



National Development Team for Inclusion

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PERSONAL HEALTH BUDGETS FOR CHILDREN AND YOUNG PEOPLE WITH COMPLEX NEEDS

A snapshot of work in three areas

2014-2016



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About this report

In 2014, the National Development Team for Inclusion (NDTi) were commissioned by Think Local Act Personal with funding from NHS England to help three council areas and their local Clinical Commissioning Groups to take more effective action in introducing personal health budgets for children and young people with complex needs.

Plymouth and Hampshire – both integrated personal commissioning sites – and Derbyshire which has been working on personalisation in social care for some time – each identified children and young people and families where existing services were struggling to meet their complex needs. NDTi then provided particular support that focused on person-centred support planning to help raise aspirations for these young people and families.

What follows is an update on what is happening in each of these three areas around Personal Health Budgets for children in young people, what the areas have tried and learned and what will happen next.

There are also some top tips for all organisations looking to prioritise the development of Personal Health Budgets for children and young people.

Finally, there is information about the policy context for this work, the support planning process used by NDTi to support the three sites, and a summary report of the work that took place between from 2014-16.

Work on Personal Health Budgets in Plymouth

Plymouth's plan to implement Personal Health Budgets (PHBs) includes working in partnership with Enham Trust, a pan disability organisation who provide information, advice and guidance to people with Direct Payments and Personal Health Budgets. The Clinical Commissioning Group (CCG) and Plymouth City Council have worked with Enham Trust and providers to develop individualised housing and support arrangements for the people they work with. Some of these are Personal Health Budgets.

At the time of writing, the number of people in Devon who have a Personal Health Budget is 126 . Seven are adults with learning disabilities, while 15 children have a PHB.

Plymouth's aim is to make the support planning process mainstream across health and social care services, including services that support young people. Work with NDTi has supported some families of young people to develop person-centred plans.

As part of work with Think Local Act Personal and NDTi, Plymouth have put on service design days for staff, including those from Enham Trust, with the aim of embedding good practice locally. Enham staff reported that the days worked really well, and was something they could build on. The presence of other professionals at the design days enabled the development of joint understanding and better networking.

Beyond Limits, a provider organisation that supports people with learning disabilities, mental health issues and other needs and which also has a strong interest in helping people move back home from 'out of area' placements, has worked with people who have moved from institutions such as Winterbourne View.

Other people living with their families are also being offered PHBs.

What are some of the problems they are trying to solve and what has been learned?

Mainstreaming the support planning process across health and social care services:

Plymouth had some difficulties getting the idea adopted beyond the NHS. Involving young people who only had access to social care funding proved difficult as processes across health and social care were different and these differences created some barriers and challenges. Plymouth had initially identified six children and young people who could benefit from a PHB, but funding eligibility then became a limiting factor and Plymouth lost potential children and young people when they were not eligible for children and young people's continuing care.

Out of area placements: there was a concern that some young people with whom social care workers are working with, will end up going out of county, possibly funded by the NHS due to a lack of local services and there is a need to develop new providers who are able to support people with a history of challenging behaviour. Since 2011, Beyond Limits has been helping Plymouth to bring some people who had been placed out of area home again through delivering Personal Health Budgets as Individual Service Funds (ISFs). The shift towards a culture of working in partnership has been critical to the successful delivery of Personal Health Budgets in this way. More details if provided in the case study that follows.

Clear and appropriate internal processes and communication: for example, Enham received a referral for a PHB from the PHB team in Plymouth for someone who already had an individual service design through a separate project. However, this information was missed and it led to some confusion and duplication and the family eventually deciding not to go ahead with the PHB. Streamlining the process to ensure that documentation is complementary at all stages, particularly at the service design, PHB resource allocation and support plan stage could improve the experience for young people and families. People have been clear that they want to provide any detailed information required to initiate the package only once, as answering the same questions more than once led to frustration.

Engaging families and helping them to understand what's possible: to date, it's possible that not enough preparation work was done with families about what Personal Health Budgets could do, perhaps because this work was seen by families as a project rather than common practice. For example one family said they did not want to do anything that would stop them getting what they had already been wanting for their son, so they may have misunderstood what Plymouth was trying to do. Once families became engaged and understood, it was very productive.

Key Learning Points

- There has been some joint planning which has worked well. For example, one plan was developed in a mainstream school. An advocate was present, and lots of actions regarding preparing for adulthood were identified. It was reported that this process was leading to a better way of working as the conversations were 'different'. However, although there is a clear link between this type of planning and Education, Health and Care Plans (EHCPs), planning is not currently well tied in with EHCPs.
- The role played by a third sector partner, the Enham Trust, and the skills around individual service design and support planning they possessed is particularly important for this type of work and should be embedded locally through the partnership.
- Clear communication is critical to the success of this work. There is a need for clear information for children/young people and families about what Personal Health Budgets are, and what can be achieved. Stories of a local child/young person with a PHB can illustrate this.
- There is a need for a clear process around accessing Personal Health Budgets that can be shared with families so that they know what the steps to a PHB are, what will happen and when.

