

Right to Control consultation: responses from individuals

Note: ICR stands for Individual Consultation Response

This document contains full responses to the Right to Control consultation from individuals.

Considering the funding streams to be included in the trailblazers: Question 1	3
Considering the funding streams to be included in the trailblazers: Question 2	8
Funding streams used by both disabled and non-disabled people: Question 3	13
Working together to support disabled people: Question 4.....	16
How we can overcome barriers to the Right to Control: Question 5	20
How we can overcome barriers to the Right to Control: Question 6	29
How we can overcome barriers to the Right to Control: Question 7	35
How we can overcome barriers to the Right to Control: Question 8	40
Support to exercise the Right to Control: Question 9	47
Support to exercise the Right to Control: Question 10	54
Challenging a Right to Control Decision: Question 11	57
Working together to develop the trailblazer sites: Question 12	61
Implications for service providers and commissioners: Question 13	64
Implications for service providers and commissioners: Question 14	67

Implications for service providers and commissioners: Question 15	71
Implications for service providers and commissioners: Question 16	74
Any other issues: Question 17	77

Considering the funding streams to be included in the trailblazers: Question 1

What criteria should we use to select funding streams to be included in the trailblazer sites for the Right to Control?

ICR02

The split proposed in the consultation excludes funding streams already paid in cash. I presume that statement means that all streams will be considered in the assessment and that all streams will continue to be paid as separate amounts from their various sources.

The confusion caused by these multiple payments and the way that changes are implemented, make payments more difficult to handle by the client for the sake of what is often called efficiency but what to the client seems more like “inter-departmental turf wars”. The following is an example of how such changes have recently been made things more complicated for a person with severe learning disability for whom we are carers.

Until February this year, Jobcentre Plus paid Disability Living Allowance and Severe Disability Living Allowance weekly into a Post Office Card account. From February this year the DLA payment has been taken over by the Pension, Disability and Carers Service and is now paid every 4 weeks in arrears. The SDLA stayed with the Job Centre Plus and is still paid weekly. As well as different periods they are paid on different days. Hence when you go to the Post Office it is not possible to predict how much will be received.

The reason given for this change was “because customers have had problems when their DLA has been paid with other benefits”. Even if this is true you have actually made life more difficult for many.

ICR03

Any criteria used must focus on outcomes leading to Disabled People maximising their potential and overall capacity of contributing to and benefiting from the opportunities in society. Disability Living Allowance is mentioned but no mention of which component part - Mobility or Care. If one takes the care component, I find this strange Direct Payments are administered locally and DLA nationally, but the money of the care component part is meant to pay for the same thing. This is muddled.

Everything is interlinked in some way, particularly, if as is mentioned elsewhere there is an acceptance that RtC will be outcome focused, so it is an artificial distinction to leave out some items mentioned e.g. public transport accessibility for Disabled People is still poor in 2009 even with the extension of the DDA service provider duties. An effective monitoring and enforcement mechanisms is needed with tougher sanctions on transport providers who fail to deliver.

This being so, any questions asked and criteria used must be related to the individual's medical condition and/or impairment and directly related to what the individual desires. The extremes of the continuum will be easy to determine, e.g. someone who is physically unable to walk and dress themselves. However, the 'middle' will be more difficult with different and creative solutions needed, e.g. life coaching and social responsibility training. Any criteria must take account of fluctuating conditions and the living environment of the individual Disabled Person and their aspirations. In the trailblazer work a number of 'ordinary' non-disabled examples could be used as comparators, to see what RtC could realistically achieve.

ICR04

Anything that is specifically for Disabled People to enable them to live at home (including going shopping), work, be educated, take part in leisure, community and belief activities.

ICR05

Ones where integration will reduce bureaucracy and both time and costs of assessment and provision of services. E.g. Social Care, Health care, ILF, Assistance Technology, Access to Work and housing should all have just one referral, assessment and provision contact. Where funding streams being more integrated will lead to greater choice and control for disabled people. Where appropriate DSA should be included in this for students.

ICR06

In concern to your memo I would forward the following. Suggestions for the receipt of the next stage of the development (In reference to component consultation Adult Services Report 20 PERSONALISATION) In a statement from the Office of Disability Issues for DWP Rt. Hon Yvette Cooper MP. In operation to trailblazers concept the right to control is disabled person right to gain independence in social fulfilment in a inclusive right of control for the assistance of themselves and their family. I would welcome Trailblazers to implemented to all local authorities and thus allowing services to be shared making a cost effective programme and maximise support by the Social Care Institute and King's fund.

ICR07

I'm afraid this question is over my head and I am not going to strain myself by attempting to answer it. Neither am I going to pretend that I can answer it. I can't take in all of the necessary information, which may not even be available to me and I am not equipped to be able to answer this question. I am sure many lay people could not answer this question.

