NICE National Institute for Health and Care Excellence

Putting NICE guidance into practice

Costing statement: Challenging behaviour and learning disabilities

Implementing the NICE guideline on challenging behaviour and learning disabilities (NG11)

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Summary

Local authorities and NHS organisations are advised to assess the resource implications of implementing the NICE guidance on challenging behaviour and learning disabilities locally.

Potential areas for additional costs locally are:

- the cost of providing care in a person's home or as close to it as possible
- the cost of providing services locally, including training and developing a suitable workforce
- the cost impact of improved care pathways
- the cost of offering a range of psychological interventions and only considering medication for people with a learning disability and behaviour that challenges if other interventions have not produced a change.

Potential areas for savings and benefits locally are:

- improved quality of life for the person, and their family members or carers
- a reduction in inappropriate out-of-area placements
- a reduction in inappropriate medication
- a reduction in admissions to hospital and length of stay in hospital.

1 Introduction

1.1 This costing statement considers the cost implications of implementing the recommendations made in the NICE guideline on challenging behaviour and learning disabilities.

1.2 Expert clinical opinion suggests current practice is highly variable and the guideline might have resource implications at a local level. Because the cost impact of the recommendations may vary, organisations are encouraged to evaluate their own practice against the recommendations in the NICE guideline and assess costs and savings locally. Some of the resource effects to be considered locally are discussed in this statement.

1.3 Costs associated with support and interventions for people with a learning disability and behaviour that challenges are likely to be incurred in primary, secondary, tertiary and community care. Services are commissioned by clinical commissioning groups, NHS England and local authorities.

Commissioners need to give particular consideration to commissioning services for people with a learning disability because they may experience poorer health than the general population (Improving the health and wellbeing of people with learning disabilities: an evidence-based commissioning guide for clinical commissioning groups Public Health England 2013).

1.4 Family members or carers provide the majority of support for most people with a learning disability. Most support from outside the family is funded by social services and provided by not-for-profit agencies. Children, young people and adults may receive special needs education services, which are commissioned by local authorities, or services that have been provided through child and adolescent mental health services that are commissioned by NHS England.

People whose behaviour challenges may also use additional specialist health services, which tend to be provided and organised by community

teams. For adults, specialist services are usually provided by community learning disabilities teams.

2 Background

2.1 The guideline covers children (aged 12 years or younger), young people (aged 13 to 17 years) and adults (aged 18 years or older) and has been developed to advise on interventions and support for people with a learning disability and behaviour that challenges.

2.2 It is estimated that 1 million people in England have a learning disability (People with Learning Disabilities in England 2013 Public Health England 2014). Around 10–17% of people with a learning disability behave in a way that challenges (Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour Allen et al. 2007). Using a midpoint of 14%, this equates to approximately 140,000 people in England.

2.3 Behaviour that challenges affects the quality of life of the person and their family members or carers.

2.4 Medication is the most common intervention used to manage behaviour that challenges, and behavioural techniques are the next most commonly used (see the full guideline).

3 Recommendations with potential resource impact

Working with people with a learning disability and behaviour that challenges, and their families and carers

Recommendation 1.1.2

3.1 Recommendation 1.1.2 states what is important when providing support and interventions for people with a learning disability and behaviour that challenges. Expert clinical opinion suggests it is especially important to provide support and interventions:

- in the least restrictive setting, such as the person's home, or as close to their home as possible, and
- in other places where the person regularly spends time (for example, school or residential care).

Background

3.2 Some people with a learning disability and behaviour that challenges are sent to an out-of-area placement to receive support and interventions. This is mainly because there are few interventions available locally (Commissioning person-centred, cost effective, local support for people with learning disabilities Social Care Institute for Excellence 2008).

3.3 Inpatient placements (both locally and out-of area) may be very expensive and can be of poor quality, which may further increase the risk of behaviour that challenges (see the full guideline).

3.4 Placements are provided by different organisations across England. In a study by Hassiotis et al. (Individual characteristics and service expenditure on challenging behaviour for adults with intellectual disabilities Hassiotis et al. 2007) the most common provider was the private or independent sector and NHS providers were the least common (see table 1).

Table 1 Out-of-area placement providers

Sector	Percentage
Private or independent	55%
Voluntary	28%
Social services	10%
Private hospitals	4%
NHS	3%

Costs

3.5 Evidence from the Hassiotis et al. study suggests that private hospital care was the most expensive; depending on the level of care needed the cost of placements ranged between £102,000 and £222,000 per person annually. NHS inpatient care was equally expensive, with placements costing between £96,000 and £197,000 per person annually, depending

on the level of care needed. Moving care to the community or to schools will help to reduce these costs (see below for further details).

3.6 The revised Mansell report (Department of Health 2007) estimates there are approximately 11,000 people in out-of-area inpatient care supported by local authorities in England.

3.7 In 2012/13, the NHS was estimated to have spent £557 million on inpatients with a learning disability in mental health hospitals (Care services for people with learning disabilities and challenging behaviour National Audit Office 2015).