Transforming care in Plymouth using Personal Health Budgets

**CASE
STUDY**

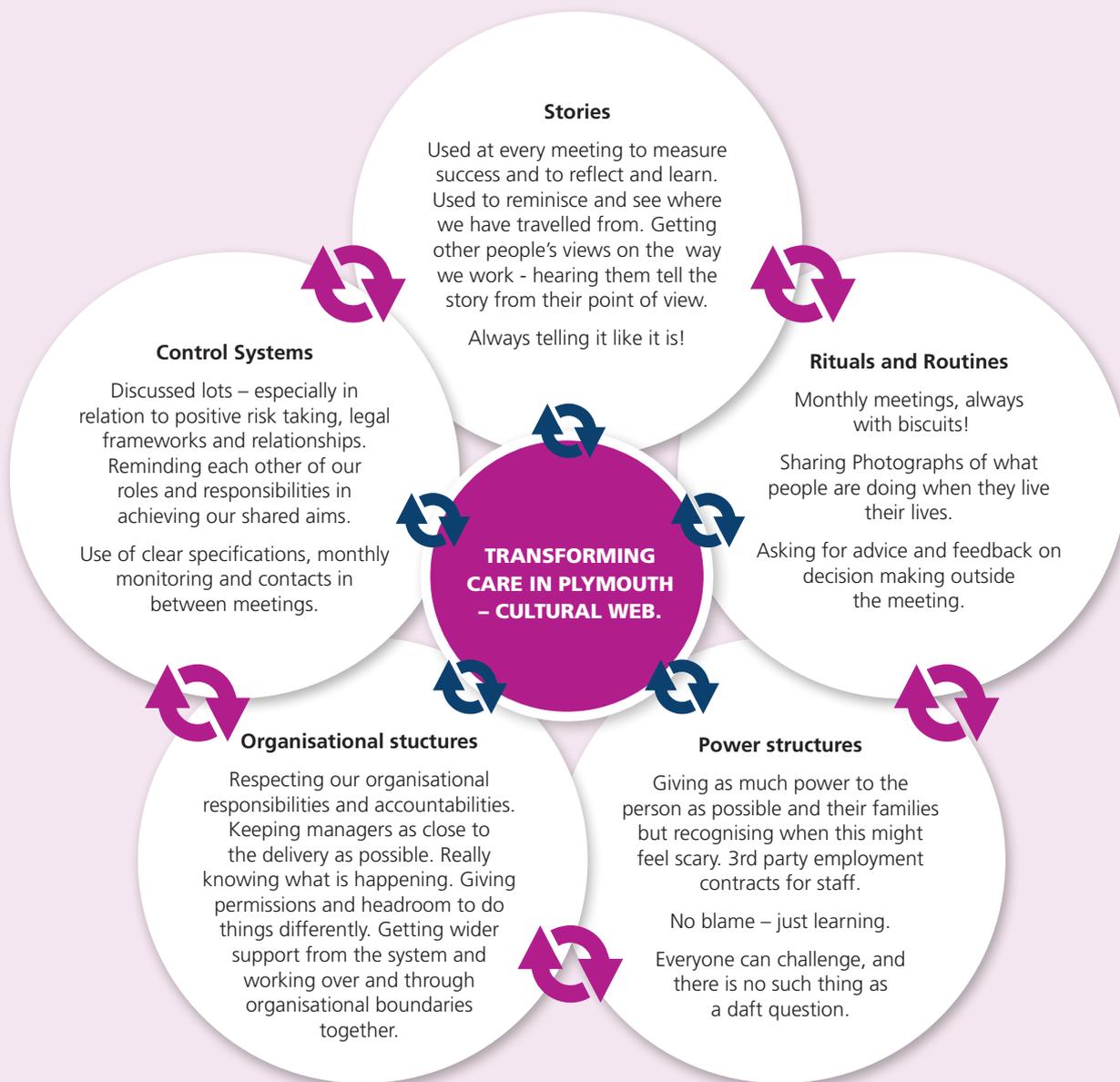
The NHS in Plymouth set up a pilot to bring people with learning disabilities in out of county in-patient units back home in 2011.

They set up a new organisation, Beyond Limits, to help them do this. There are approximately twelve people with Personal Health Budgets delivered as Individual Service Funds (ISFs). The project was set up before the current NHS reforms and the exposure of abuse at Winterbourne View, demonstrating a long term ambition in Plymouth to reduce institutional placements. Detailed information about the project can be found in the following two reports:

Duffy (2013). **Returning Home. The Centre for Welfare Reform:**
www.centreforwelfarereform.org/library/by-az/returning-home.html

Duffy (2015). **Getting there. The Centre for Welfare Reform:**
www.centreforwelfarereform.org/library/by-az/getting-there.html

This case study focuses particularly on the culture that developed in Plymouth to enable this project to be a success. Information about how Personal Health Budgets are used as ISFs to bring people back home is covered separately. The following diagram summarises the way in which people worked together to develop and maintain this culture.



The following sets out in more detail the elements of the Plymouth Cultural Web:

Power structures

Strengths based person-centred planning based on a citizenship model is a crucial foundation stone and part of the Seven Step Model that Plymouth use, and that is part of their Transforming Care Partnership Plan (see page 8). Families are involved from the start, and their knowledge and experience is invaluable. The focus on strengths and celebratory nature of the planning days is new to the individuals and families involved, many of whom have had very poor experiences of services, and helps give them faith in the process.

THE 7 STEP MODEL:

- | | |
|--|----------------------------------|
| 1) Identification and review | 5) Team recruitment |
| 2) Individual service design | 6) Move |
| 3) Decision making plans | 7) Monitoring and support |
| 4) Support and housing identified | |

Organisational structures

Ownership of the project at a senior level was gained at the start, and crucially senior managers and commissioners within learning disability services knew the individuals concerned, remained close to the delivery of support, and were thus able to respond quickly and appropriately if necessary. There has been a high degree of stability in key posts in Plymouth, enabling the development of good relationships, although the joint CCG and LA commissioner has now been moved to another part of Devon due to CCG organisational changes. The system is well embedded so it is hoped that this won't have an impact. However there is a recognition that organisational change can be detrimental to this type of project, particularly as it is such a small part of the overall health and social care services, and requires regular promotion and explanation to ensure it does not get eroded as senior personnel change.

The nurse consultant and community staff team which includes psychiatry, psychology, nursing, a social worker, a behavioural therapist and more recently, forensic services, are passionate about their work, and willing to challenge the status quo. For example, a hospital in which one woman was residing, would not discharge her to anywhere except another hospital. The team liaised with a local hospital which was closing, and were able to move her there as an interim measure. Two months later she was living in her own flat. The Nursing Times award the community team received last year was an important recognition of their work.

Monthly meetings, bringing strategic commissioners from the CCG and local authority, clinical staff, providers and the housing officer together, facilitated the process. The meetings focused on shared problem solving, reflection and learning, not blame. Joint working and shared understanding of the issues has proved to be very important to the successful support of the individuals concerned.

Control systems

Positive risk taking is an important part of the culture in Plymouth. When the risks for one individual looked particularly concerning, all involved countersigned the risk assessment, including the commissioners and family, to share the risk and 'hold hands and go forward together'. The meetings have also been used to track the financial situation for each person and use of the contingency money. For example, one woman had got stuck in a downward spiral and the contingency fund was used to take her to Cornwall for a short break, which effectively broke the cycle.

