

North West Disability Infrastructure Partnership

Personalisation Research Summary Report

Annexe A

Individual Focus Session Reports



Charity Number: 1082671



North West Disability Infrastructure Partnership
Personalisation Focus Session 1
Cheshire area

11 November 2011

Background

This focus group was the first in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NWDIP Focus Sessions Aim:

- I. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of personal budgets in Local Authority areas, and;
- II. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- III. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Cheshire Focus Group

The Cheshire DIP Personalisation Focus group took place in Macclesfield on 22 November 2011. 23 individuals were in attendance, the overall majority of who were representatives (both paid staff and volunteers) of organisations working with disabled people, some of whom also were receiving services from Adult Social Care in Cheshire. The session focused on personal budgets, and looked at some of the current policy context and opportunities to influence future implementation.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had experience across a range of impairments, including learning disabilities, physical disabilities, mental health support needs, acquired brain injury and neurological conditions as well as working with older people. The group also included a number of disabled people in paid employment with organisations, voluntary roles with other disabled people's organisations, or paid roles with provider organisations. A number of individuals were family carers.

Cheshire Context

The Cheshire session covered two Local Authority areas, Cheshire East, and Cheshire West and Chester. Local government changes had resulted in the single Authority Cheshire County Council splitting some 2 years ago, and so differing practices had begun to emerge across the two areas. In both areas, Fair Access to Care Services (FACS) eligibility criteria was set at critical and substantial need, and both areas have a relatively high proportion of people self-funding their own care.

Key headlines from this session

- 1. People did not feel that disabled people, their families and disabled people's organisations were receiving good opportunities for real choice and control yet.***

Participants at the session had a varying degree of knowledge of personalisation and personal budgets in particular. This ranged from “don't know anyone receiving a personal budget – don't know what personalisation is”, through to people who were managing their own packages or supporting family members who had personal budgets. There was patchy knowledge and experience of reablement services, and overall people felt that there was not a good level of knowledge and understanding of the personal budgets process for disabled people and families across both the Local Authority areas. Participants were aware of budgetary constraints, and a number of examples were given of personal budget allocations that were considered by individual disabled people and their supporters to be too low to be able to take control of the package. In addition, a significant number of individuals present were concerned at the lack of advice, information and support for people (predominantly older people) who were funding their own care and support.

- 2. People were concerned about the accountability of the Panel system***

In discussing the process for agreeing and signing off support plans, it was clear that people had mixed experiences of how this occurred and what was acceptable in a plan. Repeatedly raised was the question of Panel, and what and who panel was, and how it was seen as a block to creativity. Examples were given of plans being sent back with cheaper options, despite being in budget. It was concluded that Panel was a further layer in the process of budget management, but it was not clear how transparent this was in the process, nor whether or how individuals could challenge panel decisions.

- 3. People felt that there are still significant cultural challenges in the Local Authority workforce with regard to supporting disabled people and families to exercise real choice and control***

There was a general consensus amongst participants that further work is required to address cultural change in front line staff teams (with social work and occupational therapy staff). The majority of participants felt that assessments were not always thorough enough in capturing people's holistic needs, and that plans were

predominantly social work led rather than person centred. A number of organisations present had invested heavily in person centred planning and support planning training with staff, and were not seeing truly person centred plans coming in with disabled people. “It’s not personalised – told who, told how, and told what”. In the case of people with some neurological conditions, nursing home admission was seen as the only option, despite what families wanted.

4. Participants felt that there was little available assistance with support planning and support brokerage, and that there is not enough information for people to be able to make informed decisions.

Most participants that had either personal experience of the self-directed support process or had supported individuals through it felt that there was a dearth of good information to support people in making choices. Organisations were willing to assist and advise, but people were not always being directed to them, and organisations would also like more opportunities to get together and share their learning too. The Disability Information Bureau has been trying to get organisations together and will try to continue this. Family members described a feeling of being left to organise support for those they were supporting, and people generally believed the process was long and complex. Information on provider services was said to be presented to individuals as an alphabetical list, and some people said they struggled to work out what was on offer from each organisation. There was some scepticism over the Empower card in use in Cheshire East, and participants were pleased that the Council plan to make the card the default deployment option for a personal budget was under review.

5. Wider context

Participants of this session were aware of and concerned about the wider context of budgetary constraints at a national level, and were extremely concerned about proposed changes to Disability benefits and cuts to Council budgets. The closure of the Independent Living Fund for new claimants was cited as a concern for some people.

