

North West Disability Infrastructure Partnership

Personalisation Research Summary Report

Annexe B

Survey of Attitudes to Personalisation

January 2012



Charity Number: 1082671



**Merseyside Disability Federation on behalf of
North West Disability Infrastructure Partnership**

**Survey of attitudes to Personalisation
January 2012**

1.0 Summary

In the autumn of 2011, the government carried out an engagement exercise on aspects of social care provision. As part of its preparation to respond to this, Merseyside Disability Federation (MDF) and its partner organisations through the North West Disability Infrastructure Partnership (NWDIP)¹ carried out a number of consultation exercises, focussing on one particular issue in the engagement exercise in particular, that of Personalisation.²

This report presents the results of an online survey that was part of this activity.

1.1 Personalisation

According to www.personalisationagenda.org.uk, “personalisation is often referred to as the complete transformation of adult social care. It also means making universal services such as transport, education and housing accessible to all citizens.

Personalisation is about putting individuals firmly in the driving seat of building a system of care and support that is designed with their full involvement and tailored to meet their own unique needs.

This is a completely different approach to an historic “one size fits all” system of individuals having to access, and fit into, care and support services that already exist which have been designed and commissioned on their behalf by Local Authorities for example. Individuals will receive their own budget and decide how, who with and where they wish to spend that budget in order to meet their needs and achieve their desired outcomes”.

1.2 The survey

A short online survey using the programme Survey Monkey³ was available online from 01/10/11 to 28/11/11. The survey was publicised through the websites of MDF and partner organisations and by direct emails – again from MDF and from the other organisations. Recipients were encouraged to forward the link to the survey to other people, whether they were disabled

¹ For more information on NWDIP see page 9

² Other consultations, not reported here, involved six focus groups in various parts of the NW Region.

³ www.surveymonkey.com

people who had personal experience or knowledge of Personalisation, or the representatives of organisations of and for disabled people.

Introductory questions were left open. We were aware that underlying knowledge of what was included under the heading of Personalisation was not consistent among users of social care organisations or the groups of and for disabled people that work for them, and we did not want to impose any limits on the possible responses.

Other, closed, questions also asked for additional comments, which have been used here to illustrate the range of responses that were received,

1.3 Survey response

The overall response was 119, though not all questions were answered by each respondent. Three quarters of the responses were from individual disabled people (or carers) and the remainder from people representing voluntary groups or infrastructure organisations.

Of the replies, 10% were from people or organisations that did not give a locality (or were based outside North West England). This survey aims to look at a wide range of opinions and experiences of Personalisation and these responses have been included in the final totals. This gives a final maximum of 89 possible respondents for each question (allowing for those people who started but did not complete the survey).

This response is relatively low, given the wide distribution of the questionnaire through groups in the region, and the current national consultation programme by the Department of Health, a consultation on changes which potentially affect the way most disabled people will be supported in the future.

This low number of responses may be related to the nature of many of the responses to the questionnaire. There was a range, from people who believed they did not know what Personalisation was to people who were unhappy with the limited extent and scope of the roll-out of Personalisation in their area. If these levels of knowledge and experience of Personalisation reflect wider views among disabled people, then indifference to a questionnaire about it might be understandable.

Around half of the responses were from Merseyside. The overall numbers mean that it is not possible to single out identify contrasts in attitude or experiences between different parts of the North West.

2.0 Conclusions and Recommendations

2.1 Conclusions

Who is Personalisation working for? and Who is Personalisation not working for?

From this survey it is evident that in general, respondents believed Personalisation is not working largely for disabled people (52%), and they often specified that it was disabled people with limited capacity or support available to make best advantage of Personalisation (23%) who were likely to be not benefiting.

Councils are seen to be cutting back on their budgets, which is also creating problems with Personalisation and the move towards personal budgets. It was felt by respondents that this would create detrimental effects on disabled people's lives.

- *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.*

There seems to be a lack of referrals for older people in terms of personal budgets as it appears older people do not seem to be viewed as 'disabled people' or they do not class themselves as 'disabled'.

- *The feedback I have had is that older people are less interested in using personal budgets and prefer "traditional" services to be arranged...there needs to be more opportunities for managed accounts so that carers and service users who do not feel they can manage direct payments can still have flexibility and choice in their services.*

Are you or your organisation involved with how the Local Authority is making personal budgets work?

Around two-thirds of respondents reported some level of involvement with the LA on personal budgets. The most common type of involvement was 'some consultation with local authorities'. Only a dozen respondents reported carrying out 'co-production' with the LAs.

Do you think people are getting clear messages about personal budgets?

Nearly 9 out of 10 respondents felt that disabled people were not receiving a clear message about personal budgets.

- *After attending several conferences over that last few years, it still seems there are more questions than answers.*

- *A lot of people don't know what they are. There is a lot of confusion amongst disabled people of where this applies to them or not.*

When asked “where do you get the information from on personal budgets?” almost equal numbers said this was by “word of mouth” or from “voluntary groups” or from their “local authority”. This again shows that there is a need for the local authorities to work with the groups on the ground to send a clear message out about personal budgets and the personalisation agenda as a whole.

Do you think people in residential care settings could benefit from personal budgets?

Over half of respondents (55%) said people in residential care settings would benefit from personal budgets, though many people believed that this would depend on them receiving support and advocacy that was independent of where they were resident:

- *Definitely if they get told what Personalisation is correctly.*
- *This would have the potential to improve the life of residential care residents, but only if accompanied by advocacy.*

Are reablement services being delivered in your area?

When asked about reablement services, almost half the respondents did not know whether “reablement” services were being delivered in their area. Almost half answered that reablement services were offered in their area, of those that answered “yes” there were a number of comments emphasising that reablement services were limited in availability and effectiveness:

- *However very limited and with a long waiting list and also*
- *They are delivered, but not well publicised.*

Are support plans in your area focused on outcomes? Are there sufficient plans focused on outcomes?

Around half of respondents answered, “don’t know” to this question, and some commented that the process appeared to be satisfying LA budget outcomes.

- *Totally focussed on outcomes, outcomes of saving money not need or reflecting people’s ever-changing situations*
- *... only the very basic need is met, Not the choice, control and independence that should be reflected when the support plan has been focused on the holistic requirement of the person it represents.*

Many people pointed to the dominance of care managers and social workers. When asked if there were sufficient plans based on outcomes, only 10% said yes.

Are there sufficient services and support locally for people with personal budgets to buy?

It appears there are not sufficient services and support locally for people with personal budgets to buy – 69% answered no to this question.

- *Market development is required particularly around new innovations however, this will not happen as LAs are not agreeing creative use of funding.*
- *The local authority could better support VCS organisations that provide personalised services for disabled people. This support could simply be about passing on information or providing access to people who have personal budgets / direct payments*
- *Too many strings attached too little money to buy the services i.e. money per hour given does not meet how much a service would cost.*

Can disabled people buy from their choice or do they have to buy from a 'preferred provider'?

There were some ambiguities around the answers to the question. It was, however, evident that many disabled people still had to buy from the 'preferred provider list', which was seen as unsatisfactory from a number of viewpoints:

- *Yes the dreaded list, which excludes groups that wish to give people choice and variety in their lives. The list also seems to be closed and no details of how you can become a preferred provider and get onto the list.*

Even people who did imply that there was ostensible free choice suggested that this was restricted by the limited availability of services to purchase.

What do Councils need to do to ensure that 100% of eligible people have personal budgets in your area by 2013?

The following headlines were apparent:

- **Better communications** – Some of the comments included:
“Tell us what we're entitled to. And explain the jargon” “Provide clear guidance and literature that is accessible to all... a social workers, service users or voluntary sector organisations. More promotion of personal budgets”
- **Providing independent and effective support** – Some of the comments included:
“Provide honest, independent and reliable advice” “Provide a support infrastructure for those who do not have the ability or already such an infrastructure in place, to help the individual

identify opportunities and suitable resources, which might help them, and organise the purchasing of those resources and administering and accounting for the use of the personal budget”

- **The need to train staff in better understanding of Personalisation**
– Some of the comments included:
“staff still need more training”. “Expand their understanding and concepts across all staff”.
- **Councils need to work with local groups** – Some of the comments included:
“Facilitate the development of more specialist provision in liaison with the voluntary sector.” “Provide more support and fund ULOs and DPOS to support disabled people to run them.” “Better information for service users, more involvement with vol sector services”
- **Ensure sufficient budget** – Some of the comments included:
“Find money in their budgets to enable each disabled person who wants to go get individual budgets. At present if everyone applied there wouldn't be any money in the councils pot to fund the increase in spending” “I can't see this happening as they don't have anywhere near the budgets needed to get all people who need support onto personal budgets now so can't see that happening by 2013”.
- **Corporate culture change** – This ties in with the need for staff training, but at a deeper level, It suggests that the wholesale change in attitude (to positively encourage the independence and choice that Personalisation should deliver) is still often absent within the LA departments (*see recommendations below*)
- **LAs need to ‘do something’** – some people could not comment on the effectiveness of what the LA was doing towards Personalisation because they did not see anything to comment on. Some of the comments included:
“Starting them would be a beginning! So far very few known to our organisation (dealing with people with both physical and learning impairments)” “We seem to be no further than we were almost a year ago”.

