">• A copy of a recent (or recently reviewed) assessment report can be provided.• The report provides evidence of assessment of:<ul style="list-style-type: none">◦ history◦ immediate antecedents and consequences◦ genetic context◦ physical health context◦ mental health context◦ broader social context◦ communication and social skills.• The report provides evidence of involvement or attempted involvement in the assessment process of:<ul style="list-style-type: none">◦ the individual◦ the individual's family, friends and independent advocate◦ the paid carers supporting the person.• The report provides evidence of the assessment having been conducted in a manner consistent with the Mental Capacity Act.• The report includes a summary which integrates the information gathered into a coherent formulation of the factors influencing the person's behaviour

<p>There is a written, individualised behaviour support plan.</p>	<ul style="list-style-type: none"> • A written plan can be provided • The written plan is personalised (for example, includes person's name). • The written plan is different to written plans for other individuals. • The written plan is integrated with a wider person-centred plan for the individual. • A named individual has responsibility for implementing, monitoring and reviewing the plan.
<p>The behaviour support plan includes:</p>	
<p>1. a description of the person's challenging behaviour(s)</p>	<ul style="list-style-type: none"> • The behaviour(s) are operationally defined, observable and measurable.
<p>2. a summary of the most probable reasons underlying the person's challenging behaviour</p>	<ul style="list-style-type: none"> • The summary is written in everyday language and is consistent with the conclusions of the assessment informing the support plan. • The function(s) of the person's behaviour(s) is/are clearly stated.
<p>3. proactive strategies</p>	<ul style="list-style-type: none"> • The plan states how to avoid or prevent all of the challenging behaviours identified. • The plan includes one or more, clearly defined strategies for developing the person's ability to communicate or otherwise more effectively influence what happens to them without displaying challenging behaviour. These strategies comprehensively address the identified functions of the behaviour(s).
<p>4. reactive strategies</p>	<ul style="list-style-type: none"> • The plan specifies how carers should respond to instances of the person's challenging behaviour(s). • The plan includes one or more non-restrictive strategies for responding to instances of the person's challenging behaviour. • Where restrictive strategies (for example, physical intervention, seclusion, prn medication) are included, these are not identified as the first reactive strategy to be used without a clear rationale for this being provided. • Circumstances in which restrictive strategies are recommended are defined unambiguously.

5. monitoring and review arrangements	<ul style="list-style-type: none"> • The plan specifies expected outcomes (in terms of reductions in challenging behaviour, improvements in quality of life, reductions in restrictive practices) and how these will be measured. • The plan includes a timetable and organisational arrangement for review (for example, through a multidisciplinary meeting in six months).
6. implementation arrangements	<ul style="list-style-type: none"> • The plan specifies any necessary characteristics for those implementing (“mediators”) the strategies described. • The plan specifies how mediators will be trained to reliably and consistently implement strategies. • The plan specifies any additional or changed resources required, such as additional mediators or specific materials.
The plan is implemented, monitored and evaluated.	<ul style="list-style-type: none"> • Data on the consistency and correctness of implementation shows at least 80 per cent correct implementation. • Data on expected outcomes demonstrates reductions in challenging behaviour and/or improvements in quality of life and/or reductions in restrictive practices leading to review and continuation of the plan; or • Data on expected outcomes demonstrates no change or worsening in challenging behaviour and/or quality of life and/or use of restrictive practices leading to reassessment and redevelopment of behaviour support strategies.

