North West Disability Infrastructure Partnership

Personalisation Research

Summary Report

March 2012

North West Disability Infrastructure Partnership Personalisation Focus Sessions Summary Report

1. Background to the Project

This report is the summary document of a series of focus groups / listening events held in November and December 2011 across the North West region. The focus groups formed a series of seven listening sessions organised by the North West Disability Infrastructure Partnership, whereby local disabled people and family members, Disabled People's Organisations and organisations for Disabled People were asked to share their experiences of personalisation. The sessions took place in:

1. Macclesfield
2. Warrington
3. Manchester
4. Liverpool
5. Kendal
6. Carlisle
7. Blackburn

A short summary report capturing the key themes from each of the sessions was produced and is attached at Annexe A. In addition, an online survey was developed to capture additional information from people across the region. The data analysis of that survey is attached at Annexe B.

2. Policy Context

Personalisation is changing the way disabled people who are eligible for on-going community support from Adult Social Care Departments of Local Authorities receive that support. Government policy in Adult Social Care since 2007 (***Putting People First***, *HM Government 2007*) has seen a shift towards more personalised approaches, with disabled people being supported to exercise greater choice and control over the type of support and services they receive, and how the money allocated to their support is spent.

Broader work underway has been transforming Adult Social Care services with the introduction of reablement services[1] by the majority of Local Authorities, which have focused on short intensive support programmes for people with a range of support needs to enable them to live as independently as possible. Adult Social Care departments have continued this transformation work in many areas with new or improved information and advice provision, improvements to universal services and a developing focus on community based resources. Transformation Projects in Local Authorities

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[1] Reablement services are typically home based intensive support services delivered by Councils to support people following a hospital admission or a crisis. The aim is to maximise independence. The average reablement service is approximately six weeks duration.

were funded and supported by the Transforming Adult Social Care grant that accompanied *Putting People First*, with Local Authorities across England receiving £520 million over three years from 2007 to 2010.

Following the election in 2010, the Coalition Government published **A Vision for Adult Social Care: Capable Communities and Active Citizens** (Department of Health, November 2010) restating the shift towards personalised supports and services. The Vision was also followed by the publication of **Think Local, Act Personal** (TLAP)[2], a sector wide commitment to move forward with personalisation. The TLAP concordat agreement is endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. The national TLAP work programme is jointly delivered by members of the sector consortium, and coproduced with disabled people and family members acting as a national advisory group.

3. The North West Disability Infrastructure Partnership

The current project was commissioned by the North West Disability Infrastructure Partnership (NWDIP), which is funded by BIG Lottery and hosted by Merseyside Disability Federation (MDF). MDF is developing support for disability organisations 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.

4. NWDIP Personalisation Focus Sessions Aims:

   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. To produce a short report of findings that can go forward as evidence to the White Paper engagement exercise.

Additionally a survey monkey was used to capture further views from individuals across the region. The data from the survey was used to further illustrate this report.

5. Focus group process

In order to facilitate the sharing of experiences, the majority of the listening sessions were constructed with an introductory slot that gave a quick

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[2] More information on the Think Local Act Personal programme can be found at
www.thinklocalactpersonal.org.uk

overview of the core elements of personalisation in adult social care, so as to ensure all participants were familiar with the language and principles that are common to current policy and guidance. Participants were then invited to work in small groups recording their knowledge and experiences of the core elements of the seven step self-directed support process[3] they had been delivered by the Local Authority. Following the small group exercise, recorded comments were collated and themed with the groups to capture shared experiences and themes. These themes were then recorded in the detail of each local report, representing a snapshot of the experiences of local people and their organisations. Sessions were completed with a discussion about the possibilities for local activity, including using markers of progress like **Making it Real**[4] (Think Local Act Personal, 2011) with Think Local Act Personal, which at the time of writing is in development in preparation for national roll out in April 2012.

6. NWDIP Infrastructure Personalisation Project Consultant

The NWDIP commissioned Carey Bamber as an independent freelance consultant to the project. Carey is an experienced facilitator who was formerly the Personalisation Programme Manager for the NW Joint Improvement Partnership, and is now an associate of In Control, working with Local Authorities and health partners across the NW region. Carey worked alongside the project team to develop session plans, facilitate the sessions, provide technical advice, and produce each report. The project reports remain the property of the NWDIP.