3.8 The revised Mansell report suggests the first line of specialist support for people living with their family members or carers, or supported in their own homes or in residential care, may include social work, psychiatry, psychology, speech and language therapy, physiotherapy and nursing care.

3.9 Transforming care for people with learning disabilities – next steps (Association of Directors of Adult Social Services, Care Quality Commission, Department of Health, Health Education England, Local Government Association, NHS England 2015) suggests NHS England is working to develop a clearer model that will include a strong emphasis on personalised care and support planning, personal budgets and personal health budgets.

Joint working is being promoted between health and social care commissioners. NHS England will support clinical commissioning groups to co-commission specialised NHS services with NHS England and the Local Government Association. The Association of Directors of Adult Social Services will continue to promote joint working and pooled budgets between clinical commissioning groups and local authorities.

Savings and benefits

3.10 Transforming care for people with learning disabilities – next steps sets out plans to improve the quality of life of people with a learning disability.

These include reducing the number of people placed in hospital and the length of time people spend there, and enhancing the quality of both hospital and community settings. This will help to ensure that people receive support and interventions in the least restrictive settings.

3.11 Providing services closer to people's homes ensures that there are alternatives to hospital admittance available to people with a learning disability and behaviour that challenges. Expert clinical opinion suggests that although there may be initial costs in some areas to set up care facilities outside of hospitals, there will be decreased spending on expensive inpatient care, and improvements in quality of life for the person and their family and carers.

3.12 Commissioners should look to redirect resources from relatively expensive inpatient and out-of-area care to providing care locally in the community. A 3.5-hour client session in a local authority day care service for people with mental health problems costs £30 per person; 12 behavioural activation sessions with a non-specialist cost £125 (Unit costs of health and social care Curtis 2014). Although initial investment may be needed, medium- to longer-term savings are anticipated as a result of providing care locally in the community.

Staff training, supervision and support

Recommendations 1.1.6 to 1.1.8

3.13 Recommendations 1.1.6 to 1.1.8 set out training needs and support for all staff working with people with a learning disability and behaviour that challenges.

Background

3.14 NHS England, working with local authorities (see section 3.9), is aiming to reduce inpatient care and develop high-quality services in the community. It is aware that transforming services will involve developing well-trained staff to deliver the care; recommendations 1.1.6 to 1.1.8 will help to achieve this.

3.15 Inpatients are likely to have a more successful discharge from a hospital when a local multidisciplinary specialist learning disability team has worked closely with hospital clinicians and hospital outreach teams (Care services for people with learning disabilities and challenging behaviour National Audit Office 2015).

3.16 Clinicians agreed that people who would benefit from being supported in the community should be discharged from hospital, if suitably skilled and experienced staff are available to respond to their needs.

3.17 They also agreed that readmission was often not best for the person and more resilient community placements would prevent inappropriate hospital admissions.

3.18 Staff training and support may be needed in some areas to ensure that a suitable workforce is available in the community.

Costs

3.19 There is a wide range of training for staff, ranging from accredited and professional training to staff coaching. Costs for training will vary according to the skills needed locally.

3.20 A number of centres, such as The Tizard Centre offer a series of undergraduate and postgraduate degree-level courses for staff in learning disabilities services. Expert clinical opinion suggests undergraduate numbers have decreased because of high fees. Part-time postgraduate courses cost between £800 and £3,100, depending on the qualification.

3.21 NHS England and local authorities have also agreed accreditation schemes for training and developing a workforce that provides person-centred care and support for people with a learning disability in their community (Transforming care for people with learning disabilities – next steps Association of Directors of Adult Social Services, Care Quality Commission, Department of Health, Health Education England, Local Government Association, NHS England 2015).

3.22 There are also free online programmes available. The Disability Matters website provides free e-learning courses on a wide range of topics for people who work with, care for, commission or deliver services for children and young people with a disability, and their family members or carers.

Savings and benefits

3.23 It is recognised that improving services through training is a way of improving people's quality of life.

3.24 There is growing evidence that understanding the needs of people with a learning disability and behaviour that challenges leads to better outcomes. This can be achieved with well-trained staff.

3.25 Further savings could be achieved by reducing length of stay in hospital and preventing the need for readmission. The unit cost in a low-level secure service is around £400 per bed day (Unit costs of health and social care Curtis 2014). Reducing these stays could result in savings for commissioners and productivity savings for providers. These could in turn lead to a reduced need to commission inpatient care.

Organising effective care

Recommendations 1.1.9 to 1.1.14

3.26 Recommendations 1.1.9 to 1.1.14 focus on developing local care pathways for people with a learning disability and behaviour that challenges.

Background

3.27 Expert clinical opinion suggests that some NHS trusts already have care pathways in place and others should find these easy to develop. However, part of the pathway may not be available and this could lead to people being sent to out-of-area placements, with associated costs.

3.28 Expert clinical opinion suggests that implementing the guideline is likely to result in increased uptake of services and transition between services and care pathways, along with a greater range of interventions.