2.2 Recommendations

- Our survey suggests that there needs to be a cultural shift within Local Authorities. One person commented: *“Attitudes of social services (not all) need to drastically change in which way they deliver services”.* Another interesting comment was again around the Local Authorities and the need to change their culture – *“Change its culture, relinquish power, invest in disabled people, and support our organisations”.* Care

packages and support plans are not truly personalised – *“There needs to be a law to ensure that the full PCP is filled in with the full consent and backing of the user.”*

- There is a lack of communication and information around personalisation. There needs to therefore be more clarity and transparency, especially around personal budgets and how to access direct payments *etc.* and also reablement services. It was evident from the survey that there is a lack of understanding around Personalisation. More work needs to be done with groups on the ground to get the message out there.
- Our survey suggests that there is still a need to train local authority staff on Personalisation. - *“They could do with more guidance on this part of the support plan.”*
- More information needs to get out there about support plans and outcomes.
- Local authorities need to publicise – *“publicise more, invest in information and support services to make access easier”*.
- More work needs to be done around older people accessing Personalisation services

3.0 North West Disability Infrastructure Partnership

The North West Disability Infrastructure Partnership (NWDIP) project aims to improve opportunities for disabled people to influence policy, service provision, and support by ensuring that the full range of Voluntary and Community Sector (VCS) disability organisations across the North West are provided with consistently good and accessible support/capacity building services.

NWDIP was formed because of an expressed desire from voluntary and community sector organisations for the support provided to organisations of and for disabled people to be more accessible. As a result, a partnership of six sub-regional disability organisations came together to address this specific development need and obtained funding from BIG's BASIS 2 programme to build the capacity of VCS Infrastructure organisations to provide accessible services. The NWDIP project started in April 2010.

Merseyside Disability Federation (MDF) is the lead accountable body of the Basis 2 project. MDF is itself a specialist VCS Infrastructure organisation that supports around 500 organisations of and disabled people in Merseyside and surrounding areas. All other partners both deliver some infrastructure support and various frontline services to disabled people.

The six partners:

- Access Lancashire
- Breakthrough UK (*for Greater Manchester*)
- Cumbria Disability Network
- Disability Information Bureau (*for Cheshire*)
- Merseyside Disability Federation
- Warrington Disability Partnership

Appendix

Responses to the online survey on Personalisation, (November 2011)

The responses here are unedited comments provided to the online survey. To make reading easier, some obvious mistypings have been silently corrected and punctuation added. Other responses - where we are unable to assume the word that was intended – have comments in square brackets.

Q1 - Which Local Authority area are you located in?

	%	number
Cheshire	9%	11
Cumbria	1%	2
Lancashire	5%	6
Manchester	21%	24
Merseyside	46%	52
Warrington	4%	5
<i>not in North West</i>	8%	10

Q2 - Who is Personalisation working for?

- Disabled people
- Don't know anything about this
- People like me, with a Personal Budget. I have dp [? Direct Payments] and been independent all my life. Now retired, I need the extra funding to continue my interests in social care
- I don't know yet
- People who have got the ability to understand the process, the provider scene and the law or someone who has a good and competent advocate
- Organisations that provide care provision in terms of personal care needs support.
- Some disabled people who know what choice is. If they have never been given a choice before, how will they know what choice is or what choices they can make?
- It is working for me, as I am in control of my own life. It has been a big learning curve, with being able to pay my own bills and being able to save for what I want to do on my own.
- I am not sure but it seems to be working best for younger people particularly those with physical disabilities. The county does not appear to have got to grips with Personalisation and its implications for people with mental health issues.
- It should work effectively for everyone but due to restrictions now imposed on how money is spent it does not allow for flexibility in conditions /how well you are to use all your fund at one time
- People with advocacy or able to manage.
- Articulate individuals and carers with good advocacy skills and attractive personalities
- People who are able to understand the process from beginning to end. People who are able to practically deal with the logistics.
- Social Services
- To satisfy government legislation
- Councils are saving money. Some younger disabled people have more freedom. NHS continues to offload costs onto Social Services by exploiting untrained PAs to deliver medical services.
- It is working mainly for younger disabled adults who have the capacity to engage in the support planning process.
- It might help had this survey explained what Personalisation is. I don't know.
- I can't see it working for anyone at the moment as the councils haven't got the money in their budgets for everyone that needs support to go onto direct payments at the moment, most of us are getting our support hours cut, so we have less choice so no one is the winner at the moment.
- The government and some clients
- Not me

- Not exactly sure - I have Direct Payments but it is hoped that people will move over to Individual Budgets in Liverpool before too long - not sure exactly what the difference might be in reality!
- I have never heard of this word before.
- Don't know
- Me!
- Some people with learning disabilities and younger people with physical disabilities
- Should be disabled individuals
- Currently not many as local authorities keep changing rules, eligibility and cutting support
- The government as far as I can see
- ?
- Those who are in the know. Across Lancashire people who keep themselves up to date with personalisation, have social workers that are up to date with personalisation and/or have contact with voluntary sector organisations are able to use the personalisation agenda to tailor their support to their needs.
- The local authority, Learning Disabilities
- Personalisation works when the individual's needs are met by the care package. Giving choice and control over how their needs are met supports independence. This seems to work best for those who are able to manage, or at least have input into their own care packages.
- Don't know
- Care Homes and those giving personalised support with personal needs
- Some customers with capacity
- Those few people who are able to plan their own needs and take them forward
- The disabled
- The more able disabled - possibly
- People with mobility impairments
- I don't know
- Anyone who wishes to use the opportunity
- Needs further discussion in Warrington as pilot course results have not been shown yet
- People on small budgets who have good ULDPPOS [User-led Disabled People's Organisations] to support them
- Currently, there is evidence that more D/deaf Service users are taking up Direct Payments to fund Personal Assistants
- Liverpool do not involve people in Personalisation
- Disabled people and older people
- No-one here! Blackpool will tell you there are 1,323 people on personal budgets. That would be - on closer inspection - 1,323 people that have been asked if they would like to run their own personal budget, not given any support or advice how to do so and therefore choose to remain in receipt of council services as before. So in effect 1,323 have been fairly been given the choice and not taken it up.
- Personalisation is working for everyone [who] receives social care and is willing/able to make their own choices.

- Some people with a disability
- Some customers of Social Care
- Some individuals
- People who are capable of handling their own affairs
- People with moderate needs, the less disabled or the very disabled, who retain a high level of mental capacity, those already in a position to organise their own finances and their lives effectively, with an existing infrastructure of support *i.e.* family or friends
- Individuals who have good support networks and are articulate enough to be able to seek the support. Usually people with strong, hands-on, family involvement.
- Disabled people - who wish to employ their own carers, who wish to have more choice and control over their care packages.
- Disability Equality North West
- Not sure
- It's not
- Not sure - Breakthrough
- those with a realistic budget...but there are watered-down experiences for those with minimal budgets through local Mencap society.....
- To save the government money.
- Personalisation is largely working for people who use services although there are still mixed messages and confusion as to what the payment can be used for.
- No-one
- Not sure yet!
- Not many
- It should be working for us though how it will with the current economic climate is anyone's guess
- No-one as no-one appears to understand it
- People with a Learning Disability
- Some able individuals who are savvy about the system
- People who have the skills and confidence to identify their own goals/ support needs, able to manage direct payments responsibilities and tasks as an employer including supervising support staff
- It hasn't been applicable so far
- People who can understand it and know how to access and manage it.
- Some adults with disabilities but too many boundaries reducing effectiveness
- Never heard of it
- Yes, but it has restrictions
- [individual name - deleted]
- Not sure
- Private care companies who do not necessarily provide the best opportunities for adults with disabilities
- People who are NOT requiring large packages of care and/or support at home and perhaps have less complex needs.
- People with the right information, knowledge and support to enable them to express their needs, and get their needs met.
- Those who require more 'traditional' support e.g. Personal Assistant etc.

- Those who have the mental capacity to conduct their own affairs, organise staff, know if they are being abused *etc.*
- Not many of our clients
- Wirral Borough Council
- Not sure
- Still waiting after months and months for personal budgets. Still waiting years to get transition. No one.
- Personalisation is working for the more confident and outspoken people, those who challenge and fight for their rights

Q3 - Who is Personalisation not working for?