The control systems include a way of measuring outcomes. A CQUIN had been put in place in Plymouth in a previous contract to implement the Health Equalities Framework (HEF).¹ This means there is good data and an understanding of a baseline for each person. Repeating the HEF enabled the team to see how each person had progressed in each domain of their life. Information from the HEF enabled the team to focus on those areas where progress may not have been as marked for the person.

The dynamic risk register enables Plymouth to identify the providers who support people with the most complex needs, and providing more support for these providers through regular meetings is an ambition. Additionally across the TCP it is envisaged that information from the register would identify those providers who need greatest support in terms of work force development.

Stories

Using stories at every meeting was a really important way of keeping focused on the individuals and what is important for them and their families. It was important that the stories reflected what was actually happening, good and bad, as this kept everyone grounded in reality.

Routines and rituals

The monthly meetings were structured around the individuals concerned, ensuring best use of time for care managers who may be working with just one person and commissioners. There are also core meetings with families and those providing the support to ensure there is close working between support staff, families, and clinicians. However, there is also lots of contact outside meetings so that people do not have to wait to get advice and feedback if it is needed urgently.

¹ *The Health Equality Framework (HEF) is an outcomes tool based on the determinants of health inequalities designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services. For further information see: www.NDTi.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1*

Changing staff culture and people's lived experience through individual service funds

CASE STUDY

How Personal Health Budgets are working as Individual Service Funds for people with learning disabilities returning to Plymouth from out of county in-patient services.

Beyond Limits is a small provider working with the NHS in Plymouth to bring people with learning disabilities in out of county in-patient facilities back home. They are currently supporting twelve people in Plymouth who have Personal Health Budgets that are paid in the form of Individual Service Funds (ISFs) to the organisation. None of these people have had to return to hospital.

How ISFs work

Beyond Limits uses strengths based person-centred planning based on a citizenship model to develop an individual service design. Planning happens well before the move and families are involved from the start. Their knowledge and experience is invaluable. The plans focus on strengths and are thus a positive experience, which is often new to the individuals and families involved, many of whom have had very poor experiences of services.

The budget is set following the plan, although for the first year, the budget is based on what the individual was costing in their out of county placement. This budget includes the transition costs which are often £20-30,000. Thus in year two there is an automatic saving of these costs to the NHS. The money is then drawn down for each individual on a weekly basis using a pre-paid card. Each team is involved in setting the budget which includes staff pay and anything else required. There is also a contingency fund built into each budget, and the budget is top sliced to pay for things like training and recruitment.

Each individual has a working policy that describes how to support the person successfully and everyone understands and follows this policy. The staff are legally employed by Beyond Limits, but this is done in conjunction with the individual and family, using the third party agreement in each staff member's contract of employment. Staff specifications are developed as part of the individual service design, and the staff adverts are based on the specifications. Staff are employed before the individual returns home as it is important to have strong support in place in advance of the move. The staff are employed for the individual and there is a rule that staff can work with no more than two individuals. Staff working with two individuals will have two separate contracts, and there may be different pay rates. The third party contract means that the individual supported or the family can say that they are not happy with the staff member. If a staff member is asked to leave a service, Beyond Limits would try their best to find another match, although this is not always possible. Beyond Limits has a clear rule that managers do not have the authority to appoint staff, unless this has clearly been delegated by the family.

Recruiting staff

Staff recruitment is a challenge. Trying to do it in the traditional way does not work. It requires using local shops, and the local radio, and going into schools and colleges. Word of mouth and local recruitment is best. Beyond Limits are interested in people who come from different backgrounds. It is about 'digging deep' – 'doing difficult differently'.

Monitoring

The budget is monitored at a quarterly quality review which also includes a review of the plan, what has been achieved and should be celebrated (and if not achieved, what needs to happen), and a review of the safety assessment (Beyond Limits do safety assessments rather than risk assessments as it is about supporting people to do things safely). There is also a review of the team including training and status of DBS checks. If money is left, there is a discussion about what is needed. It is rare for more money to be needed.

In addition there are core meetings arranged by the care co-ordinator with the family, members of the community team and Beyond Limits staff. These can happen as frequently as needed but generally three to four times a year. Beyond Limits do safety assessments rather than risk assessments, as it is about supporting people to do things safely.

An example of how Beyond Limits is working with an individual

One individual has really challenged Beyond Limits staff since leaving hospital two years ago. Challenges have included the involvement of the police and ambulance services. Beyond Limits have found that occasionally when people leave a hospital setting, they miss the security a hospital can provide, even though their lives were highly restricted and unpleasant. They can react against their new freedom and 'put us through our paces, teaching us how to support them well'. This person has a very strong and high functioning support team, and there have been many lengthy and difficult conversations about how best to support them. Success requires attention to detail and sticking with the individual through thick and thin, as sometimes there are situations to deal with four or five times in a week. Forming relationships with the police, ambulance and other services is an important part of multidisciplinary working around individuals with these challenges. Leadership throughout the organisation is also crucial, and this means leadership that puts the person first, not the organisation, and is based on the values and principles of human rights and social justice.

Working with other providers

Beyond Limits have taken the Altrum model they used in Scotland (Altrum means 'foster' in Gaelic) where the Chief Executives from a number of small organisations came together to develop and share training and joint purchase things like personnel support and phones, and have started to develop this in the South West as Altrum SW. There are approximately five organisations involved at the moment.

For more about Beyond Limits please visit the Centre for Welfare Reform:
www.centreforwelfarereform.org/library/type/pdfs/getting-there.html

What will happen next?

Staff turnover previously had an impact on work in Plymouth. Having a critical mass of staff who have a joint understanding of the support planning process as a necessary step to Personal Health Budgets can ensure this way of working is embedded.

Steps are being taken to tie this work into Education Health and Care Plans, possibly linked to the publication of a clear local PHB offer.

More joint working is being undertaken to address the concern that some young people will end up going out of county, possibly funded by the NHS. The involvement of both Plymouth County Council and New Devon CCG in the IPC programme will help to develop a more integrated approach to planning and delivery of support packages for young people, including providing the option of integrated personal budgets. It is expected that IPC will help to overcome the existing system and cultural barriers limiting the availability of the approach tested in this pilot.

