

Right to Control Consultation: Short Questionnaire responses

This document contains full responses to the Right to control consultation from those people who completed our short questionnaire.

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Question 1: What support do you receive that you would like to have more choice and control over?

- I do not receive any support financially or otherwise, my family do this for me.
- I already receive direct payments, but would like to be able to access the funding I get from Access to Work, Disability Facilities Grant and health services.
- All my funding comes from the ext fund therefore I have total control. Long may it last. I couldn't bear to have it dictated who/when.
- More say on charges.
- None. Independent Living Fund is fine.
- I receive support from Community mental health services. I would like to be able to choose to attend a user-run art project which is in a nearby borough, but my mental health team will not fund this, but says I should attend an art group within the borough instead.
- Interpreting services - To be more widely accessible and frequently. I don't really receive any support voluntary it is usually months years before something I request is granted or refused.
- I have complete care in a residential home and I am very happy as I am.
- We are a day service for adults with physical, sensory, learning and communication difficulties. We are funded by Rotherham Social Services.

We would like our funding to continue next year to enable us to work with our service users to help prepare them for taking control of their personalised budgets by helping them understand the processes and systems by providing training to

them, to enable them to learn to do as much as they can for themselves once personal budgets are introduced.

In addition, we would like to work with our service users to move them away from thinking about 'day services' and start thinking about the 'holistic support' they will be able to choose from in the future, and how they can use the opportunity to open up new life choices to them.

We would like to undertake 'pilots' and move some of our service users forward to 'try out' their choice of personalised services to demonstrate how well the new system could work out – and then roll it out to everybody who uses our service (taking an incremental approach to introducing personalisation, rather than people having to experience big changes, which they will find difficult to cope with).

- Hearing aid service also the information given to hearing people about integration of Deaf people in the community.
- Direct Payments ought to be used to be able to pay for a PA's flight to offer assistance abroad. More control over appliance provision & wheelchairs.
- Although line manager is aware of the fact I'm hard of hearing I receive no support in terms of enhanced telephony equipment & although Fire plan has supposed to be changed to ensure I get a buddy in case I don't hear the fire alarm I've not as yet been advised of who that buddy is. (I am also a Fire Warden!).
- Other than a Concessionary bus pass and free prescriptions, I don't. My epilepsy is Semi-Stable and I work. Therefore I don't receive anything even though I'm on what I consider a low wage.
- I have a 5-minute meeting once a week to gauge how I'm feeling and nip any stress in the bud so it doesn't build up and cause sick absence due to stress. There are 2 female managers who do this with me, but if either is absent and the other is very busy, it can be difficult, especially if I have

something on my mind and I need to discuss it, and I'm having to wait 3-4 hours, say.

- The support I receive at work. I want to work but sometimes, bodily, I can't move so getting to work is a problem. The rights to work from home within my job would be the best support I could get.
- Everything, from interpreting should be level 4, and down to personal choice, and have to compromise for hospital appointments and delay hospital appointments cos need interpreter. And aids and adaptations are rubbish from social services, should be better.
- The way that I am treated by line managers, who will assume that because I have a disability that I am stupid, they will either try to wrap me in cotton wool or push my wheelchair they wont let me have a go, I will make mistakes but I am human and I can learn from mistakes that I make.
- The actual amount of DLA received. I chose not to receive this entitlement, as I was and still am working, and was informed that as I am covered under the Disability at work Act, I did not need to. But I did claim Disabled Working Tax Credits. Last year, I was told because I did not claim DLA, I should have not have claimed the Tax Credits, and was told to pay three years of credits back (which I am doing). I want control over what I can claim, and correct guidance of what is allowable. I find it psychologically difficult to claim DLA because of my self perception of the stigma in claiming it! Also, a lot of the DLA questions on the form are irrelevant in my case and I found too intrusive- surely a doctors statement from an occupational health Interview arranged by the DWP (I was working for the pension service at the time) should have been enough? Though I am manic depressive, I just want control to be able to get on with my life without too much intrusion. I still have not applied for DLA (care).
- I do not get any support at all. But if I had the choice or control I would make sure I have better choices over treatment etc.