ICR08

Any funding streams that can provide any benefit to the individual should be included. Maximising the funding is going to be the only way of potentially allowing an individual to control their life and do things others take for granted.

ICR09

Criteria which reflect the key aims of current disability legislation and are based on the social model of disability.

ICR11

Devolve Budgets/funding streams to local authorities who have an up to date assessment of local need and hold a quality assurance award at a med to high level. The local authority should have a decision making group of all funding streams, vol/charitable & private sector plus service users & carers. The group for decisions should have nominated and frequently reviewed for performance members selected from a larger reference group. Undoubtedly the interest from all organisations & ind will be large and to many members to manage or be effective. Terms of reference/code of conduct etc. should be set immediately and a frequently reviewed, open & transparent work plan.

ICR13

As my wife's carer for 21 years the only knowledge I have of 'funding stream' is the Disabled Facilities Grant. You have listed 7 funding streams, my concern is this DWP benefits for the disabled and there carers is complex and mind boggling enough already. With 7 funding streams this will only make it worse and bring carers a whole new level of fear and worry. This will lead to increased levels of stress and problems. SIMPLIFY THE LIST

ICR14

Any funding that is used to provide any service that is used to provide help, care or assistance should be included as part of the 'right to control' budget.

ICR15

Does right to control mean having to organise and pay for all services needed out of an assessed amount of money? It would have been helpful to have further information re funding streams.

Consultation pages ended a page 65. Criteria used should be effectiveness sometimes money spent providing support workers makes too little difference to disabled people. The actual balance of power should remain firmly with government. This would enable government to ensure local councils distribute help evenly and do away with post code lotteries. Health care; social care; transport; education = should all be grass roots led and funded by government and local authorities. When services are contracted out to profit making organisations they become subject to abuse and standards of care deteriorate. Disabled people with the mental ability to control their lives can and do access the support and services available. People with learning disabilities need better trained and managed support workers.

Considering the funding streams to be included in the trailblazers: Question 2

Which funding streams do you think should and could be included in the trailblazers?

ICR01

It is difficult to see how this will readily work-within my own organisation we haven't yet cracked the issue of pulling together funding streams for care and funding streams for equipment.

ICR02

The trailblazer sites must test all possible funding streams, even if they are not included in the final rollout. This is the only way that the full benefits and difficulties can be tested.

It is vital that experience is gained of single individual budgets bringing together streams from various government departments and associated with other funding not included in the pilot. All trials in the past have shown that this is a major problem. From the answer in question 3 it may be necessary to trial cases who qualify for some streams but not would not normally be assessed by the LA as critical.

ICR03

I have already touched upon this in Q1 but to have any chance of succeeding, wheelchair services must be included in any RtC scheme. Also, aids to hearing and visions if ones functioning's fall below a certain level.

The cost of different levels of support in education must also be looked at because some disabled children and adults will always need additional support, which is directly related to their impairment.

ICR04

All these funding streams and I think it is a mistake leaving out Social Care. All funding streams should be combined or made available to a central contact point so that Disabled People are not having to go to lots of different teams throughout different organisations. There should also be one holistic assessment to decide how much money and for what the Disabled Person should have so that they are not having to constantly be assessed and give the same information to lots of different people. If this assessment is maintained centrally, only the bits of information that have changed will need discussing rather than repeating the whole lot again. Therefore, funding streams should include budgets set aside for assessments.

ICR05

Social Care, Health Care, ILF, Access to Work, Funding for Housing costs for those needing 24 hour care, DFG and aids/adaptations.

ICR06

The Social Care Institute and King's Fund Institute have highlighted the requirement for Elderly Care and Disabled Persons Care. They report the ambiguity of the difficulties faced by Vulnerable Persons. I can highlight my own difficulties and that of others having had treatments for illness and problems faced by relatives who require support in personalisation for the services they entitled to receive. There are a number of key workers to input their professional acumen so that Trailblazers in concept is a success. These resources should a website on behalf of the DWP and Local Authorities in consultation to the Social Care Institute and King's Fund Institute highlighting right of reply to sences including; Transport, Housing, Support Plan Advocates in case studies, Workstep and Occupational Therapy and Panel Members of services and providers in forum meeting.

ICR07

As above, my answer to question 1 applies and also I am concerned that the gvmnt may be wishing to offload its responsibilities. Charity organisations have very limited resources and without charities, there would be no research into finding cures and treatments, to help for example, people with M.E. There would also be no-one to genuinely oversee our care and prevent abuse. We respect charities.

ICR08

Social care, NHS, ILF – Independent Living Fund, Housing Benefit – to allow the right to buy, DFG – Disabled Facilities Grant, Education.

