

Leeds Health & Wellbeing Board

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Report of: A joint report of the Director of Adult Social Care, Leeds City Council, and the Chief Operating Officer, Leeds South and East NHS Clinical Commissioning Group.

Report to: Leeds Health and Wellbeing Board

Date: 25 March 2015

Subject: Personalisation and Personal Budgeting across Health and Social Care in Leeds

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|--|------------------------------|--|
| Are there implications for equality and diversity and cohesion and integration? | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| Is the decision eligible for Call-In? | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number: | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |

Summary of main issues

The Leeds Joint Health and Wellbeing Strategy includes a priority to increase the choice and control people have over their care. One way of doing this is through health and care personalisation, and there is an increasing drive nationally for greater use of self-directed support, personal budgets, personalised care and support planning and commissioning care on an individual basis for people with care needs, long term conditions, mental health problems and for children with complex needs. This paper builds on the personalisation and personal budgeting workshop the Board held in November 2015 with service-users, summarises the progress being made in Leeds to increase self-directed support as a means to improve person-centred care and empower patients, and provides some recommendations around the coordination of this work.

Recommendations

The Health and Wellbeing Board is asked to:

- Discuss the outputs of the Health and Wellbeing Board workshop on personalisation, and the ongoing work in the city to improve care by giving people more choice and control.

- Identify specific areas of this work the Board has a high level of ambition to progress as part of delivering the Joint Health and Wellbeing Strategy, including giving an opinion on numbers or proportions of people the Board wishes to be in receipt of truly personalised care and over what timescale would they care to seek to achieve it
- Make recommendations on how this work can be coordinated across the city and consider how this coordination could be organised and resourced.

1. Purpose of this report

1.1. This report is intended to enable Board members to:

- understand national policy and strategy around personalisation and personal health budgets;
- understand the current position and activity across health and social care in Leeds;
- consider what steps could be taken to initiate transformative change in the way that personalised care and personal budgets are delivered and coordinated in the city and;
- consider how the voice of the service user is involved at all levels in the strategy and delivery of personalised care.

1.2. The report has been written by a group of specialist commissioners covering the key service-user groups discussed within it: Diane Boyne, Sue Kendal (NHS Leeds South and East CCG); Paul Bollom, Barbara Newton, Julie Bootle, Janet Wright, Stuart Cameron-Strickland (Leeds City Council), Stuart Lane (NHS Leeds North CCG).

2. Background information

2.1. What is personalisation?

At its most essential level, 'personalisation' is about care which is centred on the needs of people, with individuals who are in control of their health and care in a culture where services are organised with them rather than done to them.

The term 'Personalisation' has ended up encompassing a complex (and at times confusing) array of policies and practices across health and social care. They can include, but are not limited to:

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| • Independent Living | • Peer Support |
| • Direct Payments | • Prevention and early intervention |
| • Personal budgets | • Community capacity building |
| • Personal health budgets | • Making greater and more creative use of universal services |
| • Supported Living | • Tailoring the formal support people need |
| • Universally accessible information and advice | |
| • Person-Centred Planning | |

For the purposes of this paper, the definition of 'personalisation' is taken to be about how care is coordinated and experienced by the people who receive it. It therefore has a main focus on self-directed support and personal budgeting; with recognition these areas are a small part of a much broader culture change in health and social care.

2.2. What is Personal Budgeting?

Personal Budgets are an allocation of funding to an individual with eligible needs after an assessment, allocated in order for the individual to make decisions on how the money is spent on services which they are entitled to. In both health and social care, the budget can be provided using a direct payment into the individual's bank account, managed on their behalf by a third party, held in a trust held on the individual's behalf by a carer, friend or family member; or can be managed by either the local authority or NHS as a notional budget.

Personal budgets are one option within a range of options for facilitating personalised care and support. For some people they are one mechanism to support participation in clinical conversations and provide some flexibility in the way that funding is used. For others they are a crucial tool which transforms the type of care that is delivered and the way that it is coordinated.

2.3. Why does it matter to people and why does it matter to the Health and Wellbeing Board?

The origins and development of personalised care planning and personal budgets have been overwhelmingly as a result of hard work by disabled people and their advocates with the aim of achieving independent living and full citizenship. The driving force behind innovations, policy reform and practice change has been the motivation to empower people with long term health and care needs to have choice and control over the services that they receive and therefore the lives that they lead. Whilst national policy and local practice have not always facilitated this, it is important to have at the forefront of discussions and planning for personalised care a focus on improving how people with long term health and care needs lead their lives, and the outcomes that result.