- ILF more flexibility on what it can be spent on and who it can be spent with. E.g. Carers must be self employed, and cannot be family members living in the same household. Family members are the ones that know the disabled person best and how to handle them so why can't they be funded?
- I used to receive DLA but it was taken off me because of a physiotherapists report. A long story spanning several years. I would like more control over the assessment of this benefit. The current set up does not, in my view, treat the person with dignity or respect. If I could I would change the criteria for being awarded the benefit to one that is based on the individual living at the "best" level of health for them and then the continuing benefit would be monitored on evidence to support this. Say the person is obese and has poor balance. I think they should monitored quarterly evidence gathered to show that they are losing weight and that their current meds are checked for compatibility etc.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, Employment.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers.
- Housing, DLA Benefit, Employment.
- We need more benefits, Housing, Independent Living, Transport, Carers, Employment.
- DLA Benefit, Employment.
- Anger Management, Independent Living, Counselling, DLA Benefit, 24 hour staff, Health Care.
- Housing, Carers, Counselling, Independent Living Benefit, Transport.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, Employment.

- Anger Management, Counselling, Carers, Employment.
- Transport, Dial-a-ride, Employment.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, employment.
- Independent.
- Independent Transport, DLA Benefit, Carers, Citizens Advice Bureau.
- Counselling, Independent Living.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, Employment.
- Housing, Independent Living, Carers, Counselling, Employment.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, Employment.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Carers, Going on holiday where I want to go.
- Housing, Independent Living, Employment.
- Housing, Employment.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Employment.
- Housing, Employment.
- Housing, Employment.

- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers.
- Housing, Independent Living, DLA Benefit, Anger Management, Transport, Counselling, Carers, Citizens Advice Bureau, Employment.
- I receive a personal budget to enable me to employ my own personal assistants. I should like to be able to pay one of them to accompany me occasionally to events concerning disability issues. I also have a powered wheelchair supplied by the HNS Wheelchair Service, and I should like to be more involved in the choice of wheelchair, and the freedom to have it repaired locally if the Wheelchair Service cannot attend in an emergency.
- Care to live at home. Yes I would like more choice and control.
- I have a support worker at work partly funded by Access to Work, which gives me invaluable support, but I am restricted to what duties I can ask of him/her. My employer contributes a small amount to his/ her wage. My employer makes a bit thing of how much they contribute and how grateful I should be as a disabled person to receive this support. I find this demeaning and would like not to have to go cap in hand to my employer to ask for this support, and have full funding from Access to Work for this.
- My choice of carer as opposed to not knowing who or if they will arrive on time or not at all. E.g. Help with getting up, getting dressed, breakfast etc...
- Benefits after an accident at work, because of damages received after a Court Case. Over 10 years living off this money and refused Benefits by Warrington Borough Council. Disabled for life, and now DISCRIMINATED AGAINST. Because I have been prudent and have my money tied up by Legal and General. I will lose £20,000 if I try to cash it in and they have been provided with all the evidence, including evidence that it took place at work and have shredded all my records of my working life. I bought my own house two years ago to get away from my family because of my constant mood swings and they

also want Council Tax, surely some things absolutely wrong , and I have also lost my contributions for my retirement. It appears to me that one needs to fiddle the Benefits System and one would never have a problem.

- I manage the Direct Payments account of my adult learning-disabled son.
- "Consultation group members noted that there were some very complicated discussions between parents and social workers that they were not necessarily involved in. This can lead to misunderstandings and delays which they felt needed sorting out.

Some participants became aware in discussions about the limitations their local authority placed on their lives because of restrictive rules on emergency medication and the location of activities people using services are permitted to participate in. These restrictions were felt to be unfair.

A number of participants lived in their own tenancies and became aware in discussion that their local authority was considering taking on the leases of their properties to maximise income. Participants were concerned that this would have a negative impact on their independence.

Some participants were happy with the services they have already; others were prepared to consider trying out new arrangements that would give them more control (so long as they could revert to existing arrangements if things didn't work out); the responsibility of having control weighed heavily and one participant would not consider changing even if things would be better; a number were concerned about managing staff and.

"I like things the way they are although I want more staff since they can't do things because there are not enough staff." (Lots of people said this.)

"I wouldn't mind trying to manage more as long as you could go back if you didn't like doing it."

“It’s a big responsibility that I don’t want even if it might be better.”

“It is good to have Sense Scotland providing the service and staff. They provide sickness and absence cover.”

“It is good to have staff for emotional support.”

“I have tried different types of accommodation to see what suited so was able to decide to live by myself after trying others.”