Work on Personal Health Budgets in Hampshire

The My Life My Way initiative is aiming to make person-centred planning and personal budgets the mainstream approach for children and young people in transition, and adults with learning disabilities.

To date, 74 people in Hampshire have a PHB – 15 are adults with learning disabilities; and two children have a PHB.

NHS and council money will be included in integrated personal budgets in the future.

Person-centred support planning sessions have taken place with five families and staff were also trained on person-centred approaches.

What is the problem they are trying to solve and what has been learned?

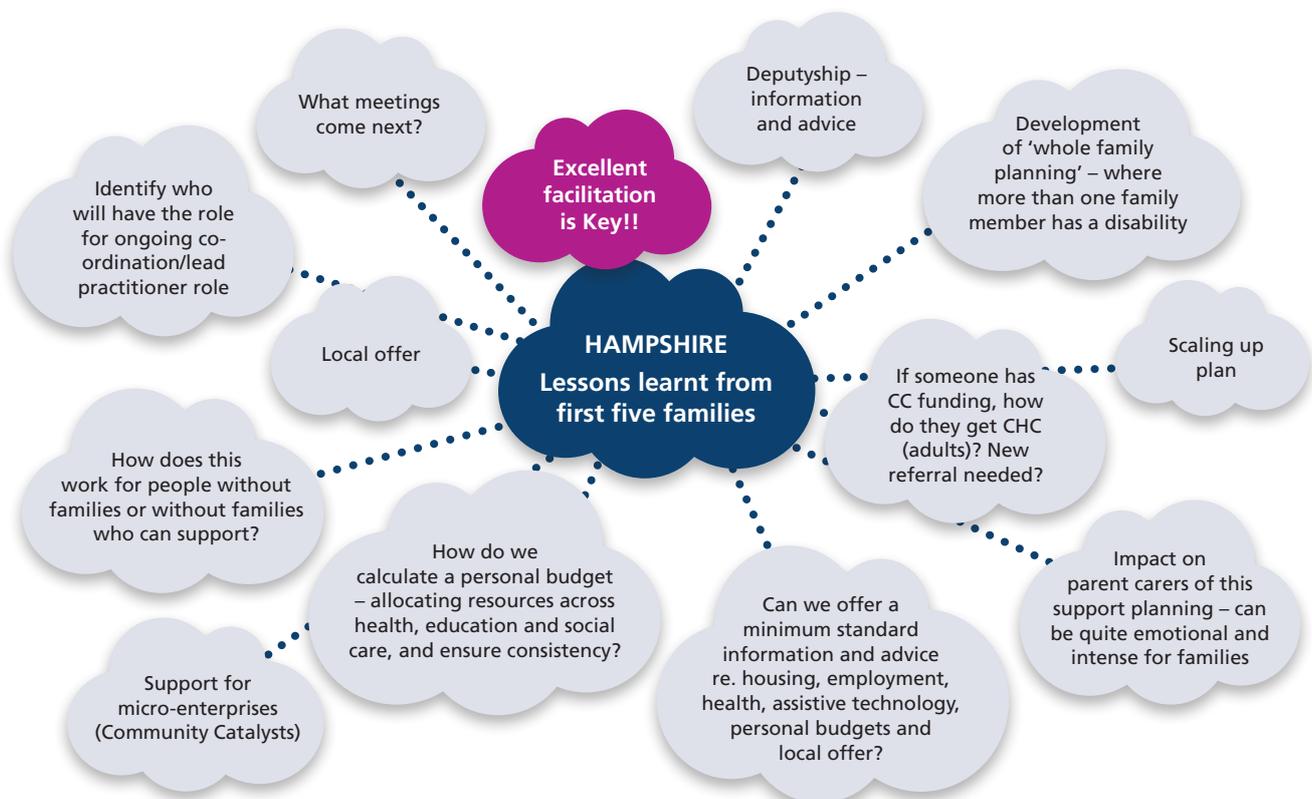
Young people and their families find the transition to adult services a stressful experience and families are not well informed about personal budgets.

NDTi with Hampshire undertook planning sessions with five children/young people and their families. Four were in the 14-18 age bracket, and one was 21. Hampshire wanted to improve overall life chances by focusing on getting it right for people before they went through transition. These families were introduced to the personalised care and support planning model. Two families also had other disabled children, so in effect Hampshire have been working with eight children, as planning has to take account of the whole family. This has been important, and has added to the learning for everyone involved.

Only one young person in this group has continuing care funding. This person does not yet have a Personal Health Budget as Hampshire do not have a mechanism for bringing health and social care funding together in children's services.

Key Learning Points

- More work is needed to get better join up between children and adult social care services and with the NHS.
- It's important to think about how to make person-centred approaches work for larger numbers of people.
- The support planning process for individuals has been really useful. It has focused on the positive and possible, and motivated staff and families. One of the planning days was held at a residential college, which tied in very well with the EHCP review, as this was also done in a person-centred way. The planning opened up possibilities that had not previously been thought about as the parents involved had not known the full range of what is available.
- The process has also meant that Hampshire have already been able to identify some blocks and barriers. For example, access to suitable housing; advice on setting up microenterprises; setting up a Personal Budget with funding from social care and health.
- The Hampshire project has summarised some key issues, questions and learning in the graphic below.



Other key points of learning from the Hampshire work include:

- The need for clarity with families about the reasons for Personal Health Budgets. For example, one parent had an expectation that their involvement would mean more funding – but by going through the planning process she realised it was about planning differently and looking at the assets of her son and what the community can offer; i.e. an asset based solution.
- This links to the importance of having really good information and advice to share at the beginning of planning in order to help to empower and motivate families.
- The benefit in implementing change that arises from good preparation, skilled facilitators and the use of reflection.
- The Hampshire initiative has been led by social care. This has provided a number of challenges when it came to scaling up the number of Personal Health Budgets or budgets with a health element in them, i.e. full NHS buy-in to the work.
- When starting a pilot with young people/children, there needs to be an understanding about where they are in other public sector systems, to ensure integration of the different processes. For example, mapping out where personalised care and support planning and the PB offer should be integrated into the EHCP process.