- Alzheimer sufferers. Youth unemployed.
- Myself and my partner
- My friend, [name deleted]. Lives with autism. Highly motivated. I kept her out of LA care as long as possible and she maximised her individuality very creatively. Had DP [? Direct Payments]. LA still has no understanding but forced by COP to house her and give 36 hours per week help, she is severely restricted, frustrated and de-skilled, trying to reject help, she is so enraged. DP removed.
- I don't know that either yet
- Those with limited understanding and those open to abuse
- Groups on the group [? "on the ground"] that are providing services for disabled people, though social or training that don't provide as part of the parcel any type of personal care. Disabled people then [?they] need to bring with them their own PA's but due to the cut back of the amount of hours for a PA they have they are unable to use these services as most people are back to square one with only personal needs. Nothing extra - or anything extra has been cut out of the individual budgets.
- A lot of disabled people are getting mixed up with what Personalisation is. Some get direct payments and don't see Personalisation affecting them or ever having anything to do with Personalisation. Personalisation needs to be explained better by people in power like the social workers who of most don't know the different ways the Personalisation can work for a person.
- 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.
- As above - for people with mental health issues.
- People in residential care - elderly services service users
- Vulnerable people carers
- Adults with mental health issues Adults with learning difficulties The elderly
- Sadly, quite a lot. People with small care packages. Sometimes people requiring help with messy or invasive aspects of personal care. People lacking social skills or who are moody or otherwise hard to work with. Some vulnerable adults who are being exploited by PAs and / or family members.
- Carers - carers are often left without the respite - they may have been used to commissioned services. Also a big responsibility is placed on carers in relation to the practicalities of managing a direct payment.
- The man or woman coping with disability, old age *etc.*
- People in institutional care. People with poorly developed support networks.
- The feedback I have had is that older people are less interested in using personal budgets and prefer traditional services to be arranged. It is still somewhat tokenistic for adults with severe learning disabilities whose families are still the ones to decide the person's outcomes /

goals. There needs to be more opportunities for managed accounts so that carers and service users who do not feel they can manage direct payments can still have flexibility and choice in their services.

- I don't know
- I can't see it working for anyone at the moment as the councils haven't got the money in their budgets for everyone that needs support to go onto direct payments at the moment, most of us are getting our support hours cut, so we have less choice so no one is the winner at the moment.
- A minority
- Me
- Not sure about Personalisation, as such but for the most my Direct Payments work well for me, but I'm looking forward to the improving benefits that Individual budgets may bring
- Do not know.
- Don't know
- Pretty much everyone else.
- Some older people.
- Not sure
- Disabled people, families
- I haven't heard good reports from my friends who've been through it
- ?
- Those who aren't able to stay up to date with Personalisation themselves or have social workers that are not up to date with Personalisation or in fact aren't fully supportive of the process.
- Older people
- I wish the above were standard across Cheshire East. It would seem that people are having care packages down-sized due to Social Services financial budgets for care services and equipment not being substantial enough to cope with the increasing demand. When this happens it becomes stressful for all involved.
- Me (A person with Parkinson's Disease)
- Organisations who do not give disabled people personal care but still do training and social integrated support
- Customers with limited or no capacity
- Most people
- NOT SURE
- Have been trying to get Personal Budget for over 12 months. Continually being let down by the system.
- Those with complex, multiple disabilities, profound learning disabilities and autism, multi-sensory impairment, high support needs
- People with mental health issues
- Adults with disability
- It depends on how able a person is to express themselves and their own needs
- As above.
- People who have no support and people with large packages
- This is in the very early stages for D/deaf people in terms of funding packages of care. Changes in the contracts between DSN and both Local Authorities have resulted in the DSN no longer having Qualified

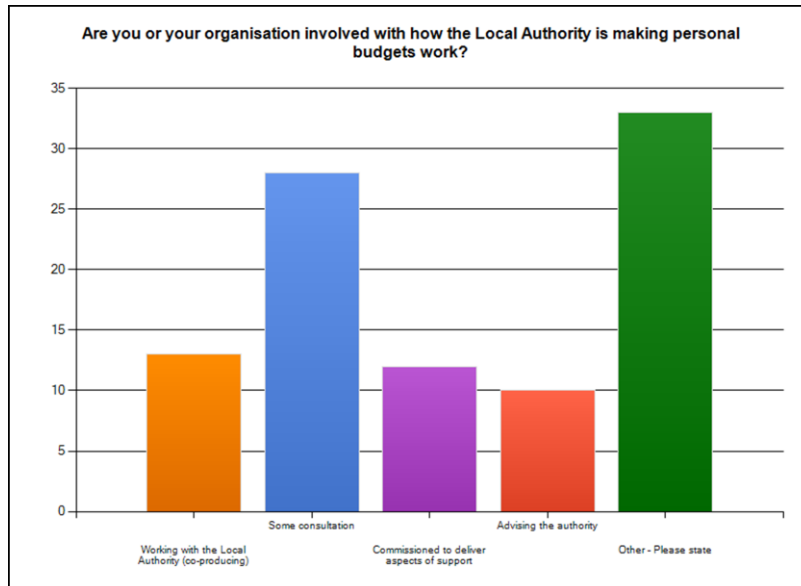
Social Workers and therefore no care management role. No evidence currently to support the notion that personalisation is not working. However, D/deaf service users in DSN Supported Living Service are currently being reassessed using the RAS [Resource Allocation System]. This may highlight shortfalls in placement funding.

- Most of the people in Liverpool especially the learning disabled
- Less so for people with mental health issues
- Everyone in Blackpool that could benefit from personalisation but doesn't understand enough about it or get told enough about it, mainly because even the professional is confused.
- Personalisation will not work for people whose experience of discrimination has made them unable to make personal choices about their own lives. We underestimate the way that discrimination impacts on and individual are perspective.
- As above
- Some customers of Social Care
- Some individuals
- Perhaps people who may have learning difficulties and older people who need support. Also may be difficult for people with mental health issues depending on their condition
- Those who are severely disabled, without the above mental capacity or infrastructure in place. Those primarily reliant on health services. People with severe learning disabilities, people who are depressed or isolated, who have little choice or ability to manage their own care. People already in nursing or care homes. Alcohol and drug misusers. People with severe and enduring mental health problems, who are unwell or unstable.
- Everyone else.
- Disabled people who fall into difficulties tackling employment related issues.
- Not sure
- Ald [?Old]
- Not sure
- Those who do not have someone to support them through the process regardless of budget or level of plan. Housing is a real problem although if 1-1 support is given we have proved that the system can be negotiated successfully.
- The needs and welfare of disabled people.
- Social Workers who still seem to be prescribing and not allowing people to self-direct. They also encounter problems when costing up Support Plans and there is an over-reliance on finance colleagues. Also on Wirral FACS {Fair Access to Care system} eligibility is built into the assessment process and therefore when support planning as long as the service purchased meets an outcome then this should in theory be OK. 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!!
- People with a visual impairment
- Everyone
- Most people with disabilities.

- Most disabled and older people who receive minimal, low level of support.
- I know that on a local level social workers and care managers within the mental health teams have a very poor understanding of direct payments which has been on the agenda for a number of years so how they will keep up with the rest of the changes is any ones guess
- Everyone
- Older people
- Less able people who struggle to have their voices heard
- People who are not able to: challenge the power imbalances of those involved in organising care packages; Manage staff; assert their needs and wishes; complete time sheets / travel expense claim forms and 'audit' them. People who are isolated or too independent to accept offers of help
- It is invisible and so I have had no direct experience of it.
- People who need additional support to understand this system. People who do not know how to contact organisations and fill out forms correctly. And of course people who have never heard of it.
- Families who are not confident to tackle the issue and negotiate their needs
- Ditto
- People like my daughter who are unable to speak. She uses a communication aid, and there is no funding available for her to fund the aid or the training of her staff to enable her to gain access to the aid.
- Children
- Secondary organisations. We are a care farm [? care firm] that can currently provide opportunities for organisations that bring carers. We are not in a time position to do the caring (e.g. toilets) ourselves. Our opportunities are life changing / improving but we need part of the budget as well as the carers
- People who have complex needs and need a large package of care and respite. It is also not working for carers in many of these situations as they are being asked to shoulder more responsibility to supplement the care packages and make them fit within budget.
- Those people without access to the right support that enables them to be truly at the heart of care planning and care and support services
- Young Adults who do not wish for 'traditional support' but think of other ways that their outcomes can be achieved. They are then informed that this is just something that they 'want' and it is suggested that they use their benefits for this.
- If it is beyond an individual's ability to have any concept of organising their own life, expressing their wishes and views how could they possibly put it into practice? Carers of people with learning disabilities, autism, mental health problems are in effect taking the role of care managers to protect and provide for their loved ones.
- A large number of our clients
- Customers and carers
- Those who are being told they can only use it for specific purposes. Surely the choice and decision parts of personalisation are therefore being taken away from them?