“I want a garden with a swing and trampoline because I get bored in the house but I was told that this is for families and a flat is best for me. I go to a drama group to get out but there are no breaks so I can’t socialise.”

“I like the house I’ve got.”

“I like my new house better than (the hospital I lived in).”

“I am very pleased with Sense Scotland staff providing services.”

“I know friends who get direct payments and have difficulty in getting and keeping staff.””

- Sign Language access to my local authority services
- Direct Payments and Access to Work [ATW]. I need ILF funding and it is ridiculous that there are two organisations [SSD and ILF] involved in funding personal care support.
- Communication support
- Direct Payments/Individual Budgets.
DLA.
NB. I would keep these two things separate as it minimises the possibility of people falling through the safety net and maximises the flexibility of what money can be spent on.

- From a work perspective, a support worker for the 30 hours I work, and the ability to combine this with transport from the support worker (rather than relying on a taxi to and from work). I would like to choose my own support worker and control the budget for my own support worker rather than receiving support worker services from an agency arranged and paid for by DWP.

Training in the use of long canes, personal assistance through Access to Work Scheme. As a blind person I would also like to receive the full mobility component of the Disability Living Allowance. Although this is now agreed my understanding is that it is still not going to be paid until 2011 which is too late for many blind people.

Re the AtoW scheme, this involves purchasing equipment to enable me to do my work. Owing to lack of information about what is available and which products would work best for people like myself, I have often wasted my own (and the State's) money on equipment that had already been improved on. Info. about equipment availability and suitability is essential.

- Independent Living – Direct Payments & ILF co-ordinate better so being able to have one set of accounts, coordinated payments. ILF assessment process (once every 2 years) is good as my needs do not change very much.

Wheelchair services, more control to buy appropriate chair.

Maintenance of adaptations are poor in LA so support to enable me to do this.

- BDPA would like to have access to some resources and formal recognition for our work
- EJF would like to have access to some resources and formal recognition for our work
- Involvement in day centres (review and provision). Cooking and Shopping: I would like to be taken out to shop by my carer or support worker, I would like to cook with assistance or help. Social Activities: Swimming to improve fitness, which in the long run supports my independence. Housing: There is not a lot of housing available where disabled people can live

independently, Sometimes people are being told they are not a priority or they are adequately housed, so they can't move where they would like to live. Some people don't seem to have a lot of choice if they don't have enough points and achieve a high score on the list of eligibility criteria.

Question 2: If you could control the funding you receive, what would you do differently?

- If I could control any funding, I would have this paid direct to family members, as they suffer more than I do.
- Regarding Access to Work, they have supplied me with a lift that lifts my wheelchair onto my car roof, so I can be independent and work. However, they are not prepared to help with repairs to the equipment (over £1000 this year alone), but will consider buying me a new one (over £3000)! This seems a ridiculous waste of money and I believe I could have got better value for money with a more flexible package. I would also like to be able to access a personal budget for my NHS wheelchair as again I believe I could have got a better quality and more reliable chair. The wheelchair voucher scheme is a waste of time, badly organised and doesn't do what it says on the tin!
- See above (Q2).
- More freedom to choose how I spend my funding.
- Nothing.
- I would pay to attend the art group which I prefer.
- No control but require a budget for personal care.
- Due to complex needs would like full control where my money is spent.
- Use it to improve my communication skills with the hearing world.
- Nothing.
- We would ask for a further years funding to undertake the work.
- Look at charity originations to identify the needs of the local community.

- Abolish charging or at the very least take the whole expenditure into consideration rather than 'disability' expenditure only.
- An awareness exercise to make people aware there is funding available to assist them.
- I would review the threshold for the Disabled Tax Credit, and the differences between how bad you have to be to claim DLA.
- I don't know enough about it, but I feel there is still a stigma to mental health disabilities as they are invisible, and they come far down the list of priorities. Also, people like me are not expected to work and have a mortgage, they are encouraged to draw benefits and sit at home drinking coffee.
- Maybe use more of it for work. It is good for the soul to 'feel' normal.
- Definitely need deaf broker to ensure accessibility from the start to end if I can't cope with it.
- I as yet have received no funding, I have only recently been diagnosed, and am awaiting reports to aid my work. I would like to be able to have a say in what measures are put in place for me not told what is going to be done with out my input.
- Use it for a support group.
- See above (Q1) - make sure I was receiving the right information, and have the choice to claim DLA or Disabled Working Tax credits as a stand alone.
- I would make sure that facilities were a lot better than they are.
- Use the funding to buy additional and a more flexible respite care package. E.g. cannot use ILF monies for Respite Care.
- I would award myself DLA from my first application. Long story.
- Shopping, Going on holiday where I want to go, saving my own money, buying myself things, shopping when I want.

