



# Pamphlet for Commissioners

## **SERVICES FOR ADULTS WITH LEARNING DISABILITIES WHO DISPLAY CHALLENGING BEHAVIOUR**

### **WELL-MATCHED AND SKILLED STAFF**

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## Aims and Objectives

This pamphlet has been produced as a guide for professionals who commission services for adults with learning disabilities who display challenging behaviour. These individuals have complex health and social needs. Service provision must be directed by the needs of the individual and there should not be an expectation that these people can be fitted into existing services if such services do not address the complexities of their needs.

The distress and trauma which can be experienced if someone is placed in an inappropriate and poorly monitored setting is all too evident with recent exposure of abuse and poor practice. Such situations can and must be prevented. With this in mind, those commissioning often expensive placements must be able to access evidence based information which can demonstrate what a good service should offer.

Services should be commissioned on the basis of local need and local resources. They should be culturally sensitive and age appropriate.



# Introduction

## Definition

“Behaviour can be described 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.” (Challenging behaviour – a unified approach; RCPsych, BPS, RCSLT, 2007)

Challenging behaviours are more common in people with learning disability as compared to their peers without a learning disability.

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. Challenging behaviour may be associated with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), other mental health problems and certain genetic and/or organic disorders. Physical disorders, particularly those causing pain, can result in challenging behaviour.

Difficulties with communication also significantly increase the risk of the development of challenging behaviour as do sensory disabilities. Psychological factors including the persons level of learning and social factors such as deprivation, stigma, abuse and neglect all contribute to the development of challenging behaviours.

Challenging behaviour is a description of a set of problems, and not a diagnosis in its own right. Between a half and a third of those with challenging behaviour show more than one problem behaviour. 10-15% of individuals who use learning disability services exhibit significant challenging behaviour.

Although people with severe or profound learning disability are more likely to display challenging behaviour, such behaviours may still be a major factor in the need for services for those with mild or moderate learning disability.

People who display challenging behaviour are more likely to experience placement breakdown. They have difficulties in accessing respite and they are more likely to move into residential settings away from their home areas. They are also at greater risk of abuse and neglect.

Family breakdown is more common if a family member presents challenging behaviours. Siblings are at risk of becoming isolated as they may experience difficulties in having friends home.



# 1) Which Professionals ("the workforce") should be involved?

## **What you should know**

The following multi-agency workforce is required to address the assessment and management of people who present challenging behaviour.

### **Psychological/Mental Health**

- Clinical Psychologist with expertise in learning disability and functional analysis
- Behavioural specialist
- Speech and language therapist
- Specialist nurse
- Occupational therapist
- Psychiatrist with training in learning disability/developmental disability/autism

### **Physical Health**

- General practitioner
- Neurologist
- Specialist community nurse
- Physiotherapist
- Occupational Therapist
- Dentist
- Optician
- Other depending on need

### **Social Care**

- Social worker/care manager
- Domiciliary care staff
- Direct support workers



### Questions to ask?

1. What professionals does the service employ?
2. What professionals does the service liaise with?

### Key point

- Best practice guidance emphasises the need to have a multi-disciplinary approach to the assessment and treatment of challenging behaviour in order to meet the individual needs of each person

## 2) What should you look for from a service?

### What you should know

Current UK guidelines highlight the importance of a multidisciplinary approach to the assessment and management of challenging behaviour that addresses individual needs and characteristics.

### Assessment should include consideration of:

- The nature of the challenging behaviour
- Level of functioning
- Communication
- Social and environmental factors including daily routines
- Additional physical and/or sensory disabilities
- Assessment of conditions causing pain or discomfort
- Psychiatric disorders
- Underlying genetic factors
- Risk and safeguarding
- Capacity



**A good service will take a holistic approach, which includes the following:**

- Ensuring partnership with parents, carers, education, health and social care.
- Understanding the importance of functional behaviour assessment and how to implement a positive behaviour support plan
- Understanding the importance of accurately recording behaviour, and using this information to regularly update and review behaviour support plans
- Understanding the importance of responding to the following needs of the person:
  - physical health
  - mental health
  - communication
  - sensory
  - mobility
  - environmental

and actively engaging with the appropriate professionals

- Adopts a person centred approach that enables and manages the taking of risks
- Promotes Active Support i.e., active engagement in meaningful activity and the inclusion of the individual in their community. This would be in direct contrast to a passive hotel/minding model of service provision.
- Be aware of and consider the following:
  - Personal Health Budgets
  - Safeguarding issues
  - Consent and capacity
  - The role of the Mental Health Act
  - Teaching, training and dissemination
  - Research and the development of evidence based practice

## Questions to ask

1. How does the service engage with parents, carers, education, health and social care?
2. Does the individual have an individualised timetable that contains sufficient meaningful activity with an appropriate balance between home and community based activity?
3. Does the service have shift plans detailing which member of staff is responsible for which element of care for each minute of the day?
4. What percentage of people who present challenging behaviour have a behaviour support plan based on a functional assessment?
5. How is behaviour recorded?
6. How is risk assessed and managed – does the service have support plans that describe prevention in addition to reactive strategies?
7. What processes are in place to ensure the service addresses the full range of the person's needs?
8. Can the service give an example of how they have implemented current evidence- based best practice guidance?
9. Is there written evidence that the service has assessed capacity, gained consent or held best interest meetings?