Costs

3.29 Currently there is variation in local practice and the cost of implementing these recommendations should be assessed locally. Implementing them will involve community and secondary care working together to provide an integrated programme of care across both services.

3.30 The revised Mansell report (Department of Health 2007) states that commissioners should allocate a budget to fund a much wider variety of interventions. These would be alternatives to placements in special units, which are often expensive and out-of-area. This would represent good value for money and high-quality preventative action by commissioners; recommendations 1.1.9 to 1.1.14 should help to achieve this aim.

Savings and benefits

3.31 If community-based services for people with a learning disability and behaviour that challenges are prioritised over inpatient placements and secondary care options, potential long-term savings should be possible.

3.32 Having more local services can allow a more personalised approach to care. Being based closer to their family members or carers can improve quality of life for people with a learning disability and behaviour that challenges.

Early intervention for children, and their parents or carers

Recommendations 1.7.1 to 1.7.4

3.33 Recommendations 1.7.1 and 1.7.2 cover parent-training programmes for parents or carers of children aged under 12 years. Recommendations 1.7.3 and 1.7.4 recommend preschool classroom-based interventions for children aged 3–5 years.

Background

3.34 Expert clinical opinion suggests that in some areas there are limited parent-training programmes available. Some examples are Early Bird and Early Bird Plus; however, these tend to be oversubscribed and have waiting lists.

3.35 Expert clinical opinion suggests that in some areas there are preschool interventions for children, but these are not available in all areas. An example is the educational service run by the National Portage Association. These programmes are free to parents or carers and children. They are funded by local authorities and charities.

Costs

3.36 In order to provide early intervention, better access to behaviourally trained staff in early-years services and children's teams is needed.

3.37 Costs to increase the number of parent-training programmes and preschool interventions will depend on what services are currently available, and therefore should be assessed locally.

3.38 The median cost of an 8–12 week group parent-training programme is estimated at approximately £950 per family. The cost of a school-based intervention (including teacher training, a programme coordinator and materials) is estimated at approximately £130 per child per year (Mental health promotion and mental illness prevention: the economic case. Department of Health 2011).

Savings and benefits

3.39 Expert clinical opinion suggests that early interventions are potentially valuable because they equip parents or carers to better manage behaviour that challenges and decrease the likelihood of it developing into long-term problems. This avoids a greater burden for the person, their family members or carers, and the wider service system.

3.40 Poor treatment outcomes for children can lead to them continuing to display often more serious behaviour that challenges as adults. This is

detrimental not only to the child and their family members or carers but also wider society, leading to financial costs, poor health outcomes and lower quality of life.

3.41 Identifying difficulties early in childhood and using evidence-based approaches to address those difficulties has the potential to deliver significant social and economic benefits. This is particularly true for people with problems that are likely to escalate over time, limit their life chances and result in significant costs to society. Benefits should be assessed locally but could include:

- a reduction in the cost of services provided by the NHS or local authorities
- a reduction in sickness absence among people with mental health problems in paid employment
- a reduction in lost productivity that occurs when employees come to work and function at less than full capacity for health reasons (The economic and social costs of mental health problems in 2009/10. Centre for Mental Health 2010).

Psychological interventions

Recommendation 1.8.2

3.42 Recommendation 1.8.2 states that antipsychotic medication should only be offered in combination with psychological or other interventions if psychological or other interventions alone do not produce change within an agreed time.

Background

3.43 For the majority of people, medication is tried first before psychological interventions. Medication is considered by most professionals to be overused.

3.44 Expert clinical opinion suggests that this is because there are few psychologists and staff trained in behavioural interventions available. It

has been suggested that this is a result of the financial pressures that NHS trusts are currently experiencing.

3.45 Psychological interventions are a range of evidence-based support to increase quality of life and reduce the occurrence, severity or impact of behaviour that challenges.

Costs

3.46 There may be a need for extra psychology staff in some areas. A trainee psychologist or psychological wellbeing practitioner would normally start at Agenda for Change band 6, costing around £36,200 a year (midpoint band 6 including on-costs) (General information about pay in the NHS NHS Careers). The mean basic annual salary for a consultant psychiatrist is £89,200 (Unit costs of health and social care Curtis 2014).

Savings and benefits

3.47 Psychological interventions by local teams can lead to potential savings and benefits by improving local support and reducing inpatient placements (see section 3.5).

3.48 A major aim of psychological interventions is to reduce the likelihood of behaviour that challenges by providing support at an early stage to address risk factors.

About this costing statement

This costing statement accompanies the NICE guideline on challenging behaviour and learning disabilities.

Issue date: May 2015

This statement is written in the following context

This statement represents the view of NICE, which was arrived at after careful consideration of the available data and through consulting healthcare professionals. It should be read in conjunction with the NICE guideline. The statement is an implementation tool and focuses on those areas that were considered to have potential impact on resource utilisation.

The cost and activity assessments in the statement are estimates based on a number of assumptions. They provide an indication of the potential impact of the principal recommendations and are not absolute figures.

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