- See 2. My daughter and my family.
- For those people who do not challenge and do not fully understand the concept

Q4 - Are you or your organisation involved with how the Local Authority is making personal budgets work?



Some consultation	36%
Working with the Local Authority (co-producing)	17%
Commissioned to deliver aspects of support	16%
Advising the authority	13%
Other	43%

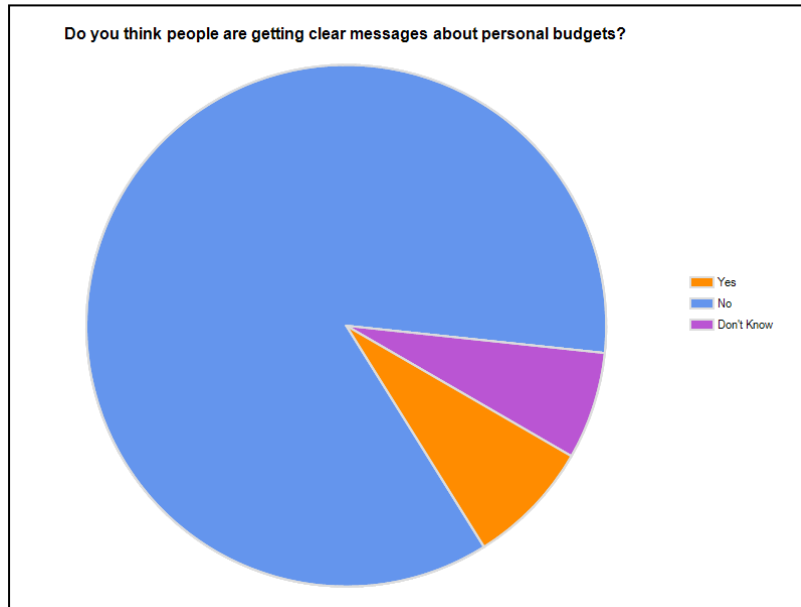
Other responses

- was a participant in the first pilot for personal budgets
- Struggling to influence. Want to video myself as demo.
- Father (Carer)
- Yes as Parents.
- Not been involved or consulted
- Our beneficiaries receive £800 p.a. [£200 per Qtr.] and help with replacement of `white goods.' e.g. cookers, fridges, and washing machines.
- No
- volunteer benefits officer
- offering a service
- I was a participant in the first pilot for personal budgets
- I work for the local authority as a social worker
- No, thank goodness as they are making a big enough mess on their own.
- I am a customer

- I have spoken to anyone who has asked questions on the subject both in an official capacity and informally. Could I just mention as I'm dyslexic I found the previous question difficult to answer / how to indicate the option (explanation / instruction would help).
- n/a
- I'm meant to be on an advisory group but it rarely meets and the other people on the group are pretty clueless.
- Social Worker
- Support to disabled people
- We are a user-led organisation that is currently the lead for The Lancashire Community Pathway project. The project is a consortium of voluntary/community/faith sector organisations that have been trained in how to help individuals plan and write their own support plans and manage their support. Our organisation also provides guidance around direct payments, becoming an employer and hiring personal assistants.
- More directly involved in NHS Funding
- Not sure
- WDP [? Warrington Disability Partnership] provides support to the person receiving personal budgets
- I left because they did not want to hear what I had to say
- Lack of contact and Easy Read information and how to get it
- I have set up a jargon-free simplified website with an explanation of PB's, [Personal Budgets] PB stories to illustrate to people how different ideas can improve their lives, simple steps and lots more. I am also running workshops in the local area, these cover national and local variations.
- Working for Local Authority
- Building up capital for home for deaf and deaf/blind
- Community and IMHA advocacy
- I am a parent of a young man who has his own budget (ISF) and is living with a friend in a rented HA house both require 24hr support....and it is working well a local Mencap society has been commissioned to provide the service in partnership with us .. His family.
- No
- Local Authority employee
- Part of a voluntary sector interest group.
- We get the odd invite to attend disability and mental health user forums which will sometimes talk about this. We could and should be doing more co-productions but the council have never really taken steps to identify and work with local talent - being officer-led rather than grassroots-led.
- No
- Not relevant as I am not part of any of an organisation
- Parents trying to make it work for our son
- No
- Parents

- Employed by Adult Services but access Children's Services as a parent of a child with disability, feed into Equality and Diversity forum as a parent
- Providing free opportunities whilst we still have Lotteries funding
- We provide advocacy to people within the Borough, many of whom are now to receive personal budgets. We try to provide feedback to the Local Authority through local mechanisms, and in individual cases by using the complaints procedure when all other forms of communication are not working
- As a Carer, in a PA capacity as an advocate for disabled member of the family (young person going into transition). Elderly disabled family member living with us
- Helping families with this issue
- No. Carer of someone suffering from Severe Learning Difficulties, autism, communication and speech difficulties

Q5- Do you think people are getting clear messages about personal budgets?



yes	8%
no	86%
don't know	7%

Comments

- The contract for helping people to take up personal budgets was taken away from Wirral Information Resource for Equality and Disability (WIRED) but has not been given to anyone else. The Council is incapable of giving accurate impartial advice and there is no consistency about the process. If your face fits you will get what you want. If not, forget it. Recent inspections and investigations have exposed corruption and institutional failure.
- But I suspect it could be better. Too theoretical.
- This has been rushed through too quickly without enough time to consider all available options
- A lot of people don't know what they are. There is a lot of confusion amongst disabled people of where
- A lot of jargon is around and no clear explanation of how personalisation fits into a person's life and how a person's individual needs fit in around that as well
- Yes if they read the Easy Read version it is written very clearly and it is good information
- It would appear social care staff are confused which is transferring over to clients

- For a number of years social workers have worked in a person-centered way and promoted the use of self-directed support as the main choice for service users and their families
- 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
- It all sounds good on paper but 'it isn't what it says on the can' or it professes to be something it's not ... there is so much confusion and differences of opinion even in the same authority about what the IB [? Individual Budget] monies can be used for...
- Liverpool have been talking about Individual Budgets for what seems like a lifetime, in theory - but no meat on the bone [? "on the bone"] has reach most Service Users who are not directly involved in the various groups that may be consulted in some way
- As I do not have a personal budget from the Council do not know about this
- I feel as policies are changing that often within the local authority it is hard to give a clear message to individuals entitled to a personal budget. I feel the process could be made simpler for workers so they can explain fully to potential personal budgets!
- LA constantly change rules, make value judgements about what is and is not acceptable spend, reducing flexibility
- Since the budget restraints there have been several mixed messages regarding what will and won't be funded. 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
- The information that is available e.g. FACS is often presented in such a way that it is difficult for the individual to work out how it applies to them. Often being put off by jargon or the negative attitudes they come across when trying to obtain information
- Told one thing and then getting less money in their personal pots due to the council cutbacks
- No defined area for use - more being used as a wish list, which is more likely to keep people dependant on services through budget review, than to move them into being able to manage their own needs
- A lot of people don't understand what the differences are between personal budgets and direct payments
- Because each local authority does it differently
- Even on my simplified site, many of the older people are still not grasping the concept and think the whole idea of running a personal budget is unachievable due to the lack of peer support and brokerage advice and the council are simply not telling people enough.
- There is more need for advocates for disabled people in order to support them in understanding the possibilities of personalisation. There is some evidence that social workers do not have sufficient time or information to effectively support an individual in making the most of

personalisation. This can result in people becoming isolated in their own homes. Although I do not support day centres I think that much work is needed to replace this service and provide opportunities for disabled individuals to play a full and satisfying role in their community

- Still very bureaucratic and mixed communications
- Some are and some are not. Those who know how to ask the right questions or have family to advocate for them are. Those who are isolated are not getting clear messages, or if they are getting those messages, they cannot understand how they will have the ability, resources, or support for it to make a difference to them
- I believe that the general marketing presents aspirational messages about what Personalisation can achieve. However sometimes those messages are lost during care planning and practice implementation of personalised budgets / direct payments. Additionally, the market place for people who have personalised budgets to spend is under developed. VCS organisations who can offer services and packages for disabled people do not know how to reach those with budgets
- Most have little information
- Confused language and inconsistent criteria for the use of the personal budget creates frustration and irritation in many
- Still mixed messages being given out
- It appears that within the Local Authority everyone interprets the legislation differently. Thus information on personal budgets is dependent on who you talk to
- It still seems to be much of a mystery. Personalisation, what is it?
- After attending several conferences over that last few years it still seems there are more questions than answers
- Even the LA have different versions. No clear definition
- Health needs not adhered to, my daughter has epilepsy, and lots of other needs. No training for her team of PAs around that, other than private training, which we have had to use
- Only a few organisations do this, I heard them from Aiming High.....
- Elderly particularly vulnerable as even if families want to go down personal budget route long drawn out timescales make them opt for commissioned care packages which they can access more quickly. Personal budget route often "sold" as being a hassle. The words "choice" and "control" are taken lightly by LA
- The personal budgets seem to have a clear definition in the title, but appears not to be the case when assessing and undertaking. Different localities are offered different things which is ironic as training attended delivers all the same information. There seems to be a distinct lack of flexibility and awareness and complete ignorance of both the customers wishes and dreams and how to implements them. The carer's side of things needs a complete overhaul as they are not recognised in the hours worked when the indicative budget does not reflect the support required by the customer, for example, when the horse riding finishes or the PA goes home, or is ill, or leaves. Ordinary people do not understand the meaning of the word indicative, it should be explained more clearly, as should employing a PA - what it entails