### Key point

- To understand the individual needs of a person who is displaying challenging behaviour a range of assessments are required and this information should be used to inform how the individual is supported

# 3) What skills are required by the workforce?

## What you should know

Appropriate training and supervision is essential. This will be dictated by the professional background of the individual but also by the role they are expected to take on as part of the comprehensive, multiagency workforce.

### Training will include:

- Why people display behaviour which is described as challenging
- Positive behavioural support/management strategies
- Communication including PECS and other means of enhancing communication
- Active Support
- The use of least restrictive approaches
- Safeguarding
- Holding/restraint (where appropriate)
- The use of medication

### Skilled staff will:

- Know how to communicate with the the person
- Work with the multiagency services involved with the individual/family
- Implement positive behavioural support strategies
- Provide an activity schedule/timetable that is used both by the person and staff supporting them
- Make sure the person knows what the next activity will be, and who will be supporting him/her
- Provide a choice within the schedule
- Work in partnership with families/carers
- Support the person to engage in meaningful activities
- Communicate well with other staff



### **Skilled staff will not:**

- Leave the person with nothing to do
- Make demands on the person that are too difficult
- Change the person's routine without warning or reason and without trying to explain
- Do things for the person without getting them to do as much as they can themselves to assist
- Talk about the person as if they are not there

(adapted from CBF A guide for advocates: Supporting people with learning disabilities who are described as having challenging behaviour)

### **Questions to ask**

1. What core training/supervision do all staff receive?
2. What additional training do supervisors/ managers receive on positive behaviour support?
3. What range of augmentative communication methods are used within the service e.g. signing, PECs, objects of reference etc
4. Can the service demonstrate how it meets the individual communication needs of each person?
5. Are all staff trained in safeguarding procedures?
6. Does the service use restrictive practices? (E.g. physical restraint, locked rooms, mechanical restraint such as arm splints, PRN (as required) medication). Are these part of an agreed multi-disciplinary approach within an individual's behaviour support plan? Is there a plan to reduce the frequency/constraint of any restrictive practices over time?
7. If physical intervention is needed, what percentage of staff have received BILD accredited training?

### **Key point**

- Supporting a person with severe learning disabilities perceived as challenging is a skilled role and support staff must have appropriate, adequate and ongoing training and supervision.

## 4) How can service provision be monitored?

### What you should know

Supportive environments need to have the following characteristics

- A robust organisational framework
- Current behaviour support plans for all individuals which include both prevention and reactive strategies
- An individualised timetable of age appropriate in-house and community activities
- Structured opportunities to develop skills
- Enough appropriately trained staff

### Questions to ask

1. What is the evidence that the individual is achieving optimum participation in in-house and community activities?
2. What is the evidence that there is a reduction in the intensity and frequency of incidents of challenging behaviour?
3. What is the evidence that the person is developing functional age appropriate skills?
4. What is the evidence for the effective and safe management of incidents of challenging behaviour?

### Key point

- Good services use a range of ways of checking and improving the quality of their service to ensure it delivers good outcomes for people and their families

## 5) Case Vignette

John is 29 years old and has severe learning disabilities, autism and displays a range of behaviours that are described as challenging. He has lots of energy and enjoys fast walks in the countryside, swimming, horse riding as well as seeing his family. John is non-verbal but is able to use approximately 20 Makaton signs to communicate.

John has had three placements breakdown in the last two years. On each occasion the service provider has terminated the contract citing difficulties managing John's challenging behaviour. In the last residential care home all permanent staff were trained to NVQ level 2 in health and social care and had first aid and food hygiene certificates. However, there were a high number of agency staff who did not necessarily have these qualifications. Staff were employed to work with all 8 people who lived at the care home, and were allocated to work with a specific individual

by the team leader at the start of their shift. Not all staff liked walking (especially not as fast as John likes to walk!), some could not swim and some did not drive. When John asked to go for a walk, to go swimming or visit his family (a short drive away) and was told "no" this often led to him pulling staff's hair and biting.

John finds moving home very difficult as, in common with many people with autism, he finds change very difficult and this makes him anxious. His family are very keen to identify a provider who will be able to meet his needs and give him the stability he needs. His family feel that staff at previous placements have not had the skills to implement his behaviour support plan drawn up by the local CLDT team.

John has been assessed as needing 1:1 support during waking hours.

### Questions to ask

1. What factors could have contributed to John's previous placement breakdowns?
2. How could these be addressed?
3. Who could provide more information about how to meet John's needs?
4. What training should staff have to enable them to meet John's needs?
5. How could a provider ensure staff are well matched to John's interests?
6. What evidence do you need from a provider in order to demonstrate they can meet John's needs?

## Vignette Learning Points:

- Lack of multi-disciplinary assessment of behaviour and behaviour support plan
- Information provided by family carer about the person's needs not utilised
- Staff training issues regarding understanding challenging behaviour, positive behaviour support and communication
- Reasonable adjustments to service provision not made
- Staff not matched to the person's interests
- Lack of consistent staffing
- Family carer dissatisfied with service
- The individual excluded putting him at risk of out of area placements
- Negative impact on the wellbeing of the family

## 6) Bibliography

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