7. North West Context

The North West (NW) region area covered by the NWDIP incorporates 23 Local Authority areas in 6 county areas – Greater Manchester, Greater Merseyside, Cumbria, Cheshire, Warrington and Lancashire. Changes to local government accountability introduced by the Coalition Government have moved away from regionally based structures, and at present, new performance and accountability structures are still emerging. In relation to Adult Social Care and the delivery of personalisation policy, much of the progress reported by Local Authorities on implementation has been self-assessed and reported through historic indicators such as NI 130[5], and a set of self-assessment indicators (milestones) developed and reported by the Association of Directors of Adult Social Services.

Up to March 2011, all Local Authorities were aiming to achieve a minimum of 30% of people with ongoing community care needs receiving their support

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[3] See www.in-control.org.uk and
http://www.incontrol.org.uk/media/18707/graphic%20on%20sds%207%20steps%20(core).pdf
[4] See http://www.thinklocalactpersonal.org.uk/Browse/joinMIR/
[5] Information on NI 130 (social care clients receiving self-directed support) can be found at
http://data.gov.uk/dataset/ni_130_-
_social_care_clients_and_receiving_self_directed_support_direct_payments_and_individual_budg

through personal budgets. In the NW region, at the end of the recording period in March 2011, virtually all NW Authorities reported having achieved this target. Self-assessment of milestones progress by Councils was collated and reported through the Association of Directors of Adult Social Services (ADASS)[6], but not widely published. NW Councils reports were shared with participating Councils.

Finally, as the *Putting People First* policy era drew to a close, ADASS undertook a further study of progress with personalisation across 132/ 152 English Councils, which detailed varied progress across Local Authorities[7]. The final survey demonstrates that solid progress was reported overall by NW Local Authorities in most areas of the milestone themes, including effective partnerships with people who use services and their carers, and self directed support and personal budgets.

8. Key Findings of Personalisation Focus Groups

Across all seven focus groups, common themes emerged. Each individual report gives a summary of the key local themes, which as would be expected, may vary from area to area. However, the themes below emerged systematically in all discussions:

8.1. Context of Council budgetary challenges

The mainstream adoption of personalised approaches and personal budgets is taking place in the context of real challenges to Adult Social Care budgets. The kind of examples of creative and inspiring support plans produced during the pilot years of individual and personal budgets were felt in many areas to be pipe dreams.

Over the *Putting People First* period, a number of Local Authorities across England (including in the NW region) made changes to their Fair Access to Care Services (FACS) eligibility criteria, increasing the threshold for eligibility. As eligibility has tightened, some individuals have seen reductions in their support. Others had been led to believe that certain tasks were not FACS eligible – with cleaning, gardening and shopping being most frequently cited as examples.

Budgetary constraint was also considered to have had an effect on what might be considered a reasonable use of resources. Individuals at every event were of the view that creativity had been stifled as Panels (which were said by participants to be operational in every one of the Local Authority areas in the NW region) were thought to regularly turn down plans that were thought to

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[6] More information on the ADASS milestones can be found at:
 http://www.adass.org.uk/images/stories/Milestones%20for%20PPF%20-%20Final%209.9.09.pdf
[7] More information on the final survey can be found here:
http://www.thinklocalactpersonal.org.uk/Browse/Nationaldeliverysupportplan/Measuringprogress/?parent=8629&child=7671

involve creative use of resources. The most frequently cited example in this respect related to holidays. Where individuals talked about respite, this was deemed to be more acceptable than where others used the term holiday to imply a break.

Participants at events in Cumbria and Merseyside had experienced being told that holidays were simply not allowed as part of personal budget support planning. Others with existing or long standing (and sometimes hard won) packages were concerned about what would happen at review. Representatives of organisations across the region gave examples of individuals whose packages had been reduced at review, despite maintaining that there had been little change to the level of need.