Personalisation is important to the Leeds Health and Wellbeing Board. One of the five outcomes in the Joint Health and Wellbeing strategy is that 'People are involved in decisions made about them'. There are priorities to 'Ensure that people have a voice and influence in decision making' and to 'Increase the number of people that have more choice and control over their health and social care services'. The recent Health and Wellbeing Board workshop which heard experiences of services users gave opportunity for greater understanding of why personalisation matters to individuals' lives and provided the Board with an opportunity to learn from first-hand experience. Further details are provided in Appendix 3.

2.4. Overview of national policy background and recent developments

The idea of personalised care and support planning and personal budgets has been in place in adult social care for a long time, with the right to take cash in lieu of services as a direct payment enshrined in law in 1996. The agenda has developed over the last 20 years with policy and funding pressures meaning that social care is moving to a much more asset based approach. The Care Act 2014 is a significant piece of legislation which places personalisation firmly at centre stage. It also places a duty on local authorities to take reasonable steps to coordinate systems and processes with the NHS to reduce the administrative burden for people receiving separate health and social care direct payments.

Personal budgeting in health is a more recent concept, and there is much emerging policy. Since October 2014 people in receipt of Continuing Healthcare have had the right to have a personal health budget.

Further details of policy development in each relevant service area are described in the respective sections throughout this report.

In June 2014 Simon Stevens, Chief Executive of NHS England said in a speech that “we stand on the cusp of a revolution in the role that patients [...] will play in their own health and care.”¹ In September 2014 NHS England initiated the Integrated Personal Commissioning Programme.² This programme has invited local areas to be early demonstrators of mechanisms for individuals to hold personal budgets which combine their entitlements across health and social care. The intention is to bring health and social care spending together at the level of the individual in order to increase individual control and facilitate integration of services. Eight sites across the country have been chosen to be early demonstrators of the Integrated Personal Commissioning Programme. Following consultation with a variety of stakeholders in October 2014 and discussion at the Integrated Commissioning Executive, it was decided that Leeds would not apply for the programme because it did not fit with the priorities and timescales that the city is working towards. Feedback from these discussions is also included in Appendix 3.

3. **Main issues**

3.1. Everyone would benefit from a more personalised experience of care. There are some distinct cohorts of people around whom there is a significant amount of national and local work underway to increase the personalisation of their care.

3.2. Focus on Service Areas

¹ Simon Stevens, speech to NHS Confederation Annual Conference, 4 June 2014

<http://www.england.nhs.uk/2014/06/04/simon-stevens-speech-confed/>

² NHS England, IPC Prospectus, 4 September 2014 <http://www.england.nhs.uk/2014/09/04/ipc-prospectus/>

Children and Young People

- Policy Context

The Children and Families Act 2014 has become law. This is separate legislation from other changes in personal budgeting, but has relevant links to the personalisation agenda. The Act replaces the current Statement of Special Educational Needs and Section 139a Learning Difficulty Assessment with the Education, Health and Care Plan (EHCP). EHCPs will:

- Give parents the legal right to have a personal budget for their children with severe, profound or multiple health and learning disabilities. This will enable them to choose the support that is best for their child.
- Run from birth to 25 years old, to help young people make the transition into adulthood and employment and independent living.
- Require education, health and social care to plan services together so that they are jointly planned and commissioned.
- Require local authorities to publish a local offer showing the support available to disabled children and young people and those with SEN, and their families.

- Current Position in Leeds

Progress has been positive in Leeds with a strong parent involvement approach throughout the development of personal budgets and direct payments. The partnership agreement in Leeds is to have a single process of personal budgets with the various funding streams coming together to become a single budget for the child and family, with a single monitoring system. The process is to be co-ordinated by the lead organization, for example if the social care direct payment came before the personal health budget then the Local Authority would take the lead on accounting systems with assurance offered to the CCGs but not duplicated. The process for delivery of the direct payment would be either through the direct payments team within the Local Authority or the CCGs' finance team.

A joint personal budget policy has been developed and is currently going through approval processes. A joint commitment has been made to provide parents with support and advice in developing and maintaining a personal budget, direct payment or Personal Health Budget. This will be delivered in the intermediate term by Centre for Independent Living (Assist Service).