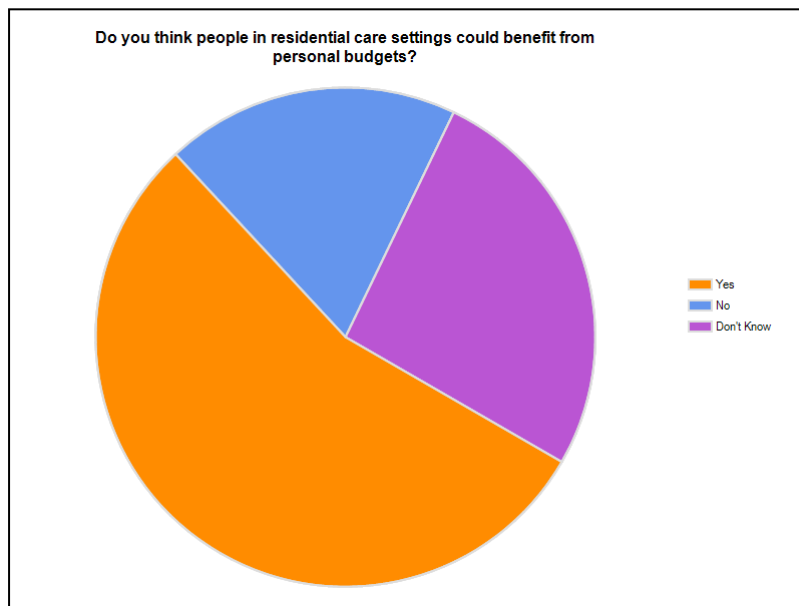
the legalities and rights *etc.*, The goal posts keep changing. Carers are not entitled to support when a customer self-funds (own experience) and in a PA capacity. resulting in the loss of employment and the customers PA through poor assessment time-consuming unclear job description and discrimination of the employer being expected to undertake two clients for one wage, both of whom had their own separate personal budgets and of whom all else included in the budget was paid individually by each person

- Conflicting information depending on who you ask and their particular agenda
- We don't even think the social workers themselves are really fully aware of the ins and outs of personalisation budgets. It is still seen by carers as a means of reducing costs because we know of many instances where the personalisation budget does not cover the costs incurred because the budget is capped

Q6 - If you answered 'yes' to question 5, where did you get your information from?

- My local authority by presentations. Working with St. Helens Carers.
- National websites like Scope and In Control are about the easiest and also have the most information in different formats. But not from the Council sources
- I get my information from the Learning Disability Partnership Board. Not the Social Workers, though, as they don't have a clue, and always seem to not understand what Personalisation is
- From attending user and cases consultation meetings.
- Information is in the form of leaflets and via peer support groups, in addition to social workers/ support workers and third sector orgs promoting the use of personal budgets
- Website national,
- Friends and my own experience
- Training days. Meetings with commissioning and contracts managers. Information literature and documents
- From our customers (vulnerable adults)
- My personal opinion from employee's perspective who has a vested personal interest
- General discussions at brew time

Q7 - Do you think people in residential care settings could benefit from personal budgets?



yes	55%
no	19%
don't know	26%

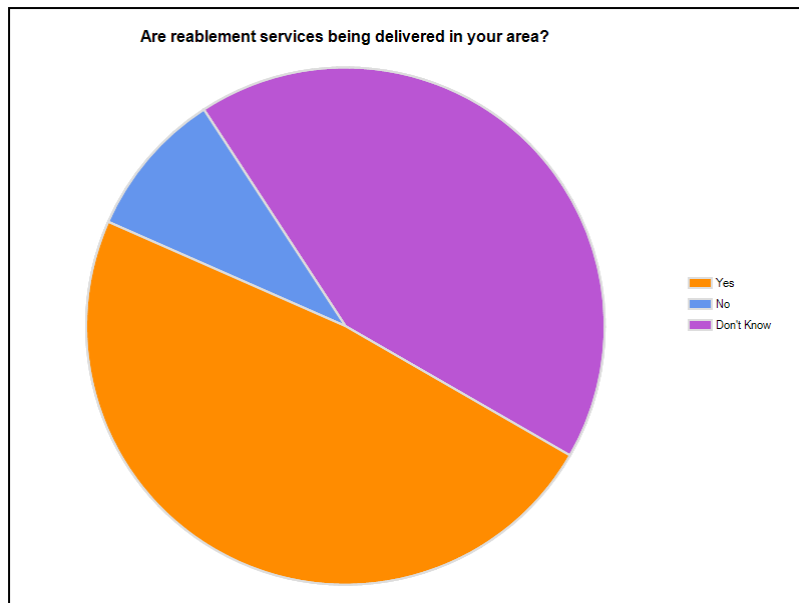
Other responses

- Private providers are thinking about providing additional services for existing customers and developing ways to bring new customers in. However, these ideas are not very well developed.
- A few could, but most lack personal initiative. This could and should be corrected.
- The places are too structured and money is pooled to make group activities mainly. So can't see how personal budgets could or would work.
- I think it could work well in enabling a resident to choose the home they would most like to live in and forcing homes to examine the services that they are offering. However, too often there are few goods to choose from and in order to maintain a reasonable level of care, homes need to be able to rely on some level of block contract, or alternatively of occurrence. This is likely to be a difficult balance to achieve. Perhaps basic care and board and needs should be block purchased whilst residents are provided with a personalised budget to enable them to purchase the activities they want to become involved with (both in and outside their home).
- Some
- That would be difficult as the council would have the contract with the residential home. It would also require the ability of residential

homes to be able to provide flexibility of support and with funding cuts this may not be possible.

- As they still won't be able to have a choice as most of the activities are planned by management with pooled resources.
- Yes, everyone has hopes, dreams, aspirations and interests that could be outside of the Residential setting... A personal budget may facilitate someone taking up an interest and being part of their local community - previously not possible!
- There would still only get the pittance of pocket money that they get now, but might have a say in how the people who live in the homes can pool their money together instead of being told
- For those with severe and complex needs the personal / individual budget is often not sufficient to meet needs
- Can be used to stimulate and provide outside interests
- Depends on the level of care needs and staff ratios, staff culture and manageable risk. Some residents could benefit greatly from increased choice and control over how they want to spend their time
- Even if a person qualifies for a relatively small budget, the points raised at the support planning stage can make all the difference to someone in a residential setting
- This would have the potential to improve the life of residential care residents, but only if accompanied by advocacy
- In theory yes, but in practice, no. Personal budgets would lead to inequality of treatment. The charging policy and funding regime would mitigate this. People who are self-funding already have their own personal budget, but it does not enhance choice other than at the point of admission, in deciding which care home to go into
- There is not enough in the pot to cover the cost of the placement and then offer something additional. This would require careful consideration and could be something for the future. Definitely not there yet!
- Would depend on who manages the budget, the individual or the residential home.
- Some, depends on individual.
- Elderly people may find this difficult and confusing. Family still expect services to be delivered. It will take a generation to undo the dependency culture but we must continue
- So long as they are not then used to pay for services within that residential care setting. If they are used as an add-on, to ensure the person then has opportunities to access the community or interests that are not catered for by the residential care unit.

Q8 - Are reablement services being delivered in your area?

