

**Personal health budgets and Integrated
Personal Commissioning quick guide:**

Children and young people



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1 Introduction

The NHS in England is implementing personal health budgets and Integrated Personal Commissioning (IPC) as part of a wider drive to make health, social care and education more personalised. This is in line with the NHS Five Year Forward View.¹

Personal health budgets are a way to improve outcomes by giving people more choice and control over the care they receive. They focus on personalised care and support planning, and let people choose how to meet their healthcare needs in different ways. Personal health budgets can be managed in three ways: a direct payment, a third party budget or a notional budget. Introductory information about personal health budgets and the ways they can be managed is available on NHS Choices.²

The evidence shows that, when implemented well, personal health budgets are a cost-effective way to improve people's quality of life and experience of care. They also help people manage their own health and reduce their reliance on acute services.

While personal health budgets are relatively new for the NHS, personal budgets have been used in social care for much longer. Building on what's been learned in both the NHS and social care, and because of the drive to increase integration across services, IPC is being developed as an approach to delivering care and support for people with the most complex needs. It enables people to join up the funding available for their health and care so they experience seamless care and support. The IPC operating model explains each element of IPC, and provides a framework that can be used to guide local implementation.³

1.1 Who is this document for?

This quick guide explains the potential benefits of personal health budgets and IPC for children and young people. It is one of a series of quick guides that explore personal health budgets and IPC for specific groups of people or services.

This quick guide sets out what is currently known about:

- the use of personal health budgets for children and young people
- what the national ambitions are
- what support is available to help clinical commissioning groups (CCGs) build the capability to deliver personal health budgets well for this group.

This quick guide is primarily intended for commissioners and providers who are developing local plans to implement personal health budgets, particularly those who are commissioning and providing services for children and young people.

It may also be of interest to people working in the voluntary, community and social enterprise (VCSE) sector, and other people interested in the role of personal health budgets and IPC for children and young people.

1.2 An overview of personal health budgets and IPC for children and young people

It is widely recognised that there is a pressing need to improve the health and wellbeing outcomes of children and young people with the most complex health and care needs. This includes those with one or more long term conditions, mental health needs, a learning disability and/or autism, or a life-limiting condition.

There is evidence that the number of children with complex health and social care needs is rising due to improved survival rates of preterm babies and babies with congenital conditions, an increase in the diagnosis of autism, increasing mental health needs, and increased life expectancy for children with complex health conditions.⁴

Many children and young people who have complex health and social care needs will require multi-agency support from education, health, education and social care. They are also less likely than their non-disabled peers to have control over their lives and over the support they receive across services.⁵ They are more likely to experience poor life outcomes.⁶

To improve outcomes and experiences, services need to adopt an outcome-focused, whole-life approach that enables children, young people and families to focus on what is important to them. Personalising and integrating the care and support these children and young people receive is key to improving outcomes.

Children and young people in receipt of continuing care, and young adults receiving NHS Continuing Healthcare, have a legal right to have a personal health budget unless there are exceptional circumstances. This is not a right to have a direct payment, but CCGs do need to have the capability to make direct payments available.

In addition, CCGs are expected to consider the extension of personal health budgets to a wider group of children and young people who have complex health needs. The Children and Families Act 2014⁷ requires local authorities and CCGs to consider the option of a personal budget for children and young people who are eligible for an education, health and care (EHC) plan.

Evidence from the pilot of individual budgets for families with disabled children⁸ and early rollout suggests that children, young people and their families benefit from having the level of choice and control that personal health budgets give. In 2016/17 over 1,500 children had a personal health budget, of which over half has a direct payment. This number is expected to grow significantly in the coming years.

Personal budgets from education or social care, personal health budgets and integrated personal budgets are mentioned in many key strategies, including:

- special educational needs and disability (SEND) reforms⁹
- Five Year Forward View for Mental Health¹⁰
- Future in Mind¹¹
- Transforming Care.¹²

They are part of a set of measures that can help to achieve the ambitions shared by all these reforms: greater choice and control; self management of health conditions; integration; early intervention; and a more flexible approach to support that enables children, young people and their families to design creative, individual support packages to help them achieve what they want from life.

Transition to adulthood (age 14-25) has been highlighted as a time when young people are most at risk of poor outcomes and fragmented support. It is essential that young people and their families receive support to prepare for adulthood, which may include moving into adult services. The Care Act 2014 requires the NHS and local authorities to provide an early indication of what support, including personal budgets, will be available to young people when they transfer to adult services. Assessment of needs should consider using personal budgets as part of the transition process. This can enable young people and their families to build resilience and develop creative support packages closer to home.¹³

Children with complex needs are one of the groups that some IPC areas are focusing on. These areas are using the IPC operating model to help them develop joint commissioning strategies that deliver personalisation and personal budgets.³ The IPC operating model can help local areas to implement key reforms which aim to deliver personalisation, integration and early intervention such as the SEND reforms, Future in Mind and Transforming Care. It can also help local areas to develop joint commissioning strategies and support for personal budgets, personal health budgets and integrated personal budgets.