What has been the benefits been for people and families?

Family feedback on this work has been positive, especially on how the Different Conversation has helped families to see what can be possible.

“You guys have helped me through a similar process now – that of viewing the adulthood of my children not with so much fear but with the thought that things are possible and that if we think positively then they can achieve their goals as would any other young person. We all need to believe that to make it happen and we now have an action plan to start that process – so thank you!”

“Brilliant!”

“Thanks for all your support – I felt exhausted but very positive after yesterday.”

Think Local Act Personal's website features Lewis's story in the Care and Support Planning Tool. He is 16 and attends the post 16 unit of a special needs school. You can read about his and his family's journey through the Support Planning Process and the benefits of working in this way by visiting: www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/lewis.

The Claire Patricia Steeples Trust (CPST) is a small Family Trust set up in 2007 to support and administer the Claire Steeples Self Directed Support (SDS) Personalisation Package. You can read more about Claire and how she and her family have benefited from a social care funded personal budget by visiting: www.cpstrust.co.uk/.

Next steps

The main challenge is to spread the learning from this project so that it becomes 'business as usual'. There are ambitious PHB targets to meet given the County's involvement in the IPC programme, and concerns about the ability of staff to respond in the timescales required. It is important that the good work around planning isn't lost as the project moved forwards

In Hampshire it is social care that has been the lead for this project to date, so although relationships with health are good, there is some work to do to ensure health can take a lead on this.

For the young person in receipt of CHC funding, work is taking place with the PHB team, the young person and his family, to map out the customer journey with the aim of creating a Personal Health Budget. This will look at the information, advice and support given to families; approval mechanisms and the risk management associated with this.

Work will be done to develop the links between EHCPs and the PHB planning process so that it can be embedded.

Also, there is work taking place with the Project Manager for the Local Offer to make further suggestions about how this could be improved for families. This includes a new website – Info4U – which is specially aimed at young people who are 16+, so that they can access information independently from their parents/carers.

Hampshire is working with Think Local Act Personal to develop the use of individual service funds.

Hampshire is looking at how to join up personal budgets in health and social care so that they work in the same way.

Work on Personal Health Budgets in Derbyshire

Southern Derbyshire CCG employed a commissioning manager for Personal Health Budgets initially for one year, although this has now been made permanent.

A NHS England grants programme for voluntary and third sector organisations has enabled two local organisations to 'gear up' for Personal Health Budgets. Umbrella and St James Centre in Derby received the grant and gained the knowledge, capacity and expertise to inform their local communities about Personal Health Budgets and both started to send in referrals, enabling the identification of potential families.

Five families from Derby City were identified for the person-centred support planning sessions run by NDTi.

What is the problem they are trying to solve and what has been learned?

Derbyshire is organisationally complex with four Clinical Commissioning Groups (CCGs), Derbyshire County Council and Derby City Council which meant that it was difficult to clarify responsibilities and to identify suitable children or young adults and their families who could benefit from Personal Health Budgets.

Five potential children and their families were initially identified, and work commenced, but three of the families then withdrew as they thought they were not eligible. All of the children/young adults involved clearly had health needs and behaviour that challenged, and were in receipt of Social Care support, but were not accessing services linked to their condition except in the school environment. The table gives an indication of the range of young people and their conditions.

Details of family and young person	Aim of PHB
Family A – Young woman age 23. Severe learning and communication difficulties. Curvature of the spine.	Manage/reduce behaviour that challenges. Reduce GP contact and use of other services.
Family B – Young girl age 14. Severe learning disabilities. Global development delays. Renal transplant.	Weight loss to improve health.
Family C – Young boy age 17. Complex chromosome condition.	Access to vital services at home (on CHC funding).
Family D – Young boy age 15. Down syndrome and autism. Severe learning disabilities.	Improve muscle tone.
Family E – Young boy age 15. Duchenne muscular dystrophy.	Improve independence.

Support planning work continued with the remaining two families. Training with staff at Ivy House School quickly identified that the staff there were already skilled in person-centred planning. Unfortunately, other professionals did not attend this session. In addition, significant input was required to help support the families' understanding of person-centred approaches and Personal Health Budgets. On average this equated to between two to three home visits per family, plus telephone and e-mail support.

More recently Volunteering Matters have become involved, and will be supporting the implementation of Personal Health Budgets locally. For example one family has a support plan in place but cannot decide what intervention is required to meet the identified needs. The plan is to utilise Volunteering Matters to act as an advocate, and develop an understanding of what is possible.

The families that initially stepped down attended a networking event at Ivy House School which included Inspirative Arts as an option: www.inspirativearts.co.uk. Understanding that a range of opportunities were available proved to be a 'lightbulb' moment for those families, and they are now re-engaged with plans for Personal Health Budgets in the future.

Additional time commitment was required to support completion of the Personal Planning Book adopted by Derbyshire for these three families – on average one to two home visits. There remains a need to help further develop the Personal Planning Books completed this far for the three families.

In addition to the above work there is a parallel programme on workforce development called 'A shared language for person-centred care' that is bringing staff together to develop a joint understanding.

Key Learning Points

The following factors have been identified as being particularly important in Derbyshire's journey with this initiative:

- The positive engagement from senior managers in health and social care in Derbyshire and creation of a dedicated post in Southern Derbyshire CCG, held by an individual who has a strategic overview and is knowledgeable about the process.
- Knowledgeable voluntary and third sector organisations working as partners.
- The input on support planning from NDTi, which included going back to the beginning with families so that there was a detailed history. This helped staff develop a joint understanding of the issues the family faced and gave good insights into what families needed.
- Developing families and young people's understanding of community supports and services so they know what is possible.
- Agreeing where support planning will sit and the role of the voluntary sector in this.
- Sourcing PAs for young people and families, which was a particular local challenge but had to be overcome.
- Persuading health and social care professionals of the value of attending planning meetings which take time, but enables the development of joint understanding and saves time further down the line.

What will happen next?

Derbyshire are now considering a county wide approach to Personal Health Budgets, as envisaged at the beginning of the programme, with a shared infrastructure and paperwork. They are planning to form a Peer Support Network which will include people who have accessed a PHB, who will be supported to share their experiences to raise awareness of benefits and share experie Southern Derbyshire CCG and the Council are also instigating work to ensure that Education Health and Care Plans are always person-centred and therefore the process can merge to form a Life Plan.