Whatever the experience, people were extremely concerned about the implications of public sector budget cuts, and it was seen as highly unfortunate that policy that should be about people having greater choice and control has been introduced at a time of such significant public sector constraint – and in some people's minds the driving force for introduction was cost saving, not choice and control. As one respondent to the online survey carried out as part of this project said:

"*The Council is now cutting back all its budgets so I can't see Personalisation working for me much longer. Without the correct support, I would be unable to live a meaningful life.*"[8]

8. 2. Personal Budget processes

There was widespread confusion about the process of allocating personal budgets to individuals with support needs which was evidenced in all of the focus group events. Local practice in some areas was to offer individuals an allocation of hours, and this made it difficult for individuals to think about how they could creatively deploy their allocation.

Individuals attending the focus groups were concerned at the lack of advocacy to support people through the personal budget process, which was seen to have become as bureaucratic in many areas as the Care Management processes it was thought to have replaced. The most frequently expressed observation across all sessions, however, was the length of time the process was taking from assessment through to Panel sign off, with many experiencing months of delay in waiting, and others going significant lengths of time without review.

No examples of robust, accessible personal budget processes were offered as experienced at any focus group session. This was also echoed in responses to the online survey, as illustrated in *Figure 1.1*.

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[8] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.15.

Do you think people are getting clear messages about personal budgets?
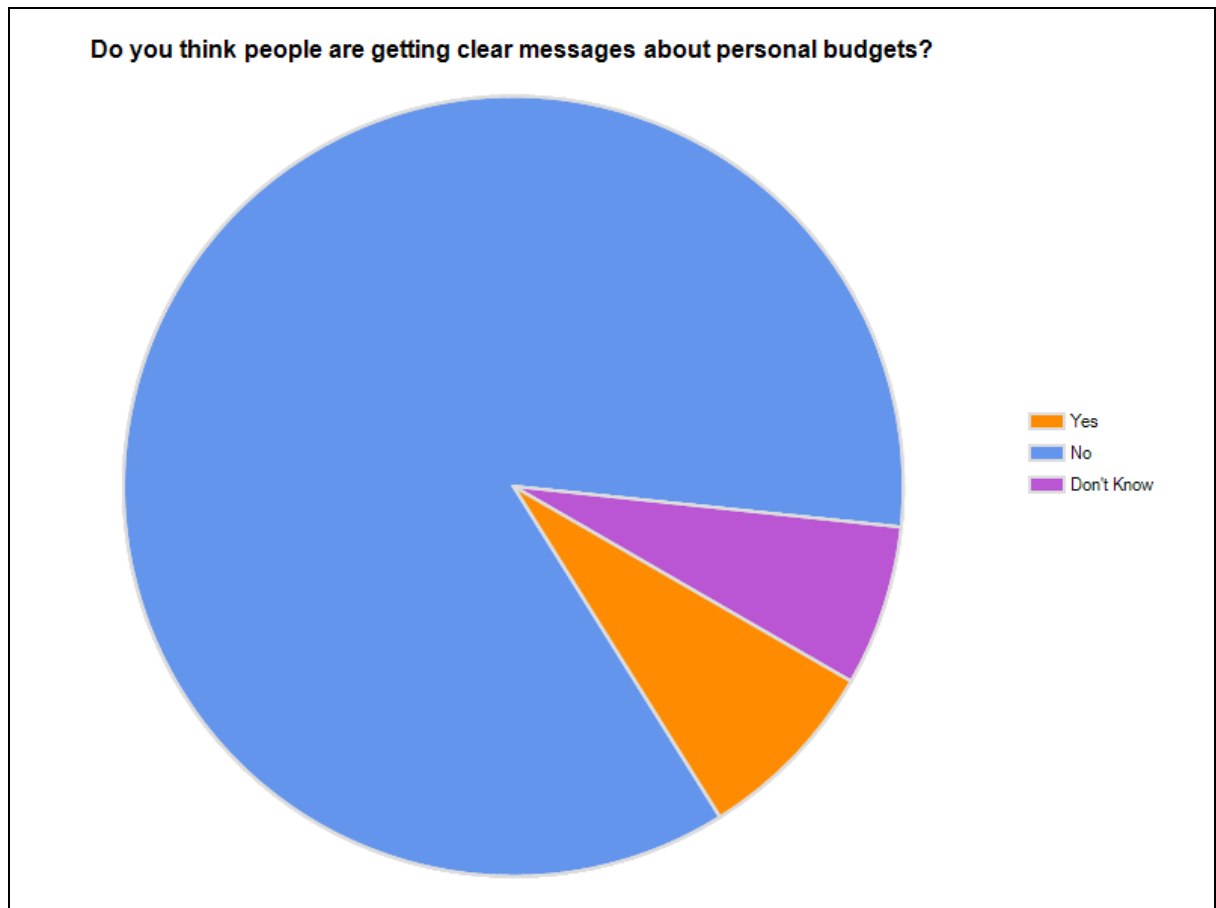
Legend: Yes, No, Don't Know

Figure 1.1.