Summary

This well attended meeting brought participation from a wide range of people with experience across a range of sectors from Cheshire East and Cheshire West and Chester. Overall people were committed to personalisation and personal budgets, but there was concern about making this work in a way that would benefit disabled people in the current climate. People were concerned that the process developed by the 2 Councils appeared to be complex, and that real opportunity for choice and control was being lost because of the reluctance of some staff to adapt to new ways of thinking and move away from traditional models of assessment and care planning. Finally, a number of participants raised the challenge of health funding and were pleased to hear of the developing work on personal health budgets with both Cheshire East and Cheshire West PCTs. People see the divide of health and social care as an unnecessary complication, and would like to see aligned or pooled

budgets that enable people to have maximum choice and control over their health and social care needs.

Recommendations from Cheshire

- 1. People will need more independent information, advice and support to take up personal budgets that are not Council managed budgets.**
- 2. The Council and partners need to ensure that opportunities for choice and control are reaching all groups, especially people with mental health support needs.**
- 3. There needs to be a more co-ordinated approach to ensuring good information is available to disabled people and families, and also to older people making decisions about care that they may be self-funding.**
- 4. Provider organisations are keen to engage but need to know what they can do to respond to the changing market.**

Thanks

Sue Pattinson at Disability Information Bureau Macclesfield for organising the venue, promoting the event and supplying refreshments.

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session 2
Greater Manchester

16 November 2011

Background

This focus group was the second in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- IV. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of personal budgets in Local Authority areas, and;
- V. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- VI. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Greater Manchester Focus Group

The Greater Manchester DIP Personalisation Focus group took place at Breakthrough UK on 16 November 2011. 14 individuals were in attendance, the overall majority of whom were individuals with support needs who were receiving services from Adult Social Care in Manchester, with a further one individual from Trafford and another Oldham resident.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had a range of impairments, including learning disabilities, autism, physical disabilities, mental health support needs, acquired brain injury and neurological conditions. The group also included a number of disabled people in paid employment with organisations like Breakthrough and Greater Manchester Coalition of Disabled People.

Greater Manchester Context

Manchester City Council and Oldham Metropolitan Borough Council were Department of Health Individual Budget pilot site areas, and as such have been working on the personalisation of Adult Social Care provision since 2005. In both areas, personal budgets have been rolled out fully for new customers, and existing customers as their care has come up for review. All three Authorities are part of the Manchester Area Right to Control Trailblazer.

The Right to Control is a new legal right for disabled people. It gives disabled people more choice and control over the support they need to go about their daily lives. Disabled adults living in seven test areas will be able to combine the support they receive from six different funding sources and decide how best to spend the funding to meet their needs. Disabled people will be able to choose to:

- continue receiving the same support
- ask a public body to arrange new support
- receive a direct payment and buy their own support
- have a mix of these arrangements.

Key headlines from this session

- 6. People do not know about personalisation***
- 7. People did not think they had been given information about personal budgets***
- 8. People were not aware of the Right to Control***
- 9. People were not aware of the Centres for Independent Living***

Whilst all but one individual present had support needs, only 1 person was able to confidently outline an understanding of personalisation, and processes around self-directed support. The same individual was also familiar with Right to Control (RtC), and was active in the RtC Design Group, and was able to share this knowledge with others present on the day. For all other participants, with the exception of Breakthrough UK and GMCDP staff, this was the first time that they had heard of Right to Control. People had mixed experiences of getting information from staff.

5. People are very interested in getting into work - “work is really important”

Participants in this session unanimously expressed interest in getting into work or education and training in preparation for work. Only the 4 participants either employed by Breakthrough / GMCDP or part of Right to Control were conversant with DWP funding available or work schemes like Workchoice. People were not clear about what support was available from where, and several had been given conflicting advice regarding volunteering and benefits, or paid work and benefits.

Participants saw work as offering numerous benefits including:

- Freedom to make more choices in life

- Opportunity to meet people
- Making a contribution
- Self esteem
- Giving status
- Opening conversations
- It makes you independent
- You develop skills and learn new things

With the exception of 1 person in the group, all those not currently in paid work were active in volunteering roles, including working with charities like the Dogs Home, Mustard Tree, hospitals, Breakthrough UK and other settings. 2 individuals were concerned that they were unable to access training and education opportunities to enable them to proceed towards work or further volunteering opportunities. In both cases individuals had been told that no funding was available.

People understood that getting into work also created potential risks for them, particularly in relation to benefit entitlement, or housing related support. Everyone considered the benefits system very complicated and too hard to understand.