Five more children will be identified who are in year 11 and who are transitioning to Education Health and Care Plans (EHCPs). The plan is for Volunteering Matters to work with these children and families to support the development of person-centred support plans if funding allows.

Further work will be done to raise awareness of community options including access to universal services through the Local Offer.

Work is to be undertaken to map and utilise the range of skills currently available (for example at Ivy House School), and develop a plan about how these can be deployed to embed person-centred planning within EHCPs.

Top Tips for Developing Personal Health Budgets



TOP
TIPS

These top tips are based on work that the National Development Team for Inclusion (NDTi) undertook for Think Local Act Personal and NHS England with Plymouth, Hampshire and Derbyshire. They have identified a number of crucial 'building blocks' that are essential for the successful development of Personal Health Budgets for children and young people:

Leadership

- **Gaining ownership and leadership from Clinical Commissioning Groups and Local Authorities** regarding the implementation of Personal Health Budgets is an important first step. There is a danger that Personal Health Budgets are seen as a 'fringe' activity and not as part of the core strategy to achieving better outcomes and value for money. This agenda needs to have explicit and high profile support from senior decision makers if all parts of the system are to engage in the changed practice and behaviour that Personal Health Budgets require. This covers not just support/action around the process of Personal Health Budgets, but also a commitment to giving children, young people and families more choice and control, so that they have better lives embedded in their local communities.
- It is important that there is a **dedicated post held by an individual of sufficient seniority** who has a strategic overview of this agenda **and** is directly engaged with the work. Engaging with families, and practitioners, and getting whole system ownership is time consuming and cannot be led as an 'add-on' to substantial other responsibilities.
- Most of the sites in this initiative faced organisational change and turbulence during this work, with key people leaving or being moved to other work. This resulted in a loss of knowledge and commitment to Personal Health Budgets. Whilst recognising these are challenging times in the NHS and local government, **strategies to ensure consistency of leadership** with any new initiative are an important factor in success.

Understanding Personal Health Budgets as Whole System Change

- Progress is more likely when there is an understanding from key players that work on pilot initiatives through programmes like Integrated Personal Commissioning is being used to **understand and prepare for significant and fundamental changes** to how the health and social care system operated for children, young people and their families. Where introducing Personal Health Budgets was seen as a discrete project, without consideration of the whole system implications or a clear intention to carry on beyond the life of the initial few families, buy-in from key players was difficult and limited progress was made.
- A specific aspect of this is the **cross-agency willingness to adapt organisational policies and processes** in order to enable person-centred practice to be implemented. For example, having a shared NHS and council policy and pathway for joint funded budgets.

Understanding and Commitment from Key Players

- Working in new ways requires **people to be willing to change how they do things and try something different**. This is particularly important in relation to families (see below) and health and social care professionals.
- **Securing the active participation of professional staff**, particularly in relation to training and other activities designed to introduce person-centred support planning is an essential building block for change – a factor previously identified by the In Control project, Me, My Family, My Home, My Friends and My Life.² The previous points about leadership clearly have a major impact on achieving this.

Families at the Centre

- Families have a crucial role to play as part of the process of change (In Control 2016). Thus, their **early engagement and the delivery of good information for families** was found to be essential. It takes time to engage with families, explain Personal Health Budgets and the potential benefits and gain support and commitment for them. Families therefore need to be involved from the outset.
- Developing **peer support networks** of families who have experience of personal health budgets and a good understanding of what is possible would be a positive step to address this.

² In Control (2016) Me, My Family, My Home, My Friends and My Life: www.in-control.org.uk/what-we-do/community-of-change/children-and-young-people/our-work/me,-my-family,-my-home,-my-friends,-and-my-life.aspx

- An important building block is **investing in and listening to families**. Family expectations are often constrained by their experiences of what has been available and possible in the past. Therefore, clear images of possibility, along with basic information about what Personal Health Budgets are, what they can achieve and how to access them are needed.
- **Keeping families and children/young people central** so that good practice regarding support planning and overall Personal Health Budget implementation is not lost as pilot initiatives move to being mainstreamed and the number of Personal Health Budgets increases.



CASE STUDY

The importance of Personal Health Budget advisors with lived experience...

“Having a Personal Health Budget can transform people’s lives! However many people can be very daunted at first and worry they will be taking on too much; but with the right support, guidance and conversations built around their needs, the experience can be very positive.”

– Glenys Newman, Personal Health Budget advisor at Independent Lives a Charity in West Sussex

Glenys works for Independent Lives and is one of three Personal Health Budget advisors with lived experience. She first heard about Personal Health Budgets in 2012 just before her daughter Natasha, who has complex health needs and learning disabilities turned 18. After it was confirmed that Natasha was eligible for NHS Continuing Healthcare Funding, an advisor from Independent Lives visited to explain how a Personal Health Budget could work. After deciding they wished to proceed with a Personal Health Budget to enable them to have more control over the support they received with Natasha’s care, the advisor worked with the family to write a person-centred support plan and draft a budget detailing how the funds would be spent. The Personal Health Budget also funded a personal assistant to go into school with Natasha during her final term so as to become familiar with all her support needs, learning how she communicates and how to best support her during activities such as hydrotherapy or riding her trike.

The budget was revised the following year when Natasha left school to provide increased support. This has enabled her to continue living at home which was what both Natasha and her family wanted. Whilst Glenys was being supported by the Personal Health Budget advisor from Independent Lives it was suggested that she might like to apply to a vacant advisor post, as her lived experience was extremely valuable for the role.

After being Natasha's main carer for 19 years and feeling unable to commit to work, Glenys was keen to be able to share her experiences to assist others through the process, having experienced first hand just how invaluable having that support was. Through the flexibility of managing Natasha's Personal Health Budget Glenys was able to tailor the support so that she was able to apply for the role and return to work part-time.

Independent Lives sees that at the heart of Personal Health Budgets are good, person-centred conversations with their customers, helping capturing what is important for and to them to remain healthy. Glenys role is to guide the customer through these conversations which are then captured in a support plan. This can be written together with the individual and their family, the Personal Health Budget advisor and health care professional.