8.3. Panel processes

The majority of focus groups had some debate about adult social care Panel processes in operation in Local Authorities across the region. Panel was described as a "mythical" element of the adult social care process. Panel was believed to be made up of Team leaders, team managers and finance people who would review support plans submitted by individuals and decide whether or not an individual plan would be signed off (agreed) by the Local Authority so that the person could get on and organise their support.

For all those who had experienced plans going before Panel, the overall experience had been negative, with plans being refused because "we don't do cleaning / gardening / holidays / etc." here, or budgets being reduced. Social Workers were considered to generally be afraid of Panel and unwilling to assist an individual with a plan that might have more creative use of resources. It was felt that there was no appeal process where Panel had made a decision, and no one had ever been invited to attend and present their case. In one area, one third sector organisation was said to be involved in the Panel, and this was seen to be a positive benefit as representatives were able to raise issues with Panel members and provide additional context to the decision making.
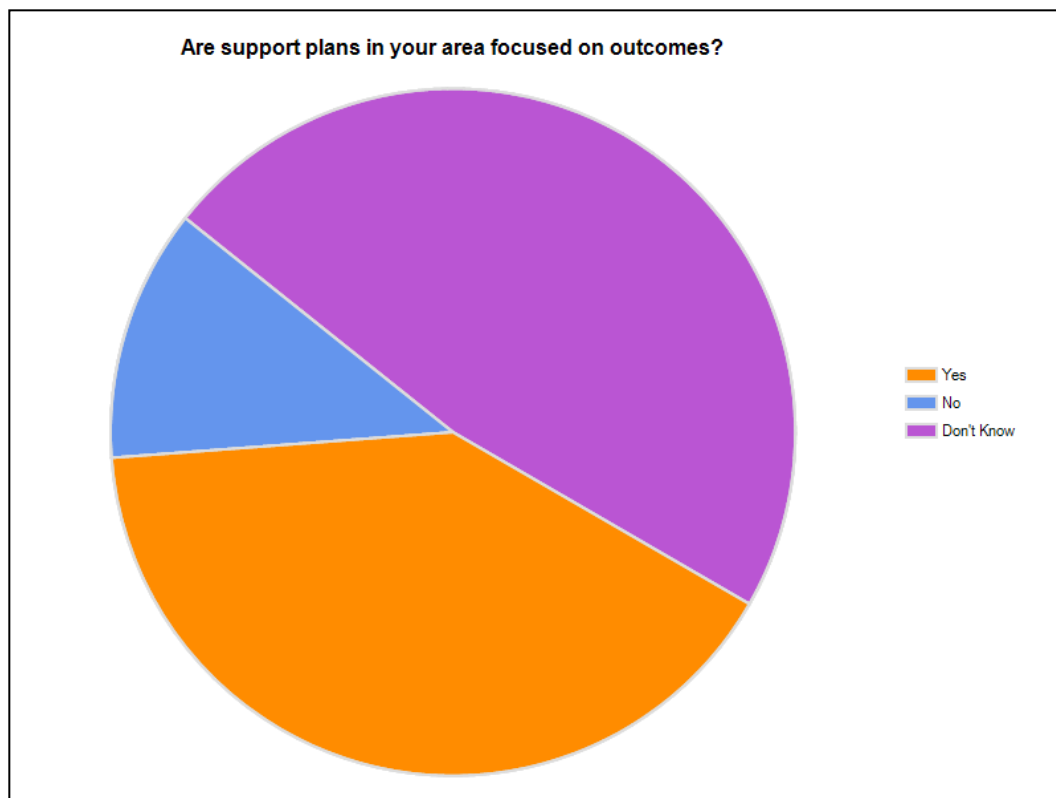
Overall, Panels were not widely understood, and were not seen as being transparent in their decision making, nor accessible in their processes.