It is too early to predict uptake. Approximately 100 families have been in receipt of direct payments historically for social care and short breaks needs associated with a child with additional needs. To date 2 families with EHC plans have asked for personal budget and at least one family in receipt of continuing health care.

Social Care

- Policy Context

In adult social care, personal budgets are the intended delivery mechanism for everyone with an eligible need, regardless of age, disability or mental capacity. The last 20 years has seen a progressive shift in policy from the old deficit model of care management as enshrined within the NHS and Community Care Act 1990, to a more positive asset based model. The Health and Social Care Act (2001) made it mandatory rather than discretionary for local authorities to offer direct payments to those with an assessed need. The Care Act (2014) provides people with a legal entitlement to a personal budget. The personal budget must be included in every care plan, unless the person is only receiving intermediate care or reablement support to meet their identified needs.

- Current Position in Leeds

The latest data suggests that by the end of December 2014, nearly 8,000 people in Leeds had received self-directed adult social care during the financial year. However in some cases the definition of self-directed care includes people who chose to continue to have their care arranged by the LA; given this the number of people who are genuinely exercising choice and control through independent spending power is significantly lower than the 8000 headline total.

Changes as a result of the Care Act are being implemented from 1st April 2015. Staff members in adult social care are currently training on the changes to the way that assessments will work. There is work underway within commissioning to develop the care delivery market, including the re-commissioning of the domiciliary care framework to be more outcomes focussed.³

- Co-design and user-involvement

The POET (Personalisation Evaluation Tool) survey is commissioned by Leeds City Council and Yorkshire and Humberside Association of Directors of Adult Social Services.

In total, 119 personal budget holders in Leeds completed the POET survey. The report benchmarks the Leeds data against responses from 1755 personal budget holders in other parts of England, who have used the POET tool this year.

The majority (87%) of respondents in Leeds said their views were taken into account in care planning, a higher proportion than other areas of England (74%). 94% of personal budget holders in Leeds reported that they had received help to plan their personal budget, a slightly higher proportion than personal budget holders in other parts of England (90%).

³ See paper to the July HWBB on the Care Act.

Learning Disabilities

Services and support to adults with learning disabilities in Leeds are commissioned through a pooled budget between health and social care. Person Centred approaches are embedded in the commissioning and delivery of support. Providers are required to evidence that the individuals they support have a Person Centred Plan developed with individuals and that all staff are trained in Person Centred Approaches. People with learning disabilities and family carers have worked together to develop a quality checkers group 'Good Life Leaders' whose role is to visit services to assess if people do have choice and control. The established practice of choice and control within Learning Disability Commissioning has influenced the development of integrated Personal Health Budgets. Currently 27 people with a Learning Disability and additional complex health needs have a Personal Health Budget. The Leeds Learning Disability Partnership Board Strategy 'Being Me' is due to be launched in April 2015. The strategy was developed by the People's Parliament, a reference group for the Partnership Board with more than 50 members with a learning disability. The strategy reinforces the importance of citizenship and supporting people to achieve the outcomes that are important to them.

Mental Health Personal Budgets

- Policy Context

From April 2015, there will be the 'right to ask' for a personal health budget for people with long term health conditions or mental health needs for those who could benefit.⁴

There are currently no plans nationally for this to become a 'right to have' and no specific national guidance available for defining who 'those who could benefit' are from within the broad scope of mental health conditions.

- Current Position in Leeds

The national mental health demonstrator programme led by NHS England concludes in March 2015. Beginning in December 2013, a number of different approaches have been taken by the 11 sites. Progress has been slow with just 3 budgets reported to be in place nationally by September 2014 - highlighting the ongoing challenges to implementing personal budgets in mental health.

No personal health budgets have been delivered specifically for mental health in Leeds. A part-time project lead has been in place from July 2015 with NHS Leeds North CCG. With the support of a Working Group of key stakeholders,

⁴ See section 2.6 in https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/386221/NHS_England_Mandate.pdf
<http://www.england.nhs.uk/2014/04/01/right-to-ask/>

the intention is to be able to outline the local position for personal health budgets in mental health in readiness for the 'right to ask' in April 2015.

From April 2015, Leeds is proposing to pilot an integrated health and social care personal budget for a limited number of individuals supported by the Rehabilitation and Recovery Service led by LYPFT and involving the third sector. It will target those with eligible Adult Social Care needs and on Care Programme Approach (CPA). This builds on a previous piece of work undertaken by Adult Social Care to increase the take up of individual budgets.