6. People are very worried about changes to disability benefits

Participants were very aware that the Government is planning changes to disability benefits, and some had already experienced changes. There are lots of rumours about what might happen, and some of these extended to changes to transport provision and bus passes.

7. People are concerned about “cuts” to services and some see personalisation as part of the planned cuts.

Everyone was aware that the Councils had to make cuts to their budgets, and there was a lot of concern about what this would mean for individuals and their families / carers. A number of individuals mentioned that care managers had indicated that carers and families would have to do more to help and support disabled people. Others had hear of examples of packages being reduced, or being told that it was no longer possible to get help with things like shopping, even if people had personal budgets and were making a choice to spend their budgets on assistance with shopping. Finally, the group mentioned their concerns at proposed cuts to the funding of disabled people’s organisations, and were worried about what this might mean for the provision of advocacy and support that is so important in the delivery of personalisation.

8. People were not clear about where decisions are made about support plans and care packages –especially what role Panels played.

Where people were aware of personal budgets and support plans, there was confusion about the process for approval of support plans. Examples were given of individuals known to those attending who had had their plans refused by Panel. The Panel process was not considered transparent, and no one new how decisions were made, and how individuals could present their plans to a Panel.

9. Care Managers

Half the group made comments on the support of Care Managers and Social Workers which included:

“She (the Care Manager) is never available when I want to see her, she just turns up and if I am not in she leaves me I note”

“I have to travel across the city to see my Care Manager”

“They have hundreds of other people to see”

“I haven’t had a review for years”

Others were not aware of who the Care Manager was.

Recommendations for Greater Manchester

1. People need to know more about Right to Control

The Right to Control is a significant opportunity for disabled people in Manchester, Bury, Oldham, Stockport and Trafford to take control of a range of funding streams and use these in a way that makes sense to them. The Right to Control Centre for Independent Living is able to support individuals through the Right to Control process, and is currently somewhat underutilised. The RtC Design group members are trained and able to undertake outreach and can raise the profile of Right to Control across all areas directly with disabled people.

2. People need more support to take up personal budgets

Local Authorities need to work with their partner DPO agencies to ensure that communication strategies and support services are accessible to individuals so that people are able to find out more about personalisation, and take opportunities for more choice and control in their lives.

Thanks

Steve Scott, GMCDP Design Group Coordinator.

Richard Currie, GMCDP Executive Board and Right to Control Design Group.

Breakthrough UK for hosting the session and hospitality.

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session
Warrington area

17 November 2011

Background

This focus group was the third in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- VII. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of p personal budgets in Local Authority areas, and;
- VIII. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- IX. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Warrington Focus Group

The Warrington DIP Personalisation Focus group took place in Warrington on 17 November 2011. 13 individuals were in attendance, the overall majority of who were representatives (both paid staff and volunteers) of organisations working with disabled people, some of whom also were receiving services from Adult Social Care in Warrington, or were family carers. The session focused on personal budgets, and looked at some of the current policy context and opportunities to influence future implementation.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had experience across a range of impairments, including learning disabilities, physical disabilities, mental health support needs, acquired brain injury and neurological conditions. The group also included a number of disabled people in paid employment with Warrington Disability Partnership, or voluntary roles with other disabled people's groups and organisations. A number of individuals were family carers.

Warrington Context

The Warrington session covered a single Local Authority area – Warrington Borough Council. Warrington had undertaken some pilot individual budget work with people with Learning Disabilities ahead of the publication of Putting People First in 2007, but most of its work on personalisation took place after 2007. Fair Access to Care Services (FACS) eligibility criteria is set at critical and substantial need, and the area has a proportion of people self-funding their own care.

Key headlines from this session

10. People were concerned about proposed changes disability benefits and the wider context of cuts in funding to Local Authorities

Participants at this session were concerned about proposed changes to disability benefits, which they saw as linked to the challenges faced by disabled people. People discussed proposed changes to Disability Living Allowance, and the move from Incapacity Benefit to Employment Support Allowance. There was a general sense that the changes would not bring positive benefit to disabled people and families. In addition, those that had experience of other associated funding streams such as Access to Work (DWP), Community Equipment Services and Disabled Facilities Grant talked about the difficulties in securing resources and getting the type of equipment, services and support that worked for people in the context of their own lives.

