People with a learning disability and / or autism

Personal health budgets and Integrated Personal Commissioning quick guide
NHS England Information Reader Box

<table>
<thead>
<tr>
<th>Directorate</th>
<th>Operations and Information</th>
<th>Specialised Commissioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Trans. &amp; Corp. Ops.</td>
<td>Commissioning Strategy</td>
</tr>
<tr>
<td>Nursing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Document purpose</th>
<th>Guidance</th>
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<tbody>
<tr>
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</tr>
</tbody>
</table>

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<table>
<thead>
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</thead>
<tbody>
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<td>N/A</td>
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</tbody>
</table>

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## Contents

1 **Introduction**  
   1.1 Who is this document for?  
   1.2 Personal health budgets and IPC for people with a learning disability and/or autism: An overview  

2 **Personal health budgets and IPC in Transforming Care**  
   2.1 Background  

3 **Personal health budgets and IPC beyond Transforming Care**  
   3.1 Support with managing long-term conditions  
   3.2 Role of personal assistants in acute settings  

4 **Ambition and support available**  

5 **More information**  

6 **References**
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 people with a learning disability and/or autism. It is one in a series of quick guides that explore personal health budgets for specific groups of people or services.

This quick guide sets out what is currently known about:

- the use of personal health budgets for people with a learning disability and/or autism
- 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 learning disability services to support the expansion of personal health budgets in this area.

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 people with a learning disability and/or autism.

The quick guides in this series should be read alongside the National expansion plan3 for personal health budgets and IPC, and the IPC emerging framework4, which provide an overview of the current policy direction and context around the delivery and development of personal health budgets and IPC in health, social care and education.
1.2 Personal health budgets and IPC for people with a learning disability and/or autism: An overview

Approximately 1.1 million children, young people and adults in England have a learning disability. Not all of these people receive NHS-funded learning disability support. Personal budgets (initially in the form of direct payments) have been available for social care since the late 1990s. In 2015/16, 143,000 people with a learning disability received services from their local authority and 99,000 of these had a personal budget.

Personal health budgets are being introduced in the NHS, and IPC will allow all of a person’s health and care needs to be integrated. People who are in receipt of NHS Continuing Healthcare (NHS CHC), or continuing care in the case of children and young people, have the right to have a personal health budget. This includes people with a learning disability and/or autism. There is no right to a direct payment but CCGs do need to have the ability to make direct payments available.

Case study

In Hampshire, the local authority and the NHS are working together to enable young people with a learning disability in transition to adulthood to be offered a person-centred plan and an integrated personal budget. This approach has been built into the local plan for Transforming Care. Personal budgets, personal health budgets or integrated personal budgets will become the mainstream approach for everyone with a learning disability in future, with one aim being that people will be able to remain living with their families or in their own homes.

Case study

Katy is 24 and lives in Dorset with her parents. She has profound learning disabilities with complex health needs. She needs support 24 hours a day, seven days a week. Katy’s personal health budget was used to prevent her moving into permanent residential care, and to pay for individual care at home. Katy’s health, including psychological well-being, weight and vulnerability to infections, has improved dramatically, says Katy’s mother, Jackie.

2 Personal health budgets and IPC in Transforming Care

2.1 Background

As many as 31,000 people with a learning disability and/or autism need high levels of support and receive NHS-funded services. On average, around 2,500 people with a learning disability and/or autism are in specialist inpatient units and it is estimated that around 24,000 people are at risk of displaying challenging behaviour, which could lead to hospital admission. Building the right support 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 behaviour, including those with a mental health condition.
Forty-eight Transforming Care Partnerships (TCPs)\textsuperscript{12} have developed plans to reshape local services based on a new service model for NHS and local authority commissioners that defines what good services should look like.\textsuperscript{13} Personal health budgets and IPC will be a key part of ‘Building the right support’. People with a learning disability and/or autism are also a core group in the IPC programme.

**Case study**
In Devon, personal budgets and personal health budgets have been built into the local approach to Transforming Care. New Devon CCG and Plymouth City Council have worked with provider organisations such as Beyond Limits\textsuperscript{14} to bring people back who were placed out of area. Each support arrangement is individually designed, with staff recruited to match the needs of each person. This lets people live in their own homes and have much more control over how they lead their lives. Personal health budgets and integrated personal budgets are now being extended more widely.