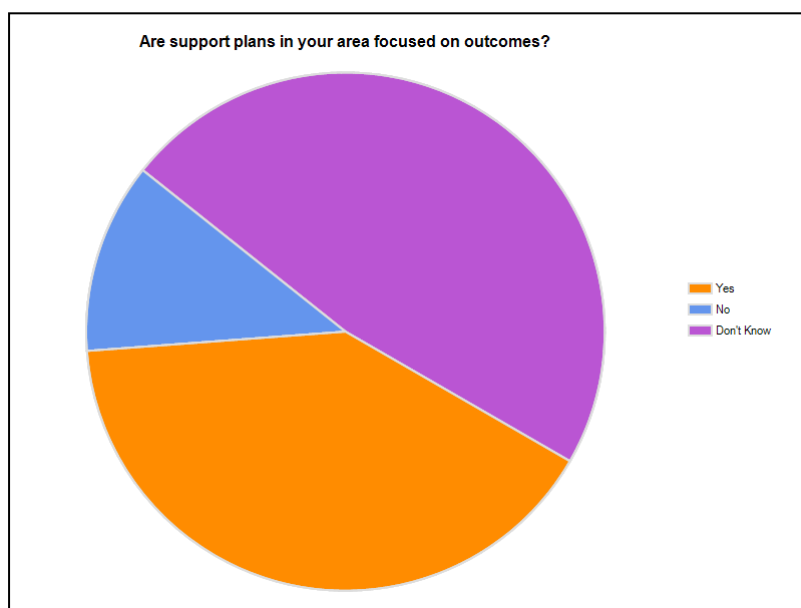


yes	48%
no	9%
don't know	43%

Other Responses

- Only on a very limited basis, however. The transition between hospital/home and independent living is a fragile one. Things tend to break down once the reablement period is over.
- Possibly, in sheltered accom. areas.
- Sort of, but not very effective as far as I can see
- Not that I know of, unless you are talking about groups of and for and being able to work together. Or maybe peer support.
- Peer Advocate support is needed to make sure that users understand what Personalisation is all about.
- But not very good
- But fewer people are now able to access it
- It is possible as a tender has been agreed recently for this service
- They are delivered, but not well-publicised.
- However very limited and with a long waiting list
- ? Not sure what these are?
- If they are, it would be very "old fashioned" kind of service.
- However, these are available only to a small client group
- We are trying to deliver these services but the way Personalisation is running for our client group (older people) is blocking this.

Q9 - Are support plans in your area focused on outcomes?



yes	41%
no	12%
don't know	48%

Other Responses

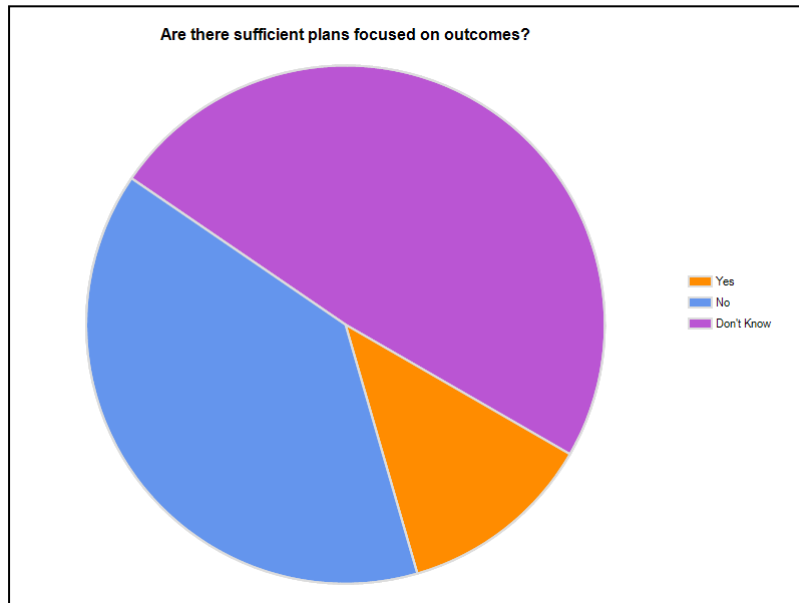
- Mine is. However, my latest audit criticised me for spending money on things which are not in my plan. I disagree because every item of expenditure was made to meet an outcome that is in my plan. There has been a change of director recently. [The outgoing director] was supportive of an outcomes -based approach but his successors [deleted] have immediately reverted to a prescriptive approach. [name deleted] used to say "you can spend your personal budget on anything legal to meet an agreed outcome in your plan". The current approach is "that's not in the FACS criteria - you can't have that". I don't see how personalisation will work under the old prescriptive regime.
- But who decides the outcomes to observe and measure? Imagination essential!
- Probably more focused on incomes.
- Support Plans seem to be focused on what the social workers say you can have and not what the disabled person wants
- Too focused on what the Social Workers remit is and what outcomes they have to achieve to make the councils targets rather than the end beneficiary needs.
- They are but not always on the side of the users. The Social Workers need to get off their backsides to make sure they listen to the user and

not just fill in the Personal Care Plan for as they think or have just been told to do by their managers.

- 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 LAs?
- Most individuals who are accessing care for the first time are unaware of their need to complete a support plan and many of these are drawn up by the care assessor, without the client knowing they have a right to input into their desired outcomes. This means that only the very basic need is met, Not the choice, control and independence that should be reflected when the support plan has been focused on the holistic requirement of the person it represents.
- They are focused around the budget and the clients assessed needs
- But only by skilled practitioners - however, there is little monitoring of this
- Only if outcomes meet the LA budgets
- It seems to be more about meeting targets for the end of year CDC report than the outcomes of individuals
- How effective this is depends on an individual and many are not aware of how to make it work for them
- Inconsistent picture. Some are, some are not. Most are focussed on maintenance and enhancing the quality of life. This is because if outcomes are achieved and needs reduce, then the personal budget should reduce too. There is too much emphasis on care and support, rather than developing skills or getting jobs. Again if this is achieved overall welfare benefits are likely to be reduced , so there is a built in disincentive to go down this line
- ... but doubt it
- But still inconsistencies between different offices.
- Would say more focused on funding availability
- At times
- Depends which way the wind is blowing and who you talk to.
- Not sure.
- Just how budgets will be spent. Not true support plans. Assessment support officers are doing social workers job on the cheap and often do not have adequate training or time to work in partnership with families to support a living plan
- They are supposed to be, but this seems to be a paper exercise and in reality they are more focused on cutting costs. People are allocated an "indicative budget" but LA policies are that these budgets should not be used in full (and staff may be subject to disciplinary proceedings if they encourage service users to use the budget to the limit). Also, if it is shown that this is insufficient to provide the care and support to meet those outcomes it is very difficult to get an increase in the budget. In fact, it is not clear how this can be done.

- Totally focussed on outcomes, outcomes of saving money not need or reflecting people's ever-changing situations
- But not sufficiently funded
- Well, 'Outcomes' seems to be the buzzword of our local authority, to be seen doing the right thing, but in practice, there are still many issues which are being ignored by those in charge of driving these changes, where the choice promised is not actually available. The needs of individuals and their careers are still being ignored and overlooked. Some in charge really do not seem to understand the complexities of medical conditions such as autism, and don't understand that very often such people do not like change and choice, but are happy with what they have and do.

Q10 - Are there sufficient plans focused on outcomes?



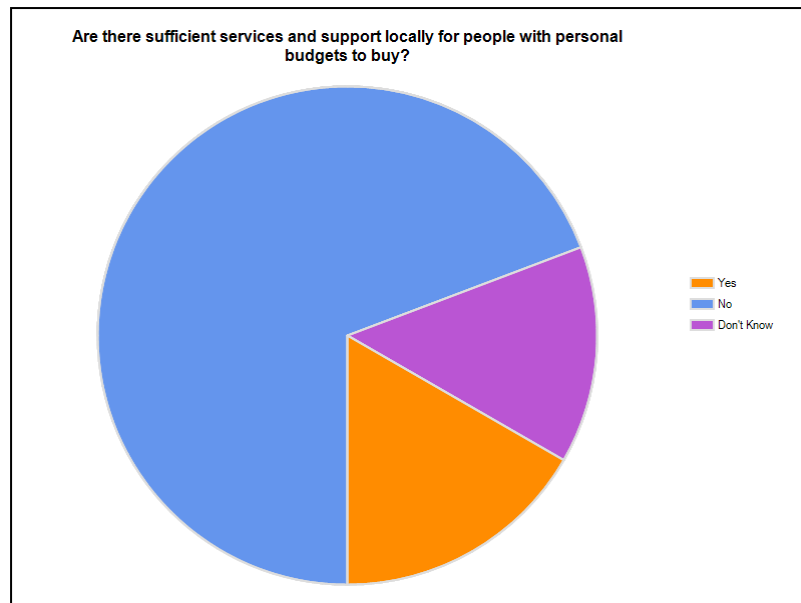
yes	12%
no	39%
don't know	49%

Other Responses

- As far as I know there is no structured training available to help people write their plans
- I can have a choice on what is written on my personal care plan and I refuse to let them get away with writing crap or jargon. There needs to be a law to ensure that the full PCP is filled in with the full consent and backing of the user.
- 'Outcomes' would be another example of your use of jargon which ordinary people don't use.
- I don't think so
- At the moment, support plans vary greatly in relation to outcomes. It depends on the individual social workers understanding of outcomes. They could do with more guidance on this part of the support plan.
- Not in my experience of talking to people who have been assessed within the last twelve months.
- Poor skills from qualified and support staff
- You would have to ask the Council for their opinion
- In the main there is a lack of vision or ambition for reasons stated in the last question. The main focus is on the here and now, maintenance and safety and security
- All plans should be focussed on outcomes. Still a little way to go!
- Plans, but don't always get followed through

- Don't know but highly doubt it!!
- Too much focus on finance rather than outcomes
- Outcomes on paper are not always reality. What is an outcome, I think it relates to a person as a die job? It should be plans focused on success, happiness, inclusion, ability to lead normal lives, opportunities. These are people with feelings, not building works. Attitudes of Social Services (not all) need to drastically change in which way they deliver services

Q11 - Are there sufficient services and support locally for people with personal budgets to buy?