11. People were not clear about the adult social care pathway, and how individuals could access personal budgets

It was generally agreed that the route for new customers into Adult Social Care was via an Access Point, where Fair Access to Care Services (FACS) eligibility was assessed. Once eligibility was agreed, people are referred to a team for an assessment of adult social care need. At this point people were not clear of how a personal budget was allocated, and what support might be available to individuals. In addition, participants were of the view that allocations for individuals were given in hourly amounts, and this made it difficult to think about anything else other than hours of support. This was seen as discouraging creativity.

12. People felt that there are still significant cultural challenges in the Local Authority workforce with regard to supporting disabled people and families to exercise real choice and control

There was a general consensus amongst participants that further work is required to address cultural change in front line staff teams (with social work and occupational therapy staff) . Participants felt that staff needed much more training around things like Direct Payments as they had heard many examples of people being actively discouraged from opting for Direct Payments, and sometimes giving incorrect information about Direct Payments. It was also felt that the issue was broader than knowledge, and in some cases related more to power and control. That said, people

were also aware of some strong, creative packages, and of staff who were embracing the opportunity of personal budgets and supporting people to make the most of their plans.

13. Participants felt that there was little available assistance with support planning and support brokerage, and that there is not enough information for people to be able to make informed decisions.

Participants were not clear of what arrangements were in place for independent support planning and brokerage. Warrington Disability Partnership were seen as offering support to people with Direct Payments, but no one was aware of other support brokerage type services. People stated that the Council offers a list of providers, but most people would look to their Care Manager for advice and support – although this was not always seen as the best idea as Care Managers might not know the range of services available. “Do Care Managers really offer people a gateway to choice?” Finally, some present were aware that the Council was working on a new website designed to help, called My Life My Way.

14. Virtual budgets were thought to be the Councils’ preferred method of personal budgets for all adults, and there was thought to be no incentive for the Council to offer Direct Payments to people

Participants in the group were of the understanding that the Council block contracts agency supports at £10.10 per hour, but the Direct Payment rate is £10.60 and so is more expensive. All participants thought that this created a disincentive to the Council to offer Direct Payments. However, many people noted that when an individual purchases an hour of care, they will receive an hour of care, whereas people receiving support on the block contract were thought to get less as staff may leave early to get to the next client, and so they felt that the Council got less value for its money than an individual would.

15. What is Panel?

A number of participants raised questions about the Panel process – although this was the first time some present had heard of Panel. People were interested to know about who Panel are, and who they account to for their decisions. People suggested that some independent input into panel would be useful, and it was thought that perhaps Healthwatch could provide some oversight of Panel decision making. People were generally concerned about Panel as it was seen to be less than transparent.

Summary

Overall, participants were keen to see the extension of choice and control across Warrington and felt that Warrington Disability Partnership had a crucial role to play in making sure that people had access to peer advice and support, as well as support in moving the Council from virtual budgets to Direct Payments as per the ambition in Think Local, Act Personal. However, the participants felt there was much work to do

yet, especially in relation to culture and workforce issues, before real choice and control were available to all adults with ongoing social care needs.

Recommendations from Warrington

- 5. People will need more independent information, advice and support to take up personal budgets that are not Council managed budgets. This particularly relates to making decisions about where to purchase support from.**
- 6. There needs to be a more co-ordinated approach to ensuring good information is available to disabled people and families, and also to older people.**
- 7. Social care staff need to be better trained in explaining personal budgets and Direct Payments options in particular to people to ensure that individuals and families are best equipped to make decisions about their care and support.**
- 8. Council staff need to be more familiar with the range of support on offer at Warrington Disability Partnership.**

Thanks

Brun Corbishley at Warrington Disability Partnership for organising the venue, promoting the event and supplying refreshments.
Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session 4
South Cumbria area

21 November 2011

Background

This focus group was the fourth in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- X. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of personal budgets in Local Authority areas, and;
- XI. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- XII. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

South Cumbria Focus Group

The South Cumbria DIP Personalisation Focus group took place in Kendal on 21 November 2011. 14 individuals were in attendance, the overall majority of which were representatives of organisations working with disabled people, some of whom also were receiving services from Adult Social Care in Cumbria. The session focused on personal budgets, and looked at some of the current policy context and opportunities to influence future implementation.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had experience across a range of impairments, including learning disabilities, physical disabilities, mental health support needs, acquired brain injury, neurological conditions and older people's supports. The group also included a number of disabled people in paid employment with organisations like DACE.

Cumbria Context

Cumbria was a member of the In Control programme and began piloting work on individual budgets before Putting People First was published. Fair Access to Care Services (FACS) eligibility criteria is set at critical and substantial.