Glenys shared her thoughts on working as an advisor:

"When I first visit customers they often have very little understanding of what a Personal Health Budget is and how it can be used to deliver their care in a more person-centred way.

They appreciate the continuity of having a named advisor who will remain available to them for support for as long as they are in receipt of a Personal Health Budget direct payment. Many customers choose to employ their own PAs and are often daunted by the prospect of becoming employers.

I am able to assist them by equipping them with the necessary tools to become effective employers, confident in managing their staff and meeting the legal obligations of being an employer.

I manage to put people at ease and for them, knowing that I also manage my own Personal Health Budget for my daughter who has complex needs can be reassuring as I have first-hand experience of the challenges they can face."

Clarity around Support Planning

- Support planning is best delivered by people who understand how to do this in a person-centred way. This is often outside the statutory sector. It is important to **agree where support planning sits** and be clear about the role of the voluntary sector in this.
- **Ensure local health and social care professionals are fully engaged in the support planning process**, and that barriers between families and professionals are pulled down. In Control (2016) found that families generally liked good practitioners because they knew they were there for them. Valuing and supporting staff through these changes is important.

Linking into Wider Service Systems

- Support planning for young people has to be **connected to the Education, Health and Care Planning process**, with clear agreement about how Personal Health Budget planning maps onto education health and care plans.
- Personal Health Budgets and support planning will lead to needing different service options (otherwise there is limited point in doing it). It is therefore important to **tie learning from support planning into market development**, so that deficits such as a lack of personal assistants can be addressed and children and young people can access a range of creative community resources.

Developing Staff Skills

- A different approach from staff is essential if Personal Health Budgets and real person-centred support planning are to be a reality. Therefore **on the job training to implement support planning and embed such skills in the wider workforce** is important. Staff need to understand how to build a shared understanding of an individual, what is needed and what is possible. An absence of plans and actions to train staff in these things contributed to there being insufficient local capacity for support planning.

The Third Sector and Community

- Personal Health Budgets, like personal social care budgets, will lead to use of a range of non-traditional support options. Some of these are most likely to come from outside the traditional service sector. Thus, it is important to **develop relationships and invest in knowledgeable voluntary and third sector organisations** locally. They have important links with families and communities, bring different perspectives and add to overall capacity. As noted by In Control (2016), although the system largely means education, health and social care, it is important to pay attention to community, housing and the rest of civic society.

An example of one Family's Experience...

CASE STUDY

This young person (K) now has a PHB, and there has been very positive feedback from the family about the whole process. This is a description of what happened with them during this project.

K and her family were referred to the PHB Project Team by Umbrella, a local charity supporting children and young adults with disabilities. Umbrella had received funding from NHS England to promote Personal Health Budgets with their service user group and as part of this they referred families into this work.

At the time of referral, K was 23-years-old. She has dermatitis, curvature of the spine, severe learning disabilities, behaviour that challenges and autism. These greatly affect her life in a variety of ways and she needs very specific support in order to enable her to have a good quality of life.

K lives with a Shared Lives Carer (a council supported service). As part of her Social Care support, K was provided with a place to live and access to activities outside the house, including attendance at services provided by Umbrella.

As part of the Support for Life Planning Process the following information was provided by one of K's healthcare workers (A Speech and Language Therapist):

"K has faced a lot of change and loss in her life, including the death of her mother. Trying to cope with the experiences she has had would be difficult for many people but far more so for K as she does not have the skills and resources of people without learning disabilities.

K's autism means she struggles to make sense of the world and her severe communication difficulties means she cannot identify, let alone share or talk through her feelings and so they can become overwhelming at times. She can also become extremely anxious. Some of this can be alleviated with appropriate communication to ensure K knows what is going to happen. However, some of the anxiety arises because there are too many demands being placed on her in terms of constant varied stimuli. For most people this is not a problem as they

can filter out that which is not the main point of focus. This is not possible for K. Approximately 70% of people with autism will have a sensory perceptual impairment. This has been described as being characterised by turbulent, fluctuating, inconsistent and unreliable perception where individuals struggle to make connections with their environments. K's presentation and behaviour suggests that she has this impairment. Unconsciously the person with such difficulties will seek the sensory stimulation to raise their arousal levels when they are under-responsive to certain sensory modalities, and react negatively to those which cause over-arousal. This can be seen in K with her need for tactile stimuli and her distress when there is too much auditory stimuli.

A lot of K's distress and agitation is caused by internal stresses (e.g. emotions, over-arousal) or because she is in an environment that is too stimulating and demanding for her. In both these cases K can be best supported by being moved to an environment that regulates the sensory stimuli in the way K needs, to calm and organise her nervous system and brain processing. This environment can be created with the use of sensory equipment."

Having collated observations of K by her Shared Lives carer, the Learning Disability Assessment and Treatment Service, and the Specialist Speech and Language Therapist, as well as her reactions when trying out sensory equipment in a day service for people with autism, it was possible to determine K's sensory needs. Her ideal sensory environment would be one in which sounds would be soothing and consistent, such as nature sounds (water, birds etc.) or soft music. K responds positively to certain visual stimuli such as colour-changing fibre optic lights, bubble tubes and projections of images onto a wall / ceiling. She also needs tactile stimuli. "Dangly" objects provide K with the tactile feedback she seeks on an almost constant basis. However, when she is distressed she requires greater stimuli. This can be provided by such things as a weighted blanket and being immersed in water of a consistently warm temperature. There had been questions as to whether equipment such as a hot tub would be necessary at home. It had been seen that K is significantly calmed by being in hydrotherapy pools; however, these can only be planned visits. K would benefit a great deal from being able to access this type of sensory input when she needs it most, at times of distress and agitation.

Personal Health Budget Use and Impact

The Support Planning process took place over a period of several months, and included a meeting of K's professional network, and three, one to one meetings between K, her Shared Lives Carer and the PHB Commissioning Manager for Southern Derbyshire Clinical Commissioning Group.

As the Shared Lives Carers' understanding of person-centred care and Personal Health Budgets was developed, it was agreed that access to ambient water temperatures, via a hydra pool, had helped K to relax and avoid anxiety. Whilst K accessed a Hydra-pool once a week for half an hour, it was recognised she often experienced anxiety and break outs at unplanned times, usually within the home. A PHB was used to purchase an inflatable hot tub.