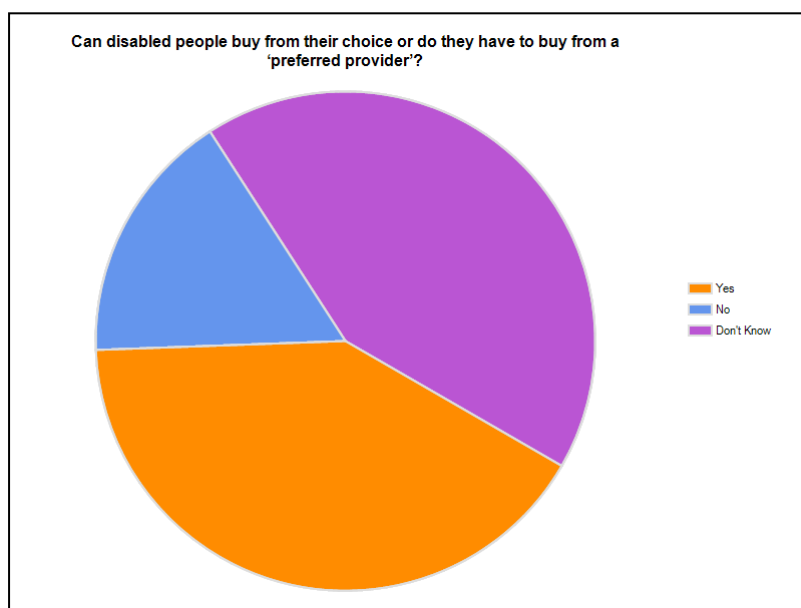
yes	17%
no	69%
don't know	14%

Other Responses

- As I said before, some private providers are thinking about providing new or enhanced services but there is not much out there. Neither is it possible to independently buy services from the NHS (e.g. the bathing service).
- In theory, if you can identify them, and they have the quality
- Obviously LAs are restricted by budget cuts.
- Disabled people who have the power of spend can still only spend where they are told to but at least they do have a few choices more than they did. The dreaded list. Where is the power of choice?
- There is choice - but not always allowed to use a service. People need to have the choice to choose openly.
- As long as the council are benefiting they are but otherwise it is proving difficult
- Absolutely not
- Market development is required particularly around new innovations however this will not happen as LAs are not agreeing creative use of funding
- Don't think so
- There are many different types of services and support for people to buy if they have the flexibility within the package to do so.

- No, I wish I could get more £££ so that I had more choose, fed up with the preferred providers list and not being able to use budgets in the way that I wish I could.
- Paucity of services, especially for home support
- Can't even get a personal budget sorted.
- There is a scarcity of PAs who can sign. [i.e. use British Sign Language] However, this has the potential to improve through the local Deaf communities. Specialist placements (fully signing environments) are currently full and there are no local community resources that have fully accessible communication for Deaf people who sign.
- Currently directories are being gathered but not enough but it is very 'chicken and egg'
- Yes, but people are not always given that information from which to choose.
- There are sufficient old-style services aimed at maintenance, but few mainstream services aimed at building capacity and ability
- The local authority could better support VCS organisations that provide personalised services for disabled people. This support could simply be about passing on information or providing access to people who have personal budgets / direct payments
- The market is still very much in its infancy although I am excited about what the future may bring and there is some innovation in places
- Too many strings attached, too little money to buy the services *i.e.* money per hour given does not meet how much a service would cost
- At least I and so many other parents do not get notify and been told in details about this....
- Yes but some to the long standing disability organisations have a cartel in St Helens so that new social enterprises cannot offer services - this is not in the best interests of disabled people
- No job opportunities No peer groups All seems leisure-focussed, needs life skills and life experiences and communication, health and safety training and vulnerable people need focussed long term on-going support, Housing, transport, PA choice needs overhauling
- Restricted choice

Q12. Can disabled people buy from their choice or do they have to buy from a 'preferred provider'?



yes	41%
no	16%
don't know	43%

Other Responses

- Theoretically we have been free to choose but there is, in reality, rather limited choice or no choice at all
- Probably. I recruit and employ my own PAs.
- Mostly by choice so far.
- Preferred providers list
- Yes the dreaded list, which excludes groups that wish to give people choice and variety in their lives. The list also seems to be closed and no details of how you can become a preferred provider and get onto the list.
- The council will only give you a choice off their list.
- I originally answered "yes" but realise I do not know whether this is true across all the areas covered as so few people are actually getting personal budgets (or indeed direct payments). Finding individual PAs very problematic for some and there is little practical back-up when things go wrong.
- Steered towards 'preferred provider'
- Own choice but feel they are directed to certain providers
- Preferred providers list that seems to be impossible to try and get onto at present
- When using Direct Payments - you can buy in services but my experience is that L/pool Social Services try to guy you to Preferred

Providers - that are the cheapest often and don't provide the quality of service that many disabled people require - emphasis on social model etc.

- In theory however preferred provider lists are circulated and recommended even down to choice of broker
- If people choose to take a direct payment then they can choose who they wish to buy services from. The local authority would not pay more than the £11.96 per hour rate that preferred providers charge unless exceptional circumstances. so the service user would have to make up the extra cost themselves. If a service user wishes to remain on the care managed pathway then they have to use a preferred provider.
- It depends what is to be purchased e.g. care can be purchased by obtaining a carer of their choice but many have empower cards and can only purchase other services from a 'preferred provider'.
- They can buy from a choice if access it via a support service. If arranged by the local authority it is via a preferred provider.
- We need one point of contact and you never see the same person twice so how are we supposed to have a choice.
- They can purchase their own support, but it is extremely difficult to access
- But little or nothing available locally appropriate to needs.
- Providing the provider is able to offer the service at the cost of the allocated funding. Costs, for specialist services for Deaf people are generally higher.
- The cost is too much
- No-one is on a personal budget they are running themselves so who can say. They should obviously be able to buy from their choice that is the whole point of Personalisation but the restrictions of each council vary and we have yet to see Blackpool's.
- Some people have their preferred choice others are pointed in other directions for best value!
- Preferred provider
- My opinion is it will depend on the person supporting the disabled person to complete care planning and their knowledge about what is possible and where people can buy services.
- this is economically led, NOT quality
- In theory!! Although there is still a need to consider Best Value especially within the current financial climate.
- Sometimes
- Choice, although most people go for an established provider as there clearly isn't enough choice or support
- Yes but fewer hours as local rate does not cover it
- I'm guessing preferred provider
- They have to buy from a preferred provider. Good reasons have to be given as to why they are not using that provider.
- Believe they have to buy from preferred providers
- The disabled person needs awareness training and support to make their own choices as do the carers involves in the support of them. There are completely different wants and needs from disabled person

and the carer, but both need a lot more support in different areas. Question is are preferred providers delivering a personal service which is what the goal is from Personalisation or is it basically shifting the goal posts again

- We should be a preferred provider as we are partially funded by the council but we have lost a number of our clients who are going to a similar service which is fully funded by the council but more expensive than our unit cost. This does not make financial sense.
- This is one of the conflicting issues

Q13 - What do Councils need to do to ensure that 100% of eligible people have personal budgets in your area by 2013?

- Inform and involve people and organisations to advise and promote personal budgets. Have sufficient literature and enable people to have the knowledge of who to contact around personal budgets.
- Contact them all presumably.
- All carers identified and good care packages in place
- Advertising
- Expand their understanding and concepts across all staff
- Bring back the time when direct payments are personal budgets started as the pilot as the pilot was successful and disabled people felt as if they were given the choice and control that they needed to enhance their lives.
- Find money in their budgets to enable each disabled person who wants to go get individual budgets. At present if everyone applied there wouldn't be any money in the council's pot to fund the increase in spending.
- They should tell the social workers to have a meeting with the user's wider networks. *i.e.* carers, family, and groups they attend. They make the whole process easier and move the process forward to the future.
- The County is attempting to look at personal budgets at case reviews, but staff still needs more training. Also in the light of budgetary cuts and the loss of services within Adult Social Care and Supporting People there are fewer services available which people can use their budget on. The more services are forced to close before personal budgets are sorted the less choice there is. Also budgetary cuts mean that people are not encouraged to think 'outside the box' to over activities. More brokerage offer to take place.
- Starting them would be a beginning! So far very few known to our organisation (dealing with people with both physical and learning impairments) have one, except for someone in Sefton who has been advised she will have one and has no idea what it means. Given the difficulties people encounter with Personalisation and social care, it is of great concern that the government is talking of extending the model for parents in relation to additional educational needs. These comments sound negative but come from someone who was evangelical about Personalisation when it started.
- Ensure the process is understood by staff and clients. To provide a help service / helpline to clients for troubleshooting, to ensure that there are responsible vetted services for people to use their budgets with and that they are advertised in a place where people on a personal budget can easily access. For social care to still have responsibility for the budget and the practicalities of using one, rather than this coming out the person's budget.
- Have simple system that carers can understand
- More info available to the general public and families who have contact with disabled within their families.