- Shopping, going on holiday.
- Shopping, Going on holiday.
- To get more money, to get more holidays.
- Holiday's where I want to go.
- Local council.
- Shopping, going on holiday.
- Shopping.
- My carers. Buy parent's holiday.
- Parent's holiday.
- Shopping, Learning to drive, going on holiday where I want to go, Local Council.
- Local council.
- Shopping, Going on holiday where I want to go.
- Carers.
- Shopping, Learning to drive, going on holiday where I want to go.
- I can go to friend's house with my carers.
- Shopping, Learning to drive.
- Mum and Dad.
- Shopping, Learning to drive, going on holiday.
- Learning to drive, Shopping, going on holiday where I want to go.
- Pay for my driving lessons, learning to drive.

- Shopping.
- Learning to drive.
- Shopping, Learning to drive, going on holiday.
- Shopping, Learning to drive, going on holiday where I want to go.
- Use some of the funding for Dental Care. I have not had a dentist since I came to live in Spalding as the only wheelchair accessible premises in this area do not accept NHS patients.
- You would get carers that wanted to work for you.
- Nothing, I have specific carer who knows my needs and is just wonderful.
- I do not receive any funding whatsoever other than my Disability Allowance from Blackpool and £100 per week off the Interest of my own savings to run a home on my own.
- I wouldn't do anything differently at present, but I would appreciate an end to the paternalistic monitoring by the local authority.
- Most participants did not know how their services were funded and wanted more choice about the kind of service they received regardless of how the funding was organised. Some would be happy to try controlling their funding and services but others were worried about the responsibility.

“I'd like to use money to get support for work.”

“I'd want to use the money to be able to choose a different house.”

“If there is another change will councils use right to control to save more money?”

- Purchase a videophone so I can use a video interpreter to access my local authority services at any time rather than only one afternoon a week(!) when there is a sign language interpreter available.
- I would be able to have more flexibility and therefore be in greater control and be able to plan Personal Assistance [PA] help more effectively.
- Increasing opportunities for communication support
- Direct Payments/Individual Budgets, I would spend it on things that improve my health, my general quality of life and increase my independence:
 - e.g. I would rather be able to buy good quality prepared food than having to pay someone else to prepare good quality food in my home which I find invasive and more expensive. (my symptoms are drastically affected by diet - and I became ill after agro-chemical poisoning while bike riding - so good quality organic food is very important and very expensive)
 - e.g. I would pay for a private clinic and the tests and supplements etc they have recommended - as there is still no treatment, thorough testing available for my illness on the NHS
 - e.g. I would get a stair-lift installed between my own and my neighbour's house so I could "go out" more.

DLA:

I would allow for people's GPs to be able to set a time frame for when the next form should be filled in.

I would allow anyone with an illness which is significantly affected by adrenaline/stress at least a year longer between reassessments to allow for improvement.

I would include a "has anything changed in your circumstances/illness" tickbox and if the answer is "no" I would not need to fill in the rest of the form again.

In the event of a change in DLA award I would allow a 3 month period before all other benefits were reduced in line with the new award to avoid the huge stress placed on people of a suddenly reduced income at the same time as trying to launch an appeal.

(I started filling in my last DLA form in July 2008, it took 6 months to complete and then another 3 months to appeal the decision. It is now September 2009 and I am still not fully recovered from the overexertion required to fill in the form and appeal ie my health was significantly negatively affected by the process to the extent that over a year later I still feel more ill than when I started filling the form in, and am struggling to get my activity level back up to where it was in June 2008)

- I would effectively remove the need for a 3rd party (i.e. an agency), hence, this would potentially be more cost-effective to the department.
- I would ensure that I made the right choices and maximised my productivity.
- The current proposals are not radical enough. I do not live my life in boxes, so it shouldn't be my concern to box my needs in this way. So it wouldn't be in boxes. Once I have met the criteria and demonstrate that I can manage reviews and assessments should be a) if I feel things have changed and b) reviewed by annually.