8.4. Brokerage and support planning

Participants had experienced a range of approaches to brokerage and support planning, and were mostly supportive of brokerage and support planning services being delivered by user led or disabled people's organisations. Despite some positive examples of mixed brokerage services in development, most areas were reported to have support planning and brokerage wholly led by social workers.

Participants were concerned that this had led to a failure to really offer Direct Payments, and a leaning towards Council managed budgets, as many care staff were not experienced in and familiar with supporting people to think through alternatives. Indeed, at 2 of the events, groups referred to many social workers thinking in "4 fifteen minute pop-ins" as that was how recent practice had led them. In addition, there was little discussion at any of the sessions on other methods of deploying a Direct Payment, such as mixed packages, individual service funds or third party arrangements. Finally, people were generally confused by the language used in relation to outcomes focused support planning. *Figure 1.2* shows that again, the online survey supported these findings by revealing that people are not clear about what this is, and whether it is happening.

Figure 1.2

Are support plans in your area focused on outcomes?

Legend:
- Yes (orange)
- No (blue)
- Don't Know (purple)

The following comments relating to *Figure 1.2* also support these findings[9]:

- "*Person Centre Plans are meant to be led by the individual but the social workers tend to say what you can and can't have and then cut the hours to suit themselves.*"
- "*No, I don't believe so - they are mainly based on what I can't do, re Direct Payments*"
- "*In theory but practice suggests no. Also whose outcomes. Persons or LA's*"

8.5. How to use your money

As would be expected, most of the participants in the focus groups were advocates of Direct Payments, and were keen to see more people being able to take up DP. Data from Councils (ADASS survey, March 2011 as above) nationally indicates that take up of Direct Payments stalled at around 26% of personal budgets in March 2011, although this figure varies considerably between Authorities. What is clear, however, is that the most common method of taking a personal budget is as a Council managed service. Participants at all events where this was considered believed that the core challenges in relation to increasing the take up of Direct Payments (as the preferred method of deployment of a personal budget, as per **Think Local Act Personal**) were:

a) The lack of robust support structures for Direct Payments (some people need significant amounts of help to get going, and this is not always available)
b) The lack of independent support in managing Direct Payments
c) Lack of good information about Direct Payments
d) The lack of understanding by social workers of Direct Payments
e) The system disincentives that mean Direct Payments are paid at lower hourly rates than block contracted services
f) The market is not sufficiently developed (i.e. not enough PA's, provider organisations not able to deal with individual purchasers, etc.)

8.7. Culture

In all focus group sessions, perhaps the most recurrent theme was the challenge of cultural change for the social care workforce (including provider services and associated service areas such as finance and commissioning).

Whilst it was recognised that in every area investment had been made in awareness raising and training workers, there was still apparently a tendency in most areas to continue with more traditional ways of organising packages of support for people. Discussion groups at the focus groups captured attitudinal challenges that related to safeguarding and risk, which whilst

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[9] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.32.

important, were seen to sometimes overshadow people having real choice and control.

Panel management and oversight of the sign off of support plans (see above) was seen as a further barrier, stifling creativity. In a number of areas, people were adamant that Local Authorities were operating approved lists of what resources could be spent on, and were dismissing plans particularly where people were using resources to assist with domestic tasks like gardening, cleaning and paperwork. The online survey responses also indicated a need for a deeper and more profound cultural shift, with individuals commenting as follows:

"*I still hear on a daily basis Social Workers informing individuals that we don't cover Domestic Services etc. as it is not a FACS eligible service!!*"[10]

"*The social workers don't know the difference between personal budgets and direct payments at the moment and they are supposed to be advising me and my groups*"[11]

"*There is also a reluctance to give service users their estimated budget to allow them to write their own support plans, with the social worker tending to write the plan on their behalf. However the local authority has recently begun developing clearer guidance around support planning and personal budgets but it still has a way to go to make it a clear and transparent process*".[12]

"*We don't even think the social workers themselves are really fully aware of the ins and outs of personalisation budgets*".[13]

8.6. Older People and people with mental health support needs

In undertaking the personalisation focus groups, and from the online survey responses, it was clear that there are still some areas of service where personalisation has a longer journey to become established. Of all the participants in the focus group sessions, only a handful of individuals were able to represent any experience of older people receiving personal budgets. That is not to say that older people are not receiving personal budgets. On the contrary, given that the majority of people receiving support in most adult social care areas are older people, undoubtedly older people are being offered personal budgets in the NW and beyond.