There are plans to use the remaining funds from the PHB to purchase a Sensory Lamp for the small sensory room the Shared Lives Carer has created within the small terrace house in which K lives with Family A.

K and her Shared Lives Carer have recently attended a Community Support Delivery Group Meeting, where her Carer has talked about the positive impact on K's health and wellbeing as a result in her accessing a PHB. This has included K no longer taking medication linked to her condition. K's review will take place with her key healthcare worker (in K's case her Speech and Language Therapist) where K's identified health outcomes will be reviewed against the Support Plan, which was put in place as part of the PHB application process.

Policy Context for Personal Health Budgets

Current policy emphasises the importance of increasing choice within health services and empowering people with long-term health conditions to shape and manage their own health and support.

The Government's mandate to NHS England 2017-18³ includes an overall goal to increase Personal Health Budgets to 50,000-100,000 by 2020. To support this commitment, Personal Health Budgets are now included in the new Clinical Commissioning Group (CCG) Improvement and Assessment Framework (IAF) for 2016-17⁴ and the Sustainability and Transformation Plan (STP) process. The Integrated Personal Commissioning Programme (IPC),⁵ a key part of the Five Year Forward View,⁶ is driving the expansion of Personal Health Budgets. The Transforming Care programme also has a strong focus on increasing choice and control for people with learning disabilities and their families, and the new service model⁷ includes a key action for health and social care commissioners to plan for and deliver the offer of personal budgets, Personal Health Budgets and integrated personal budgets beyond rights guaranteed by law.

3 Department of Health (2016). *The Government's mandate to NHSE 2016-17*: www.gov.uk/government/uploads/system/uploads/attachment_data/file/601188/NHS_Mandate_2017-18_A.pdf

4 NHSE (2016) *CCG Improvement and Assessment Framework 2016/17*: www.england.nhs.uk/commissioning/ccg-auth/

5 LGA and NHSE (2016). *Integrated Personal Commissioning. Emerging Framework*: www.england.nhs.uk/healthbudgets/wp-content/uploads/sites/26/2016/05/ipc-emerging-framework.pdf

6 NHS (2014) *Five year forward view*: www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

7 LGA, ADASS and NHSE (2015). *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*: www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

Despite this, there has been very limited progress on Personal Health Budgets being used with and for young people with complex support needs, so this project set about trying to understand why that is the case and what could be done to speed up delivery of the Personal Health Budget policy.

Work on introducing Personal Health Budgets also had strong links to the Transforming Care Programme, as the focus was on young people with the most complex needs. These are the young people who, experience has shown, are most at risk of going into residential care or even being admitted as inpatients in inappropriate 'assessment and treatment' units.

Summary report of the work undertaken by NDTi with TLAP and NHS England

In 2016, the National Development Team for Inclusion (NDTi) were commissioned by Think Local Act Personal with funding from NHS England to help three council areas and their local Clinical Commissioning Groups to take more effective action in introducing Personal Health Budgets for children and young people with complex needs.

This work took place in Plymouth, Hampshire and Derbyshire. All three areas were committed to the development of personalisation in varying ways. Plymouth and Hampshire are Integrated Personal Commissioning (IPC) sites, and Derby City has been working on personalisation in social care for some time. Each site engaged with the project as an opportunity to learn by doing, making a difference for a small number of young people and sharing with others what has been tried and learned to change practice both locally and nationally.

In outline, each site identified children/young people and families where the existing services and supports were struggling to meet their complex needs. NDTi then provided particular input around ensuring effective individualised support planning that was designed (in part) to help raise aspirations. Whilst local services then sought to put support in place in response to this, including through the use of Personal Health Budgets, NDTi engaged with service leaders and managers to identify and address the issues that were the organisational and strategic blocks to change being achieved.

Central to the work was a strong focus on person-centred support planning:

Support planning process

Life Plans look at what is positive and possible. A plan won't stand the test of time if it is not built around a person's strengths, skills, hopes and dreams. All too often traditional planning centres on the negatives; if there is planning at all.

The process also starts with the family story. Families have noted that they find this particularly helpful as it builds a joint understanding of their journey and thus their current situation. Life planning is a facilitated process drawing out the views of the people who love and care about the person as these are the people who know what is best for them. By the end of the Life planning process there will be a concrete plan for where the person wants to live, what they will do with their life, what and who will make a dream support team and what they want to achieve. Finally, everyone knows what the next steps are and who is going to do what.

Importantly, the planning is based on the concept of citizenship – having a meaningful life with a sense of purpose. For further information see Duffy (2006) Keys to Citizenship: www.centreforwelfareform.org/library/by-date/keys-to-citizenship2.html

“Remember the answers to a good life are in the detail. You just have to listen to those who know.”

– Sam Sly, NDTi associate

What happened in each area has been outlined earlier. NDTi concluded at the end of the project that the process of achieving Personal Health Budgets for children and young people was much more time consuming than originally envisaged. During this project, only a limited number of Personal Health Budgets were achieved, although much groundwork has been done that now needs to be built upon. There were a range of reasons identified for this, varying from (for example) difficulty in identifying families and young people, through challenges in gaining commitment from significant parts of the service system, to the implementation of this new way of working.

These differing challenges can, at their core, be traced back to four key cultural and organisational factors that need to be addressed if Personal Health Budgets for children and young people are to become a reality, namely:

- Effective senior leadership that creates a culture and belief system around Personal Health Budgets being a core part of the future service framework, alongside a willingness to implement the necessary whole system change.
- Families being seen and understood as key players and partners from the outset, with investment in enabling families to fully understand about Personal Health Budgets, including through that being led by families themselves.
- An understanding about and commitment to person-centred support planning from all key players – in particular from families and professionals.
- A partnership approach to Personal Health Budget implementation, in particular with the third sector and the education system.

For more information about implementing Personal Health Budgets for children and young people, please visit:

www.england.nhs.uk

www.NDTi.org.uk

www.thinklocalactpersonal.org.uk



Think Local Act Personal

Think Local Act Personal (TLAP) is a national strategic partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

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