I'd like to know my care package can go wherever I go, I am thinking of moving from one area to another due to work, but I'm not guaranteed that I'll get the same level of care. This is wrong.

- BDPA will Activate the "Buy-The-Money Project" as a tool for work.
- EJF will Activate the "Buy-The-Money Project" as a tool for work.
- I would do things I like doing, without having to worry if the money could actually be used for these activities. I would

choose who would support me. I would choose a care worker I would really like and get on with.

- And what would they like an opportunity to do – bowls, sports, going to Blackpool, art, arts and crafts. People expressed a feeling that “going to Mariners is not a life.”

If you don't have control you have to put up with the idiosyncrasies of care assistants and care provider companies, e.g., it is difficult to persuade a provider not to send an assistant with strong body odour.

If you don't have control, you have to live your life within the daily operations of the care provider, e.g., being expected to be prepared for bed at 6.30 p.m. One user commented pointedly that “it is as though the care system had been taken over by the Kremlin.” However, users complain that even when they have control of the budget strings, it is still difficult to request a more flexible response if they want to go to the theatre, etc, in the evening..

If you have your own budget, you have the freedom to go where you want, e.g., swimming.

Those people who have tried Individual Budgets feel more in control, even though you have to manage your own care provision.

Some Users like the idea about employing a family member rather than the money given to a carer who they don't know or trust. But, others said that family members might seek to control their disabled relatives. However, it depends on the checks and balances that are put in place.

Question 3: What help do you think you would need to take up the right to control?

- I would like somebody to listen properly and make informed decisions.
- The support of an organisation run and controlled by disabled people would be very useful. Many of my friends who live in a nearby authority have such an organisation and get great support and a quality service. Unfortunately, in the East Riding, the support services are provided by non disabled organisations and people and they do not have the independence, understanding of the social model or the willingness to challenge the local authority when required.
- Personally, none. Brain still working!
- Advice and a contact officer.
- Just advice, but not needed.
- None. I have a master's degree and am quite capable of handling the money and doing the administration.
- Formatting as government documents never come in 24pt
- Advocacy.
- It would be lovely to be able to have latest communication aids such as text link, digital top of the range hearing aids, home appliances for fire/phone/door/security that are wireless free.
- I don't know.
- We cannot help prepare our service users to make the most of the new personalised budgets until we have information about the systems and processes involved. When we have this information we will be able to train out service users in the process and empower them (to their optimum level) to take control of the parts they are able to manage for themselves.

- Very little perhaps a couple of work shops
- Information on any legality.
- For more people to be educated that mental health disabilities are manageable, with the right medication, and people like me can live a full and happy life.
- Advisors / Champions.
- Deaf broker.
- I would like people to take the time to learn about my disability, how it effects me and how it effects my work. I have numerous problems and there is very little or no understanding of my condition or very little want to understand. I would like to be the voice of people with the same problems as me, to take it to workplaces everywhere and help to give a broader view and encourage other people to make the best of what they can do and not focus on what they can't do.
- Mentoring to set up this group
- Not sure - possibly focused support from a case worker who knew me.
- To be able to take up the control would be handy first.
- Need someone to organise and administer the provision and funding.
- The opportunity to know what is being discussed, given relevant info and the opportunity to take part in the discussion. There are all sorts of control and I would like to think that those making decisions that would affect me are in some way qualified by experience rather than paper.
- My family, Teachers, Uncles, Brothers, Sisters in Law, Aunties and both Cousins.
- Local Council.

- Parents and Teachers.
- Local Council. Family.
- Carers.
- Where I want to go, Carers.
- Parents.
- My parents.
- My parents.
- Teachers, Parents.
- My Brother.
- Teachers, my family.
- Carers.
- Teachers.
- Teachers, Carers.
- Mum and Dad.
- Mum and Dad.
- Teachers.
- My Family.
- Teachers and Parents.
- Family.
- Family.
- Teachers.

- Teachers.
- I am not sure, but I should need to be appraised of the legal and regulatory conditions governing the help I receive.
- Advice for a back up if you needed it for sick and holidays
- I know what I need and already use my Attendance Allowance to buy in care up to its limit, a little more would help, but I am grateful for the help I get.
- What ever Benefits possible.
- A significantly different attitude by the local authority (which is one of the UK's most forward-thinking in social care reform but still dogged by traditional paternalistic approach).
- Some participants were worried about taking up the right to control as they felt they had no experience. Most noted they would need support, eg of the sort provided by agencies which currently administer ILF monies and those which act as employers of personal assistants on behalf of self-directed support recipients. Some noted advocacy as a support. All would need assistance in finding out what types of support are available.