It was clear, however, that where disabled people's organisations are concerned, few are currently actively working with older people. In some areas, organisations like Age UK manage brokerage services working with older people, but it may be that older people have less access to independent

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[10] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.17.
[11] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.24.
[12] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.24.
[13] Appendix B, *Survey of Attitudes to Personalisation*, January 2012. p.26.

brokerage than younger people with disabilities. People with mental health support needs were also seen as one of the most unlikely groups of people to be being offered personal budgets currently – and few mental health organisations were involved in the focus groups. There is clearly further work to do to ensure that choice and control is available to all adults with ongoing community support needs.

8.7. Investment in User Led and Disabled People's organisations

In several of the areas hosting focus group sessions, Centres for Independent Living had been established and were delivering support to people as part of a commissioned service paid for by Local Authorities. Other organisations led by disabled people were also contributing to the support of individuals and families through the provision of advice and information services, partly funded by Local Authorities, health services and some grant funding from charities like the National Lottery.

In most areas, user led, disabled people's organisations, and organisations for disabled people are struggling with future funding arrangements and sustainability. Few had benefited from the increased funding to Local Authorities from the Transformation grant. Others were struggling to compete against larger, national providers in local contract tendering processes where the weighting of contracts was 70% cost, 30% quality.

8.8. Market Development

Although market development did not come up significantly as a major theme in the overall focus group discussions, it was clear from the comments by organisational representatives that many provider organisations are still struggling to get to grips with the new world of social care. Support is needed to organise business processes to enable provider organisations to effectively market and sell their services to local people. In addition, local markets are yet to develop a sufficient diversity of choice that might encourage people to look beyond what has been traditionally delivered in an area. Robust commissioning strategies that outline the shift towards personal budgets, and good market intelligence are prerequisites for the market to flourish.

8.9. Wider Context of Welfare Reform

The focus group sessions took place during the passage of the Welfare Reform Bill, which had generated significant media debate about disability benefits, and at a number of the sessions participants talked about their fears about proposed changes. Many of these concerns are captured in the disability campaigner led blog http://diaryofabenefitscrounger.blogspot.com/ Participants also talked about a perception of the demonisation of disabled people, with individuals talking about experiences of social, cultural and organisational discrimination. Some people felt that media representation of

disability had entirely misrepresented people who had ongoing support needs, and this had upset many.

Finally, several of the events raised the issue of the closure to new claimants of the Independent Living Fund (ILF)[14]. The Fund, in operation since 1993, was closed to new claimants in 2010, and the longer term future of ILF funding for existing claimants beyond 2015 is not clear. For some, ILF has made the difference between Independent Living and residential care, and people are concerned at the impact on existing claimants and for those for whom dreams of independent living will be limited or curtailed by the loss of funding.

9. Summary

The focus groups revealed a significant level of interest in personalisation amongst disabled people, families, support organisations and service providers. Four years on from the launch of *Putting People First*, however, there is still a huge amount of work to do to ensure that people with ongoing community support needs are able to have a real opportunity to take up choice and control through personal budgets should they choose to do so.

10. Next Steps Actions

1. Share local reports with local areas, including Local Authority personalisation leads

2. Share overall report with participants, Local Authorities and DPULO Ambassadors for the region.

3. Present the findings at Merseyside Disability Federation AGM in March 2012

4. Share report with Think Local Act Personal Board and coproduction group

5. Work with NW Transition Alliance personalisation programme and Think Local Act Personal to promote Making it Real – the TLAP markers of progress.[15]

6. Build capacity amongst NW DPULOs and associated organisations to promote and contribute to Making it Real across the NW.

11. Thanks

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[14] For more information, see http://www.dwp.gov.uk/ilf/about-ilf/how-the-ilf-works/ilf-eligibility/index.shtml
[15] http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/MakingItReal.pdf

The NWDIP would like to thank everyone who participated in this study, both via the online survey and through attending a focus group. In addition, special thanks go to the organisations which hosted the sessions.