Key headlines from this session

16. People do not know enough about personalisation in South Cumbria – this includes disabled people and families, and middle managers / front line staff and some provider agencies

17. People did not feel that individuals and their support organisations had been given enough information about personal budgets

People had mixed experiences of getting information about how personal budgets processes work across Cumbria. Individuals and organisations all said that they struggled to understand and negotiate the system. Information on the internet was described as “crap”, and there was felt to be a dearth of impartial advice. All felt that the Council needed to do more to share its process and assist people and their organisations in navigating their way.

18. People felt that there are still significant cultural challenges in social work teams with regard to the supporting disabled people and families to exercise real choice and control

Whilst there was broad recognition that Senior Managers at the Council were committed to the principles of choice and control, participants described a front line and middle management social work culture that was less supportive of personalisation. Several people described a sense of feeling that they were “begging” for support, and of condescending attitudes from some front line staff. Whilst some people had navigated the system effectively, this was not without challenge, and they had used knowledge that they had developed themselves. Quotes included:

“Not letting people experiment with delivery methods”

“Plans still structured towards what is known to work in the social worker’s eyes”

“Stop telling people how to use their money – choice and control!!”

“Social work culture of we know best, and doing it FOR people”

Where people had gained choice and control, they described the following feelings:

“Nice to have choice”

“A lot of trial and error to get it right”

“Life is good when the care is going according to plan!!”

19. Not everyone in Cumbria is getting to have choice and control

Overall, participants felt that the people who were having the most effective access to choice and control were people with physical disabilities and people with learning

disabilities. Older people and people with mental health support needs were not felt to be getting opportunities for real choice and control across South Cumbria. Most of the individuals and organisations present on the day had little experience of how things were really working for older people, and it was clear that organisations for disabled people are not currently working with older people. This may be because older people do not necessarily consider themselves to have disabilities, and would not tend to access support from organisations of and for disabled people.

20. The Council pays a higher hourly rate to agencies for people with Council managed budgets, than it does to people who take a Direct Payment

Participants were unclear how and why the Council would pay a higher hourly rate to an agency in Council managed budgets than it would offer as a Direct Payment hourly rate to an individual. Some people thought that agency rates for Council managed budgets were in the region of £16 per hour, whilst DP hourly rates seemed to range between £10.50 to £12.50 per hour. This does not create an incentive to individuals to take up Direct Payments, and may make it difficult for the Council to achieve the Think Local, Act Personal ambition of a move towards the majority of adult social care users taking their personal budgets as Direct Payments.

21. Reviews

Participants reported that where reviews took place, they were an opportunity to look at how things were going for an individual. However, one group reported that they did not think that reviews were always taking place, and another group felt that reviews were not yet adequately addressing the need for flexibility and contingency planning. A number of individuals felt that contingency planning overall was poor, and that when things go wrong support might not always be rapidly available.

Recommendations for South Cumbria

- 1. Cumbria County Council and local disabled people's organisations may wish to consider how they jointly best reach disabled people and families to share information about personal budgets**
- 2. People need more support to take up personal budgets that are not Council managed budgets**
- 3. The Council and partners need to ensure that opportunities for choice and control are reaching older people and people with mental health support needs.**

Thanks

Ollie Flitcroft, DACE, for organising the session and arranging the venue and hospitality.

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session 5
North Cumbria area

22 November 2011

Background

This focus group was the fifth in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- XIII. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of personal budgets in Local Authority areas, and;
- XIV. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- XV. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

North Cumbria Focus Group

The North Cumbria DIP Personalisation Focus group took place in Carlisle on 22 November 2011. 14 individuals were in attendance, the overall majority of who were representatives (both paid staff and volunteers) of organisations working with disabled people, some of whom also were receiving services from Adult Social Care in Cumbria. The session focused on personal budgets, and looked at some of the current policy context and opportunities to influence future implementation.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had experience across range of impairments, including learning disabilities, physical disabilities, mental health support needs, acquired brain injury and neurological conditions. The group also included a number of disabled people in paid employment with organisations like DACE, voluntary roles with other disabled

people's organisations, or paid roles with provider organisations. A number of individuals were family carers.

Key headlines from this session

22. People did not feel that disabled people, their families and disabled people's organisations were receiving good opportunities for real choice and control yet.

Although roughly half the participants of this session were workers offering advice and support to disabled people, many were unclear about the Cumbria County Council process for personal budgets, and in particular, practices relating to what individual people could or could not use a Direct Payment for. Whilst many understood the policy and guidance, all were of the view that real choice and control was being limited by restrictions on spend, rather than a focus on outcomes. People had a range of experiences of wider funding streams beyond adult social care – and there was some debate about apparently differing practices relating to Disabled Facilities Grant in some districts.