- Co-design and user involvement

Development stages for personal budgets in mental health have been co-designed with a working group, on which partners have included Volition, Leeds Involving People, Leeds Mind, Community Links and Touchstone. This co-design work has also been included in the wider scope of developing the Mental Health Framework for Leeds.

Continuing Health Care

- Policy Context

Personal health budgets were piloted across England between 2009 and 2012. The Government has since announced a phased approach to expanding the implementation of personal health budgets, starting with those people who have higher levels of need.

As a first step from April 2014, people eligible for NHS Continuing Healthcare (CHC) had the "Right to **Ask**" for a personal health budget, including a direct payment. From October 2014 this was strengthened and this same group were granted the "Right to **Have**" a personal health budget, including a direct payment.

- Current Position in Leeds

In their duty to respond to these requirements, Leeds South & East CCG (on behalf of all the three CCGs in Leeds) began a pilot project to develop the necessary systems & processes to implement Personal Health Budgets for Adults with Physical & Mental Health disabilities who are Continuing Healthcare (CHC) Eligible.

As a result, thirty four individuals eligible for continuing care have now been offered a PHB. All of which have taken control over their budget via a direct health care payment. Initial outcome focused reviews indicate that each individual has benefited from having more say over their care. The direct payment has provided them with more control over their lives and more choice and flexibility over the care they now receive.

Positive productive partnerships have been formed between Leeds South & East CCG, LCH, Leeds Adult Social Care and Leeds Centre for Integrated Living which has led to increased project capability and capacity. Efficiencies

have been made via integration with Adult Social Care self-directed support procedures and cross fertilisation of personalisation developments.

- Co-design and user-involvement

Pre-project service user interviews were conducted in order to shape the project content and ensure service users concerns and considerations were incorporated. More recently, a model of Peer Support has been proposed so that there is a strong voice of and contribution by people with 'lived experience' in the design and delivery of services and direct support. This will include the informal support that we all value in our lives and that builds and grows genuine connections to our communities and friendships. Our ambition is that people who get support will also give support.

Service user feedback and evaluation has been captured via local PHB evaluation questionnaires the results of which have been largely positive. (Appendix 4)

- Evaluation and the Evidence Base

NHS England commissioned an evaluation of the 2009-2012 national pilots. One of the central findings was that personal health budgets led to an improved quality of life and a reduction in the use of unplanned hospital care. Benefits were particularly evident for people with high levels of need.⁵

3.3. Personal Health Budgets – Most recent policy

The NHS Planning Guidance 2015/16⁶ states that CCGs are expected to:

"...lead a major expansion in 2015/16 in the offer and delivery of personal health budgets to people, where evidence indicates they could benefit"

In February 2015 NHS England released guidance on the expansion of personal health budgets beyond Continuing Healthcare to other groups who could benefit.⁷ It states:

"In 2015/16 CCGs are required to set out their local personal health budget offer and include this in their Joint Health and Wellbeing Strategy. This should result in a clear accessible and well-publicised local offer."

The local offer should be published and should set out how personal health budgets can benefit more people, how partners will work together, how many people the CCG expects to take up personal health budgets and how progress will be measured. NHS England perceives major progress within three years to be 200-600 people receiving a personal health budget per CCG.

⁵ Full evaluation outputs can be found at: <https://www.phbe.org.uk/>

⁶ <http://www.england.nhs.uk/wp-content/uploads/2014/12/forward-view-plning.pdf>

⁷ http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2015/150303-FAQ_Introducing_PHB_beyond_CHC.pdf

3.4. Areas for Strategic Development

Given these discrete strands of work around specific cohorts in the city, and with several emerging challenges and opportunities for the city in implementing the Five Year Forward View, this is an opportune time to bring commissioners together across the city to consider a number of questions, the answer to which may help us step up another level as a city in the personalised, tailored and seamless approach to care and support planning and personal budgets. It is proposed that a personalisation strategy group or similar would consider three key areas of work:

- The strategic direction of personalisation across the city
- Transition issues between children and adults and between health conditions
- A single, simple and clear financial system tailored to the needs of the patient