2 Special educational needs and disability (SEND)

The Children and Families Act 2014 covers children and young people with special educational needs, and disabled children and young people. While there is a big overlap between these two groups, some children will just have special educational needs and some disabled children and young people will not.

The Children and Families Act 2014 introduced a range of measures to improve outcomes for children and young people with SEND:

- Education, health and care plans: Children and young people requiring a statutory plan to secure the relevant provision to meet their special educational needs will have an EHC plan.¹⁴ CCGs must make sure mechanisms are in place to ensure practitioners and clinicians can support the integrated EHC needs assessment process.
- Personal budgets: Young people and parents of children who have EHC plans have the right to request a personal budget, which may contain elements of education, social care or NHS funding. This request can be made when the local authority has completed a statutory EHC assessment and confirmed that it will prepare an EHC plan. Young people and parents can also request a personal budget during a statutory review of an existing EHC plan. As explained in the SEND code of practice, young people and families should be given an indicative allocation of funding which they can choose to request as a personal budget.¹⁵ The SEND code of practice makes it clear that the expectation is that where appropriate a personal budget should include elements of education, health and social care funding, i.e. an integrated personal budget.¹⁶ CCGs must have mechanisms in place to agree personal budgets where they are provided for those with EHC plans. These arrangements should be set out with education and social care in their joint commissioning arrangements.

- **Local offer:** Local authorities have a statutory duty to set out a SEND local offer that describes, in an accessible way, what support is available locally for children and young people with SEND and their families. This needs to include personal budgets (personal budgets from social care, education and personal health budgets). CCGs should also have a clear offer for personal health budgets.
- **Joint commissioning:** The Children and Families Act 2014 places a statutory duty on local authorities and CCGs to jointly commission provision for children and young people up to 25 years with SEND. This must include developing joint commissioning arrangements that support personalisation and agreeing personal budgets.

3 Looked after children

Looked after children are over three times more likely to have a diagnosed mental health disorder than other disadvantaged children. They are over five times more likely to have a diagnosed mental disorder than non-disadvantaged children. They often find it difficult to access services appropriate to their circumstances and particular diagnosed mental health needs. The Future in Mind report pointed out that “there are barriers in the system itself which prevent change”, and called for “a flexible, integrated system to meet the needs of vulnerable children and young people”.¹⁷

The data collected on looked after children makes it difficult to estimate how many are disabled, as this is only recorded if it is the primary reason for their being taken into local authority care. However, it is known that outcomes for disabled care leavers are poorer than for their non-disabled peers, with less than 1 in 10 living independently at age 19.

The evaluation of personal health budgets found that they can create more personalised, integrated and flexible systems where individuals have greater control over their lives and support.¹⁸

NHS England is leading an integrated personal budget pilot for looked after children with mental health and other support needs that is running from October 2016 to March 2019. It is exploring the potential of personal health budgets and integrated personal budgets to improve the health and wellbeing of looked after children, with a view to these being rolled out across all children and young people with mental health needs. These pilots are taking place in IPC areas.

4 Transforming Care

There are around 41,500 children and young people with a learning disability who display challenging behaviours. A smaller number have severe learning disabilities. Children and young people in this group are at risk of inappropriate admission to assessment and treatment units (ATUs) away from home, and of having poor life chances.

A national programme involving NHS England, the Local Government Association (LGA) and other partners aims to transform care for children and adults in this group. Building the right support¹⁹ is a national plan to develop community services as an alternative to inpatient facilities for people with a learning disability and/or autism who display challenging behaviours, including those with a mental health condition.

Forty-eight Transforming Care Partnerships (TCPs)²⁰ are working to reshape local services, based on a new service model²¹ for commissioners across health and care that defines what good services should look like. Personal health budgets and IPC will be a key part of the new approach, and people with a learning disability and/or autism are a core group in IPC.

It is essential that children and young people who display challenging behaviours receive joined-up person-centred support early on to achieve improved life chances. Person-centred planning and personal budgets play a critical role in developing tailored support that enables children and young people to participate in education, stay in their local communities and achieve ordinary lives.