23. People were concerned at DACE's loss of the contract to provide support to people on Direct Payments in Cumbria.

Given the number of representatives of DACE at this session, it was not surprising that people were concerned at the recent loss of contract by DACE to provide a Direct Payments Support Service to DP recipients in Cumbria. This concern was also shared by other organisation representatives and individuals in attendance. It was stated that the contracting and procurement process had been weighted 70% cost, 30% quality, and participants were concerned that user led organisations and organisations of and for disabled people were unlikely to fare well in such contracting scenarios as they tend to be smaller, more locally connected and knowledgeable services than some of the larger providers that operate regionally or nationally. People also expressed concern at the forthcoming contracting of advocacy support, as this was seen as having a crucial role to play in making sure that disabled people's voices were heard, and that individuals were properly supported in taking up opportunities for choice and control.

24. People felt that there are still significant cultural challenges in social work teams with regard to the supporting disabled people and families to exercise real choice and control

Whilst people were wholly supportive of the shift towards personalisation and personal budgets, there was a strong sense that the cultural and organisation changes were not fully embedded. Participants were not surprised that there was a tendency towards Council managed budgets by social workers, who were thought to generally not have the time, knowledge or expertise to think beyond traditional package models. That said, participants were able to offer examples of social work team staff who had embraced the changes and were working creatively and innovatively with disabled people and families, but they were concerned to be in the

minority over all. All present believed that there was no contracted independent support planning or support brokerage across the County, although a number of organisations were willing to offer this and did with the people they had contact with. The general consensus was that the process of personal budgets in Cumbria was not yet fully person centred. Quotes from participants included:

“(Social workers) see their role as managing budgets”
“They have preconceived idea of a package”
“Still not able to effectively explain Direct Payments”.

Participants also commented on what they understood was emerging practice around things that were “allowed” in support plans, or not. Examples of what was understood to not be allowed were cleaning, gardening, going out, gym memberships and holidays.

25. Wider context

Participants of this session were acutely aware of the wider context of budgetary constraints at a national level, and were extremely concerned about proposed changes to Disability benefits and cuts to Council budgets. This was creating something of a climate of fear.

Summary

When asked what personalisation in Cumbria felt like so far, participants provided the following statements:

“1939 Germany”
“ Gap between theory and practice”
“ Looks good on paper, but is it doesn’t happen”
“Patronisingly shambolic”
“Reinforcing inequalities”
“We know best culture still”

Despite this, people firmly believed that personalisation is “one of the best things”, and want to help the Council to really make this work for disabled people across Cumbria. People were aware of some great examples and felt that these needs sharing. With more joint working, dialogue, better information and greater consistency things could really work.

Recommendations from North Cumbria

- 9. People will need more independent support to take up personal budgets that are not Council managed budgets.**

- 10. The Council and partners need to ensure that opportunities for choice and control are reaching all groups, especially people with mental health support needs.**
- 11. Third sector and user led organisations may struggle to compete in financially driven contract and procurement processes, and will need support and investment to continue the development of peer led support services that can add benefit to the extension of choice and control for users of adult social care services across Cumbria. Disabled people, disabled people’s organisations and organisations for disabled people would like to be consulted on what “quality” looks like in tendering and procurement processes. “Third sector organisations are close to people with lived experience, adapt quickly, and show more compassion” (participant).**
- 12. Cumbria County Council will need to continue to work with social work and other teams to ensure that the necessary cultural change is in place to enable disabled people and families use personal budgets in a flexible and creative way to meet their outcomes.**

Thanks

Ollie Flitcroft, DACE, for organising the session and arranging the venue and hospitality.

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session
Merseyside area

24 November 2011

Background

This focus group was the sixth in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- XVI. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of p personal budgets in Local Authority areas, and;
- XVII. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- XVIII. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Merseyside Focus Group

The Merseyside DIP Personalisation Focus group took place in Liverpool on 24 November 2011. 15 individuals were in attendance, the overall majority of who were representatives (both paid staff and volunteers) of organisations working with disabled people, some of whom also were receiving services from Adult Social Care in Liverpool, Sefton, Knowsley, Halton, Wirral and St Helens. The session focused on personal budgets, and looked at some of the current policy context and opportunities to influence future implementation.