“How would I know if decisions about money were fair?”

“It’s first come first served and the rest wait a long time for services.” (Several people reported this.)

“It’s important to have advocacy to speak up for you and have as a back up in a service review meeting.”

“Not everyone knows how to get an advocacy service.”

“How do you get the money? Is it from the social worker?”

“Resource allocation should be about quality of life. We can speak and move but some people need more support than us to have fun, it’s not just about hours of support.”

“Who would help manage my money? I am involved in deciding how much to spend on shopping and going out.”

- A tender from the local authority for a video interpreter service that can be accessed 9-5 Monday to Friday instead of the present half a day a week arrangement like with London Borough of Islington.
- Some advice on controlling/managing and budgeting.
- Communication support from the word "go" - right through all processes that follow
- I would need someone else to do all the paperwork and auditing etc for me as I find it very stressful and exhausting - or for the council to have interactive forms online or downloadable/printable forms on the web which actually state all the info they require rather than me having to guess some of it!
- Advice on managing the budget, and advice on employment and payroll issues and health and safety relating to setting up the support worker.
- I would need systematic information about :
 - my situation and how it compares to other people with similar conditions
 - what is available
 - the products and services that could help me overcome my barriers
 - their success in overcoming such barriers
- Adequately funded local CIL and peer support services.

I am concerned by the ambiguity of what is meant by disability related benefits...What does this really mean. I am apposed to

local authority administering AA or DLA (although DLA is the only one that I personally receive).

I also understand that how care budgets are funded is only being looked at from within the relevant government departments. I believe a total government department review of funding should be re allocated (in particular: Defence and moneys found to prop up financial institutes, people need to be invested in and particularly those with needs.

- Physical action such as a access to an named DWP Officer to make loans in exchange for benefits happen.
- EJF Physical action such as a access to an named DWP Officer to make loans in exchange for benefits happen.
- A person-centred and meaningful care plan. Being listened to - by who is doing the assessment and review - by people who support me - by people who allocate the money. I would like to receive help and support with budgeting and spending my money wisely. I would like support from an advocate, someone who I choose to be my advocate. I would like help from a support broker, to find the support I need. I would like a friend to be my support broker or someone who I know and trust to help me find the service I want. I would like to have debt support.
- Users need more training in being in control, e.g. daily management of their care assistants.

People need training in how to plan their own care and how to make decisions.

Others felt as though in control was too much for them to take in. They are scared by the idea of having to take responsibility for budgeting, managing care staff and payroll.

Some users say they are holding back from adopting individual budgets, because they take the presumption that 'it won't happen to us, so why bother.' They suspect that they might not be eligible, or that another benefit will be cut back.

People feel daunted by the prospects of being in control and need support in designing a life plan.

Question 4: If the right to control is tested in your area, public bodies and organisations that run your services may want to ask you about how it should work. How would you like to be involved?

- I would like to be involved and help in anyway possible.
- I think it is important that a range of methods are used. Some disabled people may prefer face to face meetings; some may prefer emails, etc. However, what ever method is used, it is important that disabled people's access needs are taken into account and we are offered expenses, etc for our time. Organisations would expect to pay consultants for IT, etc, and disabled people are experts in our needs, so why shouldn't we be recognised as such and rewarded appropriately?
- No.
- To be asked.
- Do not require involvement.
- I would like to attend a focus group or other meeting.
- By being in consultant roadshows.
- In taking part in roadshows.
- Oh yes please.
- I am very disabled and like the care that I am getting, I don't want to live on my own. I am not very good with money.
- Our service can become involved by facilitating access to our service users and empowering them to become involved in the trailblazer pilots.
- I would want to be consulted on behalf of our local deaf community provider.
- Via local meetings.