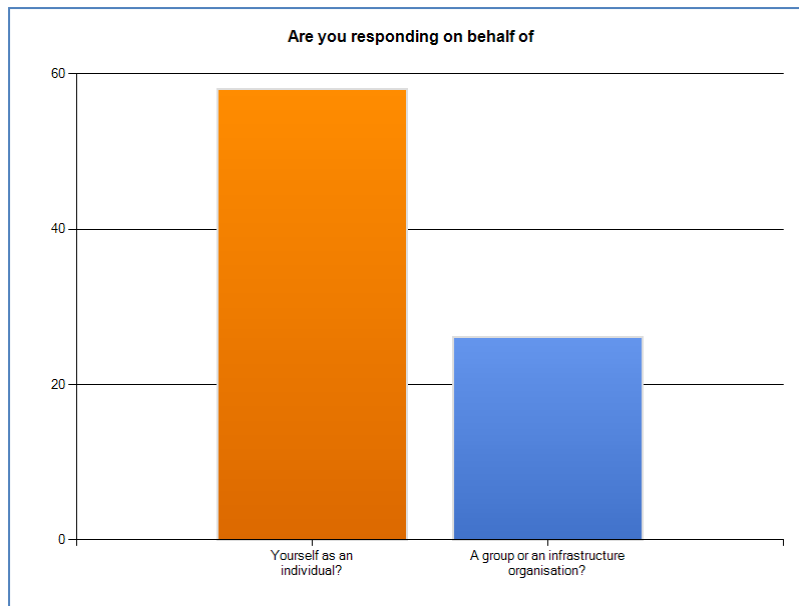
- Provide honest, independent and reliable advice. Provide money up front for people to get their plans written properly. Abandon their bunker mentality and get back on track with an outcomes-based approach.
- To ensure that all service users are reviewed and offered the opportunity if they have not done so already.
- Tell us what we're entitled to. And explain the jargon
- Start listening to the disabled people and get social workers who are trained to a higher standard and the will listen to a person's choices. I can't see this happening as they don't have anywhere near the budgets needed to get all people who need support onto personal budgets now so can't see that happening by 2013.
- They need to do their homework and all sing off the same page
- Appreciate that people using services have enough intelligence and can find the support they need from independent organisations that are best placed to support this process. Not everything has to be done by social service and neither should it be! There are some great organisations in the voluntary sector!
- Don't know.
- Spread the word and do it.
- Develop a centre for independent living
- Keep up-to-date with annual reviews.
- Easy to say 100% will have personal budgets. however we need to dig deeper and scratch the surface, many people have restricted choice, receive poor advice and support often with a negative slant. Real culture change supported by legislation along with peer evaluation which is validated and made public in addition to real co-produced managed and monitored systems particularly around financial management and audit that are proportionate to the level of risk identified. ULOs and disabled people with real lived experience that are adequately supported and funded to provide support to organisations and individuals
- Provide clear guidance and literature that is accessible to all ... a social workers, service users or voluntary sector organisations. More promotion of personal budgets.
- Start working closer with the client to make sure all of the options is offered and adequate support is provided.
- Put more money into the system and make it more user friendly and easier to understand,
- Give us more money to get the overall support that we require instead of cutting our direct payments back to just personal support only, which gives us no money to do anything else.
- Stop using it to buy people cars, reduce the admin side as this is too time consuming and takes away from the actual focus
- Not sure
- They need to keep you informed and need to keep in contact with you. People are being ignored.
- Facilitate the development of more specialist provision in liaison with the voluntary sector.
- Make sure they go to forums and speak to local people

- Provide the staff and funding for staffing to put this in place, plus make sure there are services that people can buy into.
- Provide more support and fund ULDPPOS [User-Led Disabled People's Organisations] to support disabled people to run them
- Ensure that frontline staff is fully trained and aware of the policy and procedures.
- Employ people who are interested and willing to help disabled people
- Speed up
- Provide more information and support and train the social workers up to have a better understanding of the word personalisation
- Councils should use improved publicity, ensure that Health Watch is independent and sufficiently well-funded to meet advocacy needs, provide effective training for social workers
- Conduct the relevant assessments and speed up their internal processes
- The question is, is everyone treated the same? Do we really understand Personalisation?
- Communicate a lot more and provide more support for individuals and organisations to help people through the process
- More publicity
- Provide a support infrastructure for those who do not have the ability or already such an infrastructure in place, to help the individual identify opportunities and suitable resources, which might help them, and organise the purchasing of those resources and administering and accounting for the use of the personal budget. This is absolutely essential for people with dementia, who live alone or with frail elderly carers, and those who lack the mental capacity to manage their own affairs
- Ensure that there is plenty of community advocacy available particularly when a crisis hits or problems occur. Currently this service is beyond capacity.
- More promotion, external evaluation of what is working well and not so well and more support for those who have trouble tackling employment issues.
- Invest in their assessment resources. Provide access to advocacy.
- Speak to people
- The increasing able Voluntary sector to mentor/broker services ,, It will be cheaper and more successful in the long run. Another thought is to fund pass it on planning [? Personalisation planning] for groups via the voluntary sector or the small groups (mainly unpaid family carers) now uniting together who could do independent plans for presentation to the LA for personal budgets! This would cascade out and create more self-reliance rather than the gift relationship which LAs have fostered for so long. Front line workers often still don't offer direct payments instead of day opportunities for example....or they need to weed out the workers who don't get it and pay more to fewer more competent social workers who do get it and thus manage higher caseloads efficiently, reduce higher management and stop reorganising!
- Provide the care that the personal budget will provide.

- Ensure that all reviews take place. There is no other offer on Wirral other than a personal budget.
- Deliver information
- Instead of just 'consulting' have disabled people as representatives with the decision makers
- Change its culture, relinquish power, invest in disabled people, support our organisations
- Understand it and work with current ULO [User-led organisation] who has been delivering services for 20 years - NOT to bring in providers from outside of town as they have done with our Carers Centre services.
- Better information for service users, more involvement with vol sector services
- Put in the right sort of support to enable people to manage and use personal budgets effectively. Remove some of the responsibility for 'back office, recruitment and line management'
- Make information accessible to all, offer support in applying and accessing services people really want. Seek out people who need support and help them.
- Look at other successful examples nationwide - then be far-sighted, flexible & prepared to try things outside the box!
- Be consistent and confident about knowing the facts. Understanding two sides of the coin.
- Follow their own guidelines instead of fobbing people off.
- Have disabled people run the service. Have disabled people and families tell others about the benefits of personal budgets. Do it right.... get the proper support for individuals and families with health needs and communication needs as a priority
- I think needs more advertising esp. thru the school our children are attending, tell us about courses or meetings that explain stuffs and teach us what to do *etc.* ... also advertise on TV, paper, radio *etc.*
- Consult more with carers groups and ensure the sufficient funding is available
- Lower threshold criteria, as currently only Substantial and Critical are what is known as FACS eligible (Fair Access to Care) and therefore receiving a personal budget. False economy as what preventative work is being done? Carers reach crisis *etc.* Fire fighting comes to mind
- Ensure a clear process is in place. The system in this [LA area] is complex, lengthy and not user friendly. It is more for cutting costs of providing services and has lost the original values that personalisation was meant to introduce.
- Publicise more, invest in information and support services to make access easier
- Address the issues outlined here and in correspondence/meetings with them. We seem to be no further than we were almost a year ago.
- Be dedicated to understanding different disabilities warrant different support encourages flexibility. Prepare for change on-going at all times, respect the customer and assess the carer as a carer in their own right, look at their needs away from the situation *e.g.* what would the carer be doing if they did not have this responsibility?

- Listen and be honest
- Get the ball rolling and get young people on to transition and support plans and assessments on the go. Have been waiting years for transition and months and months for child budgets and I am on the first cohort of parents.
- Have a register of all those who qualify for personal budgets.

Q12 - Are you responding on behalf of yourself as an individual/group or infrastructure organisation?



as an individual 73%
on behalf of a group or an infrastructure organisation 33%