Participants

In order to illustrate the range of organisations represented at the focus session, those in attendance had experience across a range of impairments, including learning disabilities, physical disabilities, mental health support needs, acquired brain injury and neurological conditions. The group also included a number of disabled people in paid employment or voluntary roles with other disabled people's groups and organisations. One individual self-funded his support.

Merseyside Context

The Merseyside session covered a number of Local Authority areas – Liverpool, Sefton, Knowsley, St Helens, Halton and Wirral. All Authorities were implementing personal budgets with some having undertaken development work prior to the publication of Putting People First in 2007. All were on record as having achieved a minimum of 30% of adults with ongoing community support needs being offered personal budgets by April 2011.

Key headlines from this session

26. People were concerned about proposed changes to disability benefits and the wider context of cuts in funding to Local Authorities, and were also concerned about current public perceptions of disability.

Participants at this session were concerned about proposed changes to disability benefits, which they saw as linked to the challenges faced by disabled people. People discussed proposed changes to Disability Living Allowance, and the move from Incapacity Benefit to Employment Support Allowance. There was a general sense that the changes would not bring positive benefit to disabled people and families. In addition, those that had experience of other associated funding streams such as Access to Work (DWP), Community Equipment Services and Disabled Facilities Grant talked about the difficulties in securing resources and getting the type of equipment, services and support that worked for people in the context of their own lives. Furthermore, participants gave examples of the type of prejudice and discrimination they experienced as disabled people in society, and there was a strong sense that such experiences were increasingly common as social attitudes appeared to be hardening.

27. People were not clear about the adult social care pathways in localities, and how individuals could access real choice and control through personal budgets

Whilst people understood the fundamental steps of self directed support processes, many participants struggled to relate these to the actual processes in operation across Local Authority areas. Representatives from Sefton were still being told that personal budgets work was still in pilot form across the Borough, and in Liverpool representatives said that people were not given indicative allocations in cash figures, but in hours of care. Wirral representatives believed this to be the case in Wirral too.

28. People felt that there are still significant cultural challenges in the Local Authority workforce with regard to supporting disabled people and families to exercise real choice and control

Across all the LA areas, examples were offered of people being limited on what they could spend personal budgets on. Participants described a sense of some staff having a “mental list” of what people can and can’t do – holidays were one example given across a number of areas where people had been offered traditional respite

provision, but when they had wanted to use the resource differently to manage their respite, they had not been allowed. Disabled people's organisations across all areas were still experiencing low levels of referral for support planning and brokerage where this was available, and in some areas there was said to be no external assistance with support planning at all. Culturally people were widely familiar with the professional gift model and there was a strong sense in the room that this was still firmly embedded in the culture of social care services. It was recognised that in some areas there was poor morale in social work teams, and staff were still not clear themselves about processes and possibilities. In addition, finance staff and those undertaking audit processes for Local Authorities were considered to be having a limiting effect on people's choice and control. Auditing processes, with the exception of Knowsley, were roundly described as "scary" for people. Finance staff were seen to be questioning how people were choosing to spend their resources, and examples were given of myths of the things you "can't have" – Sky TV, season tickets, communication aids etc.

29. Participants felt that there was little available assistance with support planning and support brokerage, and that there is not enough information for people to be able to make informed decisions.

Participants felt that the shift towards personal budgets, and the current policy aim of Direct Payments as the preferred method of deployment would be unattainable without better support for disabled people and families in support planning and brokerage. Most areas continued to invest their support planning systems in social work teams, and this was seen as offering little different to disabled people.

30. Why is there still Panel?

A number of participants raised questions about the Panel process – although this was the first time some present had heard of Panel. People were interested to know about who Panel are, and who they account to for their decisions. People suggested that some independent input into panel would be useful, and it was thought that perhaps Healthwatch could provide some oversight of Panel decision making. People were generally concerned about Panel as it was seen to be less than transparent.

31. Market Development

Across all areas it was felt that there was still much work to do in developing the market so that disabled people have choices about where to buy support. Despite this, there are clearly some services that are engaging with the agenda and have worked with people to develop some creative and innovative packages. This is not just about bringing in new providers, but about a need to work with existing ones to enable them to work differently and provide the type of services local people would want to buy.

Summary

The Merseyside DIP session covered the widest range of LA areas of all the events, and despite local differences in approach and systems, there were core themes that resonated across the LA areas. These themes were consistent with those emerging from other NW LA areas, and focused on the ongoing cultural challenge of delivering the policy ambition in a way that is authentic for disabled people. It is clear that much work has gone on in all LA areas, but for many individual disabled people and the organisations that support them, the SDS pathways still appear confused and complex, and there is insufficient independent support to navigate the system.