The National Development Team for Inclusion (NDTi) and the Challenging Behaviour Foundation have produced resources for the Transforming Care Partnerships to support them to meet the needs of children and young people whose behaviour is challenging.²²

5 Other relevant areas of work

5.1 Wheelchairs and equipment

Children and young people with SEND, and those with complex needs, receive a wide range of NHS-funded services. Some are condition-specific and others more generic. These include, for example, wheelchairs, equipment, orthotics, speech and language therapy, hearing services and continence services.

Personal health budgets and IPC could improve the integration of these services and people's experiences. Work has already begun in wheelchair services but more work is needed to fully understand the implications and impact of introducing personal health budgets or integrated personal budgets in other services. During 2017/18, NHS England is working with key partners including: IPC areas; VCSE organisations; and people with lived experience to explore the potential and develop practical models.

5.2 Personal assistants in hospital

Providing care to someone when they get admitted to hospital is the role of ward staff. However, personal assistants can play a valuable role in helping ward staff care for children with SEND or complex needs. The personal assistant's detailed understanding and knowledge of the child means they can provide a range of support to the child in hospital including:

- postural care, handling and movement
- communication
- reducing anxiety/challenging behaviour
- nutrition – having time to help someone eat and drink where they cannot do this without an aide
- personal hygiene.

During 2017/18 NHS England will work with key stakeholders, including acute providers and people who employ personal assistants, to explore how personal assistants are supporting people in hospital and whether this is something that can be promoted in future.

5.3 Delegation of tasks to personal assistants

Some areas have processes in place that allow healthcare tasks to be delegated to personal assistants, and people like the flexibility this brings. The Personalised health and care framework contains best practice and learning around delegation. As the rollout of personal health budgets continues, NHS England expects to see an increase in the number of people who want their personal assistants to carry out health tasks.²³ During 2017/18, NHS England will further explore what this might look like and analyse what the implications are for providers.

For example, South Warwickshire NHS Foundation Trust has a longstanding process for the delegation of healthcare tasks to personal assistants and carers of children with complex needs, supported by e-learning and skills-based training. They have been exploring the expansion of the current model of training from children to young adults.

6 More information

The Personalised health and care framework provides more detailed advice and practical tools to support local implementation.³

The Council for Disabled Children is working with NHS England to support the development of IPC. They have developed a flyer to help local areas see how IPC can help them deliver related policies for children and young people.³

This quick guide has been produced by the Personalisation and Choice Group at NHS England. You can contact us at:

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7 References

- 1 **NHS Five Year Forward View**, NHS England 2015.
- 2 **NHS Choices**.
- 3 The IPC Operating Model, The PA Delegation Framework, and wider framework documents can be found on the **personalised health and care section of the NHS England** website.
- 4 Pinney, A (2017) Understanding the needs of disabled children with complex needs or life-limiting conditions: What can we learn from national data? Council for Disabled Children and The True Colours Trust.
- 5 Disability in the United Kingdom 2014, The Papworth Trust.
- 6 **Improving Lives - The Work, Health and Disability Green Paper**. London: Department of Work & Pensions, Department of Health 2016.
- 7 **Children and Families Act 2014**.
- 8 Prabhakar, M, Thom G, and Johnson R. Individual budgets for families with disabled children, Final evaluation report: **The IB process**. London: Department for Education 2011.

- 9 **Special educational needs and disability code of practice: 0 to 25 years.** London: Department for Education, Department of Health 2015.
- 10 **Five Year Forward View for mental health.** NHS England 2016.
- 11 **Future in mind. Promoting, protecting and improving our children and young people's mental health and wellbeing.** London: Department of Health 2015.
- 12 **Transforming care for people with learning disabilities – next steps.**
- 13 **Preparing for Adulthood Factsheet: The Links Between the Children and Families Act 2014 and The Care Act 2014,** page 7.
- 14 **Special educational needs and disability code of practice: 0 to 25 years.** London: Department for Education, Department of Health 2015. Chapter 9.
- 15 **Special educational needs and disability code of practice: 0 to 25 years.** London: Department for Education, Department of Health 2015. Chapter 9.
- 16 **Special educational needs and disability code of practice: 0 to 25 years.** London: Department for Education, Department of Health 2015. paras 3.38 and 3.13.
- 17 **Future in mind.** Promoting, protecting and improving our children and young people's mental health and wellbeing. London: Department of Health 2015.
- 18 **Personal health budgets evaluation.**
- 19 **Building the right support.**
- 20 **Transforming Care Partnerships.**
- 21 **Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.** LGA, ADASS and NHS England 2015.
- 22 **A pathway for children.**
- 23 **What is Integrated Personal Commissioning and where has it come from?** Council for Disabled Children.

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The information provided in this framework can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

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