- Q & A I don't mind.
- I would like the chance to put my point of view about disabilities like mine.
- Any way that I can be of help to others. I don't mind
- Need ask established deaf organisation that know what they talking about for their professional expertise, pay them for consultation, don't ask deaf volunteers cos always wrong volunteers because those who are smart, are too busy to volunteer in user forum or whatever,
- Yes most definitely, in every way that I can .
- Yes.
- Yes.
- To be able to sit on a committee and we all agree how it's used and not leave it to one person.
- Fully.
- I would like to know what they are doing and be a part of that learning process. Why are they doing it and what are they hoping to achieve? Can this work? How can it work cheaply and like clockwork?
- Advisory Panel. Committee. Council. Surveys. Administration.
- Council. Committee.
- Advisory Panel.
- Council.
- Sit on the Advisory Panel with a badge that says boss.
- Committee. Admin.

- Council. Committee.
- Committee.
- Committee.
- Surveys.
- Advisory Panels. Committee. Administration. Careers. Surveys.
- Committee.
- Committee. Survey. Council.
- Committee. Survey.
- Council. Advisory Panel. Committee. Administration. Surveys.
- Committee. Council.
- Committee. Survey. Council.
- Committee. Administration. Survey. Council.
- Advisory Panel. Survey.
- Committee. Survey. Council.
- Committee and Surveys.
- Administration.
- Administration.
- Surveys.
- Advisory Panel. Committee. Administration. Council. Survey.
- I should like to attend and conferences / meetings / workshops.
- Yes.

- Just show them how I live now and the help I receive.
- They are a total waste of time because they simply do not care for anybody other than them selves.
- I am a trustee of the local DP support service and a member of the SDS customer reference group, so am already well involved.
- We understand that there are no plans for pilot projects in Scotland. Should further consultation be organised, the consultation groups would be delighted to be involved
- Yes
- I am willing to be involved in consultation/planning meetings.
- In any way possible, but only with communication support
- In the least invasive way possible!
- I would like to be involved in a local pilot and would like to be contacted in the early stages of its development. Over the past 2 years I have worked with Hartlepool Borough Council and the Department of health on the national development project for In-control/RAS
- In planning the enquiry and in helping to evaluate the effectiveness of the program from my personal perspective
- By being truly involved, not just consulted. My time valued (expertise paid for etc).

Happy to do most things if it leads to real and genuine change and empowerment.

- BDPA will lobby to get into an area for testing where we can participate. BDPA will be involved by encouraging local people to participate, especially (hard to reach people)

- EJF will lobby to get into an area for testing where we can participate. EJF will be involved by encouraging local people to participate, especially (hard to reach people)
- Workshops: Find out and have a say. Special events in more rural areas, so people who live there and have difficulties with transport can be included. Talk to me on a one-to-one basis. Be included in workshops and steering groups around housing choices . I would be interested to help finding out and identifying where the gaps are. I would like to be involved in workshops around person-centred approach and individual support.

Question 5: Do you know of any rules, laws or procedures that apply to the funding you receive that might stop you using the right to control? If so, please tell us about them here.

- I am aware that current legislation does not allow health services to pay individual budgets to disabled people, but this is being looked into. However, I think the biggest problems disabled people will have in using the right to control is the attitude of “professionals” and the procedures of statutory authorities. When direct payments were first introduced, many professionals were openly against them as they saw them as a threat to their jobs and services and that disabled people would be unable to “cope” I believe that the same barriers will have to be overcome regarding individual budgets.
- No.
- No.
- No just our county council as in Cumbria County Council do not use this they still £10 per hour.
- Fixed price countrywide.
- Lack of advocacy and support to make appropriate choices and manage own budgets will cause our service users and their families a big problem.
- The paperwork and systems of administration need to be simple and easy to manage – to prevent inadvertently creating an access barrier for disabled people via the administration process itself.
- None.
- Nothing that I know of.
- I’m fit, healthy, my Epilepsy is relatively well controlled, I work and earn a living. Therefore I am not entitled to anything.

Therefore it would not surprise me if I am not entitled to the Right to Control.

- No, I don't know enough about the laws, rules and procedures to answer that question properly.
- No I am not aware of any rules that apply to funding.
- Nope.
- I am not sure as my disability is mental not physical.
- Where people want to continue to use current services, often this is because they value the support of peers, and feel the service is non-judgemental and safe. People who use current services need to be supported to be more involved in running them, so they become service user-led or –run, and that peer support has more meaning.
- Inextricably linking Disabled Living Allowance to Disabled Tax Credits.
- DLA should be paid at a higher rate for those unable to work at all, and Tax Credits paid to those who can work with their disabilities.
-
- Only the restrictions related to the ILF.
- I don't.
- How many hours I can work in paid employment, I don't know many rules etc... I do know one law rule, procedure.
- I do know one rule / procedure, I do not know many rules etc...
- How many hours I can work in paid employment, No, I do know one law rule, procedure.
- I do not know.
- No don't know many.