In tackling these three aims, the group would have to consider:

| Topic | Key Items |
|--|---|
| <i>Integration of Personal Budgets</i> | Between health and social care and mental and physical health |
| <i>Processes</i> | Including developing joint assessments, support planning, brokerage and advocacy. |
| <i>Workforce Development</i> | Including the Care Coordinator role, embedding a culture of personalisation, training and the workforce development strand of Transformation Board |
| <i>Market Development</i> | In order to ensure that there is a diverse market in which peoples have choice over which services they wish to receive. |
| <i>Funding</i> | Including the way that payments mechanisms work for the individual and how budgets can be pooled between organisations and how funds can be disaggregated from current contracts. |
| <i>Lifecourse Approach</i> | How do we ensure a lifecourse approach to personalisation and personal budgeting, and particularly what is needed to bridge the transition between childhood and adulthood? |
| <i>Co-design and user involvement</i> | To make sure that people are at the centre of planning people-centred care |
| <i>Evaluation and Planning</i> | What evaluation would be required for projects and resources and leadership required for city-wide initiatives |

3.5. Next Steps and Project Scoping

The Health and Wellbeing Board may want to consider how progress could be made on joining up work across the city and developing these areas for strategic development. Some considerations include:

- Whether existing developments would benefit from dedicated city-wide work to enable coordination
- What scoping work needs to be done across the city and when this should be completed by
- If there is scoping work to be done, how this should be resourced, coordinated and who should do it
- How any project development should fit in with existing Transformation Board and ICE arrangements

4. Health and Wellbeing Board Governance

4.1. Consultation and Engagement

4.1.1. In the wide range of work being done on personalisation across the city engagement with service users and the consultation and involvement of people in their care is paramount, and some examples of outputs are included below. The very nature of personalisation is person-centred, and this is reflected in the personalisation approaches of LD services, continuing healthcare, children's complex needs team, mental health services and other partners. It was also the motivation for holding the HWBB service-user workshop.

4.2. Equality and Diversity / Cohesion and Integration

4.2.1. The paper does not recommend any decisions relating directly to equality and diversity, based as it is on the rolling programme of increasing personalisation

4.3. Resources and value for money

4.3.1. This paper raises a number of resource implications:

- Personalisation of health and social care may save money in the long run, as a lifecourse and preventative approach to these conditions may reap the benefits of better care and healthier living. However in the short and medium term, resources are needed to achieve the better outcomes personalisation may offer.
- There are some aspects of personal budgets which may save the system money, but other areas in which the cost of new models is higher; the national evidence is inconclusive on the overall financial implications for a health and social care system.
- Additionally, moving *en masse* towards truly personalised control over spend is inherently more expensive because it requires considerable 'double running'. More traditional forms of intervention still need to be

funded whilst cash is released to transfer to those individuals wishing to purchase their own care, it takes many years for traditional services to be downscaled to affordable levels

- Locally, the decision to pursue a higher ambition around personalisation will require investment of resource into a personalisation strategy group or similar and appropriate programme management.

4.4. Legal Implications, Access to Information and Call In

4.4.1. There are no Legal Implications or Access to Information implications arising from this paper. It is not subject to call in.

4.5. Risk Management

4.5.1. There are no direct risk management implications arising from this paper.

5. Conclusions

- The 'personalisation' agenda is broad and complex, but is at the forefront of much current national and local policy
- The most useful aspect of personalisation, which will have the maximum benefit for people's lives is the primary aim of enabling people with health conditions to achieve independent living and full citizenship
- By its very nature, personalisation is about the complexities of individuals' lives. It is therefore difficult to implement blanket approaches for a whole population across health and social care
- There are some changes that can be made to make health and social care more personalised and integrated. The majority of these changes are already in development through the various strands of work across health and social care, as referenced in this report.
- For longer term change and coordinated city strategy, there could be more joined up work on the personalisation agenda between health and social care, mental health and physical health and children's and adults.

6. Recommendations

The Health and Wellbeing Board is asked to:

- Discuss the outputs of the Health and Wellbeing Board workshop on personalisation, and the ongoing work in the city to improve care by giving people more choice and control.
- Identify specific areas of this work the Board has a high level of ambition to progress as part of delivering the Joint Health and Wellbeing Strategy, including giving an opinion on numbers or proportions of people the Board wishes to be in receipt of truly personalised care and over what timescale would they care to seek to achieve it.
- Make recommendations on how this work can be coordinated across the city and consider how this coordination could be organised and resourced.