Recommendations from Merseyside

- 13. People will need more independent information, advice and support to take up personal budgets that are not Council managed budgets. This particularly relates to support planning and brokerage.**
- 14. Social care staff need to be better trained in explaining personal budgets and Direct Payments options in particular to people to ensure that individuals and families are best equipped to make decisions about their care and support, and referring to DPOs and ULOs for independent advice and support for people.**
- 15. There is more work to do with provider organisations to ensure that they are best equipped to offer the types of support that individuals will want to buy.**

Thanks

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.

North West Disability Infrastructure Partnership
Personalisation Focus Session
Lancashire area

6 December 2011

Background

This focus group was the seventh in a series (n7) of sessions organised by the NW Disability Infrastructure Partnership (NWDIP). Merseyside Disability Federation is developing support for organisations of and for disabled people throughout the region as the lead and accountable body for the NWDIP, which will enable members to learn from one another's resources and to join forces to create knowledge and skills to address any identified gaps.

NW DIP Focus Sessions Aim:

- XIX. To develop a narrative of the experience of DPO's, ULO's and disabled people from across the North West region in relation to the implementation of p personal budgets in Local Authority areas, and;
- XX. To identify opportunities for individuals and organisations to influence local and national implementation and activity.
- XXI. Produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Lancashire Focus Group

The Lancashire DIP Personalisation Focus group took place in Blackburn on 6 December 2011. Despite extensive invitations, only 1 individual from a user led organisation attended. The discussion focused on personal budgets and the implementation of personalisation across Lancashire from the perspective of one organisation. This report has been generalised so as not to identify the individual or agency that attended.

Lancashire Context

The Lancashire session was intended to cover 2 Local Authority areas – Lancashire County Council and Blackburn with Darwen. Both Councils had undertaken some pilot individual budget work with people with Learning Disabilities ahead of the publication of Putting People First in 2007, and both areas were active members of the In Control programme prior to national roll out. Fair Access to Care Services (FACS) eligibility criteria is set at critical and substantial need in both areas, although this was a relatively recent move from moderate at Lancashire.

Key headlines from this session

32. A community pathway model was rolled out in Lancashire from April 2011

Lancashire County Council has funded the development of a community pathway model for ULO and DPO organisations to be enabled to offer support planning to disabled people and families across Lancashire. Lancashire Centre for Independent Living acts as the hub for the model, and signposts out to around 20 organisations across Lancashire. Organisations that deliver support planning are paid £12 per hour, and planning time falls in to 3 bands of 5 hours, 10 and 15 hours for individuals. Referrals from SW teams were slow to start with, but are beginning to pick up now. Organisations participated in the pathway are expected to deliver the Support Plan within 2 weeks, and this can be quite challenging.

33. A Resource Allocation Questionnaire has been developed

Lancashire County Council is still working on its resource allocation system, and recent changes with the increase in Fair Access to Care Services eligibility has meant the introduction of a new questionnaire. People with moderate needs are signposted to Help Direct, which aims to identify community based supports that are universally accessible. There was some anecdotal evidence from the experience of people with support needs that some of the earlier creativity and innovation in packages was being lost. For a while earlier in 2011 people were told that shopping and cleaning were not services that a personal budget could be spent on, but this has been clarified and people are able to do this if it meets their outcomes and is within their allocations.

34. Budget and cultural challenges at Lancashire County Council are limiting decisions about what people can spend their personal budgets on

The representative in attendance gave a number of examples of staff comments and decisions about what disabled people were allowed to spend their personal budgets on. Whilst there was some strong creative practice, one SW had commented “why would she want to wash her hair more than once a week” when reviewing an individual’s Support Plan.

Summary

In going over the main themes from other sub regional sessions, it was recognised that the shared themes for Lancashire include:

The challenge for some Social Work staff to effectively explain personal budgets to disabled people and families, and to ensure that people have access to good information, advice and advocacy in order to maximise the potential of their budget;

Panels are, in some cases, focusing on the items and services people are buying, and are therefore restricting choices, instead of focusing on whether or not people are achieving outcomes;

The community pathway model in Lancashire offers a real alternative for organisations to get involved in assisting individuals with Support Planning, but there is work to do to ensure that Social Work teams refer people to the hub.

Thanks

Lindsey Sadler and Kate Kindlen at Merseyside Disability Federation for administration.