- Yes, I do know one law Rule / Procedure law.
- Work in paid, Many rules etc...
- Don't know any rules etc...
- No, do not know many rules etc...
- No, do not know many rules etc...
- How many hours I can work in paid employment, I don't know many rules etc... I do know one law rule, procedure.
- How many hours I can work in paid employment, I do know one rule procedure law.
- No, I do know one law.
- How many hours can I work in paid employment, I do not know many rules etc... I do know one law rule / procedure.
- How many hours I can work in paid employment, I do know one law rule / procedure, I do not know many rules etc...
- How many hours I can work in paid employment, I do know one law rule / procedure, I do not know many rules etc...
- How many hours I can work in paid employment, I do know one rule procedure law.
- How many hours can I work in paid employment, I do not know many rules etc... I do know one law rule / procedure.
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- How many hours can I work in paid employment, I do know one law rule / procedure.
- How many hours can I work in paid employment, I do not know many rules etc... I do know one law rule / procedure.
- I am not familiar with any of these.
- Care getting paid by Primary Health Care Trust direct payments are a no.
- Sorry don't know!
- If so, please tell us about them here. I knew nothing about the benefits system until in recent years when my father (pensioner) applied to them to help me, only to run into the Berlin Wall.
- This is the crux of it ... the development of SDS and personal budgets is not being underpinned (as the EHRC has demanded) by modern principles of citizen rights. Perfectly competent citizens are having their life choices monitored and subject to approval by local authority officials. It is a fundamentally different regime from other forms of state support that help people overcome their disadvantages (benefits etc), and it is in stark contrast to the freedoms given to self-funders. It amounts to blatant discrimination and certainly does not reconcile with the government rhetoric about “making sure disabled people have the same choice, freedom, dignity and control over their lives as non-disabled people.” Unless you change the guidance to local authorities and end this paternalistic monitoring and power of veto under SDS you will not get close to delivering basic citizen equality.
- One of the participants noted that the rules on public procurement and tendering seemed to be at odds with the right to control. The participant had direct experience of a very worrying and difficult period where the service being provided by a trusted organisation was put out to tender by the local authority which argued that it was required to do so under

European rules and to ensure value for money. The participant would prefer these rules to be changed so that this doesn't happen again, or to other people.

Many participants didn't understand how the arrangements were made to provide the services they were currently using, eg contracts, funding, regulation and so on. It was therefore difficult for them to envisage how arrangements might change and felt it was difficult to have control without information.

- No
- No
- There is no protocol for funding communication support for deaf people, who do not sign (i.e. the majority of deaf people). Without this communication support I feel any Right to Control is stopped dead in its tracks
- As I am DWP staff, this may exclude me from using Right to Control under Access to Work.
- Not really sure except the social model needs to be really understood to transform legislation and care services.

If I'm independent, I employ others, I pay my taxes and contribute to my community. Without this disabled people stay as second class citizens.

Many thanks for the opportunity to contribute.

- No. the "Buy-The-Money Project" has been tried and tested quite successfully
- No. the "Buy-The-Money Project" has provided for this by using the method of a benefit in the form of government loans for residents to get and keep work this is for the whole community where disabled people can live without constant fear.
- Point system and eligibility criteria. Means tested benefits. Strict rules that say what the allocated money can be spent on.

Housing benefit regulations. Strict rules on how much money I can earn without having my benefits taken away or cut.

- On the first day that I tried to introduced the concept, by the end of the meeting, customers were stunned into silence by the newness of the ideas.

It is better that the disabled person should control the money rather than the Council or provider.

Others expressed a view that giving money to disabled people to potentially spend on going to football, to learn to play a musical instrument, or learn to fly were frivolous and a waste of public money. Some people felt spending should be restricted to getting people better, or getting back to work

We are also concerned that different parts of govt are going at different speeds with the in-control agenda. The dept of health seem to be pushing local authorities to adopt in-control. The Office of Disability Issues give an impression that they are only just getting round to consulting, and they talk as though the early implementation trials are in the future (when the trials actually ended last year.)