Organisations

What the organisation needs to do	Evidence that this is happening
Provide leadership for, and take ownership of, the implementation of Positive Behaviour Support (PBS)	<ul style="list-style-type: none"> • Clear, written statement of policy and practice commitment to PBS that is available to all staff and accessible to service users and family members. • At least one member of executive team/ Board has specific responsibility for organisation-wide implementation of PBS. • At least one member of executive team/ Board (probably the same person as in 2) has experience and training in using a PBS approach with individuals.
Develop and maintain an inclusive strategy for organisation-wide PBS	<ul style="list-style-type: none"> • The strategy includes components relating to: <ul style="list-style-type: none"> ◦ the primary prevention of challenging behaviour through organisation-wide procedures and methods of working ◦ the secondary prevention of challenging behaviour through the identification and support of at-risk individuals; ◦ the implementation of PBS with individuals who display challenging behaviour of a defined severity. • The strategy is informed by consultation with service users, frontline staff and family members and is reviewed annually.
Provide person-centred supports and services	<ul style="list-style-type: none"> • Services provided to individuals are clearly related to the needs and aspirations of those individuals and their families/friends/ advocates. • The organisation can provide recent and checkable examples of having changed aspects of its provision in response to requests/complaints by individuals and their families/friends/advocates. • The organisation can provide recent and checkable examples of having changed or audited aspects of its organisational procedures (for example, duty rotas, staff recruitment, quality assurance etc) to adapt them to the needs and aspirations of individuals and their families/friends/ advocates.

<p>Provide acceptable physical environments</p>	<ul style="list-style-type: none"> • The physical environments where services are provided are within a typical range (for that type of environment) in respect of: <ul style="list-style-type: none"> ◦ space ◦ aesthetic appearance ◦ noise ◦ state of repair. • Standard adaptations to fittings and fabric have been made to increase environmental safety without disrupting the environment's typical nature. • The organisation can provide recent and checkable examples of adaptations being made to the physical environment to reduce the likelihood of challenging behaviour and/ or to increase the safety of the individual or others.
<p>Provide an active support model of care</p>	<ul style="list-style-type: none"> • All service users routinely participate in personalised, meaningful activities for the majority of their time. • All service users have personalised and predictable routines and timetables. • Staff are skilled in providing personalised levels and kinds of assistance – enhancing participation, preventing challenging behaviour and reducing risk. • The organisation collates information on levels of participation in meaningful activity and uses the information to review and change support arrangements
<p>Provide well-trained and supported staff, deployed in the right places at the right times</p>	<ul style="list-style-type: none"> • All support staff receive in-house training in PBS which is refreshed at least annually. • All support staff with a leadership role (for example, shift leaders, frontline managers) have completed, or are undergoing, more extensive training in PBS which includes practice-based assignments and independent assessment of performance. • All staff with a role (which may be peripatetic or consultant) in respect of assessing or advising on the use of PBS with individuals have completed, or are undergoing, externally-validated training in PBS which includes both practice- and theory-based assignments with independent assessment of performance at National Qualifications Framework Level 5 or above.

	<ul style="list-style-type: none"> • All staff involved in the development or implementation of PBS strategies receive supervision from an individual with more extensive PBS training and experience. Staff in consultant roles are supervised by an individual (within or outside the organisation) with a relevant postgraduate qualification, for example, applied behaviour analysis, positive behaviour support, clinical psychology. • The organisation can provide examples of (or equivalent plans for) the flexible deployment of staff to support an individual during a period of crisis.
<p>Have a quality assurance strategy which is driven by data and a desire for organisational development and learning</p>	<ul style="list-style-type: none"> • A range of data is systematically collated and considered within the organisation on a monthly basis, informing organisational responses in respect of specific individuals or services: <ul style="list-style-type: none"> ◦ frequency and severity of challenging behaviour ◦ use of restrictive practices (physical intervention, seclusion, prn medication) ◦ injuries sustained as a result of challenging behaviour ◦ safeguarding alerts ◦ extent and variety of service user participation in meaningful activities. • A range of data is systematically collated and considered within the organisation on an annual basis, informing organisational responses in respect of specific services or more widely: <ul style="list-style-type: none"> ◦ attainment of specific objectives identified in PBS plans for individuals ◦ service user and family carer/friend/advocate satisfaction ◦ support staff turnover, sickness, stress and morale ◦ changes in the abilities and general health of service users.

Winterbourne View Joint Improvement Programme

This programme is led by the Local Government Association (LGA) and NHS England, and funded by the Department of Health.

Our vision:

Everyone, with no exception, deserves a place to call home. Person by person, area by area, the number of people with learning disabilities and autism in secure hospitals or assessment and treatment settings will permanently reduce. At the same time local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting.

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