



Pamphlet for Commissioners

SERVICES FOR CHILDREN AND YOUNG PEOPLE 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 children and young people who display challenging behaviour. This group of children and young people have complex health, education and social needs. Service provision must be directed by the needs of the individual and there should not be an expectation that these children and young 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 the 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 biological, psychological and social factors which interact together. Challenging behaviour may be associated with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), other childhood 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 child or young persons level of intellectual functioning 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. Nearly half of those with challenging behaviour show more than one problem behaviour. 10-20% of individuals with learning disability exhibit significant challenging behaviour.

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

Challenging behaviour is likely to be persistent with 70-90% of individuals exhibiting difficulties over 5-7 years. Early intervention is important to minimise the impact of the challenging behaviour. Problems are likely to continue into adulthood.

Children and young people with challenging behaviour are more likely to experience breakdown of their educational placement. They have difficulties in accessing respite and they are more likely to move into residential settings away from the nurturing family environment. They are also at risk of abuse and neglect.

Family breakdown is more common if a child displays challenging behaviour. Siblings are at risk of becoming isolated as they cannot have 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 children and young people who display challenging behaviour

Mental Health

- Psychiatrist with training in child and adolescent psychiatry – particular expertise in learning disability/developmental disability/autism
- Psychologist with expertise in neuropsychology/learning disability and functional analysis
- Behavioural therapist
- Speech and language therapist
- Specialist nurses
- Occupational therapist

Physical Health

- General practitioner
- Paediatrician
- Paediatric neurologist
- Specialist community nursing
- Physiotherapist
- Occupational Therapists
- Dentist
- Optician
- Other depending on need

Social Care

- Social worker/care manager
- Domiciliary care staff
- Personal assistants/support workers



Education

1. Teacher
2. Teaching assistant/learning support assistant
3. Educational psychologist
4. Access to range of expertise/provision

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 child/young 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 treatment of challenging behaviour that addresses individual needs and characteristics.

Assessment should include consideration of:

- Psychiatric disorders
- Behavioural disturbance
- Level of functioning
- Underlying genetic factors
- Additional physical and/or sensory disabilities
- Assessment of conditions causing pain or discomfort
- Social and environmental factors including daily routines
- Educational issues
- Risk and safeguarding
- Capacity

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

- Ensuring the involvement of 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 child/ young 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
- Be aware of and consider the following:
 - Personal Health Budgets
 - Safeguarding issues
 - Consent and capacity
 - The role of the Mental Health Act
 - Transition to adult services
 - 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. What percentage of the children who display challenging behaviour have a behaviour support plan based on a functional assessment?
3. How is behaviour recorded?
4. How often are behaviour support plans reviewed?
5. What processes are in place to ensure the service addresses the full range of the child/young person's needs?
6. How is risk assessed and managed?
7. Can the service give an example of how they have implemented current evidence-based best practice guidance?
8. Is there written evidence that the service has assessed capacity, gained consent or held best interest meetings for any young person aged 16-18?

Key point

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

3) What skills do the workforce require?

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 children display behaviour which is described as challenging
- Positive behavioural support/management strategies
- Communication including PECS and other means of enhancing communication
- The use of least restrictive approaches
- Safeguarding
- Holding/restraint
- The use of medication

Skilled staff will:

- Know how to communicate with the child/young person
- Work with the multiagency services involved with the child/family
- Implement behavioural strategies
- Provide an activity schedule/timetable that is used both by the child/young person and staff supporting them
- Make sure the child/young 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 child/young person to engage in meaningful activities
- Communicate well with other staff

Skilled staff will not:

- Leave the child/young person with nothing to do
- Make demands on the child/young person that are too difficult
- Change the child/young person's routine without warning or reason and without trying to explain
- Do things for the child/young person without getting them to do as much as they can themselves to assist
- Talk about the child/young 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 child/ young person?
5. Are all staff trained in child protection?
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. What percentage of staff have had BILD accredited physical restraint 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

The use of outcome measures for this group of young people remains in its infancy. Almost all the evidence based outcome measures have been validated with children and young people without a learning disability.

Options to consider when monitoring what the service offers are

- Parent satisfaction surveys
- Child/young person satisfaction surveys
- Burden of care surveys
- Before and after measurements/ observations of the intensity and frequency of the challenging behaviours
- Maintaining child at home and at school
- Well matched and skilled staff (see previous section)

Questions to ask

1. How is the service monitored?
2. How do you measure the satisfaction of children, young people and their families?
3. How many children and young people have been excluded from the service in the last 3 years? Why were they excluded?
4. Can the service demonstrate how they have recruited staff to match the individual needs of children?

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 children/young people and their families

5) Case Vignette

Sam is 9 years old and has severe learning disabilities, autism and displays a range of behaviours described as challenging including self injury and aggressive outbursts. Sam lives with his parents and two brothers aged 11 & 5 years old. Sam is full of fun and enjoys swings, walks, bouncy castles, swimming and water play.

Sam attended a local short breaks centre every other weekend and one evening after school. At the short breaks centre support workers are matched with children when they arrive on shift, this means that staff usually work with different children each week. Sam's mother provided written instructions on the use of the visual timetable and provided staff with a training session as well as providing detailed information on Sam's likes and dislikes and how to meet his needs.

Sam was excluded 6 weeks ago due to an escalation of his challenging behaviour, with the short breaks centre citing health and safety issues as the reason for exclusion.

Since then his family have not received any short breaks. Sam's mother reported that support workers did not understand Sam's challenging behaviour, did not use the visual timetable as instructed and did not make any adjustments to accommodate Sam.

She is angry and distraught that her family are not receiving any support and Sam's behaviour was becoming increasingly difficult to manage at home. She feels unless an overnight respite is provided the only option is a residential school, but she would prefer for Sam to grow up in the family home.

Questions to ask

1. What factors could have contributed to an escalation of Sam's challenging behaviour?
2. How could these be assessed and managed?
3. Who could provide more information about how to meet Sam's needs?
4. What training should staff have to meet Sam's needs?
5. What evidence do you need that Sam's needs are being met by the team managing him?

Vignette Learning Points:

- Lack of multi-disciplinary assessment of behaviour and behaviour support plan
- Information provided by family carer about child'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 child's interests
- Lack of consistent staffing
- Family carer dissatisfied with service
- Child excluded putting him at risk of out of area placements
- Negative impact on the wellbeing of the family

6) Bibliography

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Acknowledgments

This resource has been produced in collaboration with the Challenging Behaviour – National Strategy Group

An accompanying resource is available for commissioners of adult services "Services for adults with learning disabilities who display challenging behaviour. Well-matched and skilled staff" by Dr Peter Baker, Consultant Clinical Psychologist, Sussex Partnership NHS Foundation Trust and Honorary Senior Lecturer, Tizard Centre, University of Kent.

To order additional copies or for more information visit:

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