“People ... should have choice and control over how their health and care needs are met – with information about care and support in formats people can understand, the expansion of personal budgets, personal health budgets and integrated personal budgets, and strong independent advocacy.”
Building the right support\textsuperscript{15}

### 3 Personal health budgets and IPC beyond Transforming Care

#### 3.1 Support with managing long-term conditions
It is well recognised that long-term conditions are more prevalent in people with a learning disability and/or autism than those without. People with a learning disability and/or autism are also more likely to need additional support with managing these conditions. Personal health budgets may be an alternative to community and district nurses providing that support. Personal assistants, funded by local authorities or CCGs, can be trained and deemed competent (with appropriate clinical oversight) to perform specific clinical tasks, for example giving injections, administering nebulisers, and changing dressings.

**Pete and Michelle’s story\textsuperscript{16}**
Pete is a young person with learning disabilities who lives with his family in Nottingham. Pete has an integrated personal budget and a person-centred plan which covers all his needs including health, social care and education. He and his mum have chosen their own personal assistants who have been trained to help Pete manage his diabetes. As a result he is able to stay living at home rather than entering residential care.
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. During 2017/18, NHS England will further explore what this might look like and analyse what the implications are for providers.

People with a learning disability and/or autism may access other services where personal health budgets are being considered, for example specialist equipment, wheelchairs, continence services, hearing services and end of life care. More work is needed to fully understand the implications and impact of introducing personal health budgets in these services.

During 2017/18 NHS England will work with key partners, including IPC areas, VCSE organisations and people with experience of receiving personal health budgets, to explore the potential and develop practical models for introducing personal health budgets into new areas.

### 3.2 Role of personal assistants in acute settings

Personal assistants can play an important role when the person they care for needs treatment in hospital, or visit as an outpatient. Personal assistants can develop a detailed understanding and knowledge of the person they care for, which hospital staff cannot fully develop in a busy acute ward or during an outpatient appointment. The personal assistant they know can help the person understand what is happening and help them communicate their wishes and preferences. In addition, the presence of a personal assistant can reduce the stress and anxiety of being in a clinical environment, and so help to remove a cause of challenging behaviour.

During 2017/18 NHS England will work with key stakeholders, including NHS 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.

### 4 Ambition and support available

NHS England is supporting all 48 Transforming Care Partnerships in England make personalised care the mainstream approach for people with a learning disability and/or autism who have challenging behaviour.

This means all areas will put in place the capacity to deliver personalised care and support plans. They will also proactively offer personal budgets for social care, personal health budgets, and integrated personal budgets (which join up funding from health and social care).

Many people with a learning disability and/or autism already have the right to a personal budget for social care or a personal health budget for NHS Continuing Healthcare (or children and young people’s continuing care). The aim is for this to become the mainstream approach for people with a learning disability and/or autism who have challenging behaviour. This will include people being discharged and people who may be at risk of admission to specialist settings. The approach should include children and young people.
In 2016/17, around 4,100 people with a learning disability and/or autism had a personal health budget or integrated personal budget, with 1,600 of these being direct payments. By March 2021, 10,000 people with a learning disability and/or autism could have a personal health budget or integrated personal budget, the majority of which will be for learning disability support but will also include others with a learning disability who have one or more long-term conditions, or are living with frailty. This is in addition to the 99,000 people who receive social care via a personal budget.

NHS England has set up a delivery support programme for Transforming Care Partnerships. This includes:

- access to support from NHS England regional teams and regional personal health budget networks
- information on the NHS England website including a guide to personal health budgets for people with a learning disability and/or autism and personal stories which demonstrate the benefits
- additional support for areas that are introducing IPC.

5 More information

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

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

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6 References

1 NHS Five Year Forward View, NHS England 2015.
2 NHS Choices.
3 The IPC Operating Model, The IPC and Personal Health Budgets Finance Expansion Plan, The PA Delegation Framework, and the wider framework documents can be found on the personalised health and care section of the NHS England website
6 From NHS Digital’s Community Care Statistics and SALT publications, quoted in the data tables accompanying the IHAL report.
8 Guidance on the right to have a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People’s Continuing Care. NHS England 2014.
10 Transforming Care and Commissioning Steering Group, (2014.) Winterbourne View: time for change.
11 **Building the right support.** LGA, ADASS and NHS England 2015.
13 **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.
14 **Beyond Limits.**
16 **Pete and Michelle’s story.**
Personal health budgets and Integrated Personal Commissioning quick guide: People with a learning disability and / or autism

www.england.nhs.uk/personalisedcare

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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. Please contact 0300 311 22 33 or email england.contactus@nhs.net