ICR09

All those listed in Appendix A of the consultation document if a realistic trailblazer is to be undertaken.

ICR10

I would like to see further and higher education direct payments included into the local authorities Right to Control trailblazer sites. Currently disabled students have no entitlement to individualised support and access to equipment when participating in mainstream education whilst at college or university. This results in disabled students not having the same opportunities as their non-disabled peers to access mainstream courses. We want all disabled students to have maximum choice in what mainstream courses they apply for and that they have enough financial resources to complete their studies and participate in student life. Appropriate quality and quantity of individualised support is important for learners so they can choose to access higher education courses if they wish to do so. Unlike their university peers, college students receive no financial assistance with the additional disability-related costs for completing their courses, and this is unfair and unjust.

It makes no sense for the Government to continue to prevent disabled students from accessing a direct payment when in further

or higher education or training. Disabled students must be given the opportunity to opt for an individualised support package via the Right to Control provision.

ICR11

All. When individual assessments are carried out it can be decided by the assessor, individual and if appropriate carers/parent/guardian which streams/they wish to access. Cash flow forecasts for the nos. and already known particular needs of service users/carers could be worked up to anticipate/predict expenditure per annum.

ICR13

Not only the ones listed but also the large companies and businesses e.g. gas and electric companies who like to have disabled customers registered with them to solve problems and issues.

ICR14

Anything that provides assistance, help or care should be included.

ICR15

Work; independent living; home care; transport / work and education; health; foster care.

ICR16

We would like to see further and higher education direct payments included into the local authorities Right to Control trailblazer sites.

ICR17

I would like to see further and higher education direct payments included into the local authorities Right to Control trailblazer sites.

ICR18

I would like to see further and higher education direct payments included into the local authorities Right to Control trailblazer sites.

Funding streams used by both disabled and non-disabled people: Question 3

Where a funding stream is used by both disabled and non-disabled people, how should we decide which users would be entitled to exercise the Right to Control? What funding streams used by disabled and non-disabled people could be included in the Right to Control?

ICR02

This question is somewhat rhetorical.

There is a statement that only disabled people have the Right to Control. If both disabled and non-disabled access funds then the ruling is clear who can apply the Right to Control.

I suspect the problem is much more difficult where disabled people qualify for a particular funding stream but do not meet the LA (critical or severe) criteria for funding or even obtaining a full assessment. Are they then entitled to RTC on the common stream or are they classed as non-disabled?

This has the possibility of long litigation.

ICR03

This all depends on how one defines what constitutes a Disabled Person and whether this is a permanent or temporary state the persons finds themselves.

As mentioned earlier we all live in an interdependent society, so for full citizenship Disabled People should have full access and inclusion to all the opportunities non-disabled people take for granted. Any RtC scheme must take this on board.

ICR04

I like this personally as I am very independent and don't like people to assume that my husband should be my "carer", and therefore do things for me. For instance, if I am given the right support to be a good parent and take my child to out of school activities, or do house work, and my child does not have to become a "young carer". For some people, though, they may want others to access the funding streams for them due to lack of confidence, the difficulties of complicated systems, or because of learning and mental health issues. However, this has to be very carefully controlled. Disabled People should be used as advocates whenever possible.

ICR05

All users should be able to exercise choice and control. Can't think of any funding streams that are used by disabled and non disabled people (this depends on how you view ill/sick people of course).

ICR06

In helping disabled persons to decide their needs with friends' carers and relatives the important provision should be entitled to making the funding stream available to the expected requirement of service. Thus allowing the needs of agreement set up local forum groups to achieve the best possible results and allowing more persons to participate in key decisions through a chaired person/spoke person(s).

ICR07

It is necessary for the word 'disabled' to be clearly defined. People with M.E. are 'severely' disabled, though they continue to fight against this disability and they have to maintain a very positive outlook to get through each and every day. People with M.E. are very courageous people. They may appear to be perfectly well when they are out in public. I once had to sit down on the floor, in the middle of a shopping centre myself, for one example. It took every ounce of strength I had to get myself home that day. Who knows about all of this? Only me really. And that's why I need

'control'. I would then need to rest, to recover from this episode, or cause more serious damage to my body systems, struggling to cope. It used to take me 6 months in bed to recover, because I had done myself that much damage, trying to continue with full time work, 2 college courses, the gym and an active social life. Now, my life is reduced and my collapses are much more sudden, much more serious (breathing difficulties for one) but I can recover in weeks with the help of prednisolone that I've had to fight and cry for. It is very important for us that we 'avoid' collapse and the damage done at such times, or we will become much more seriously ill and much more dependent on the state.

ICR11

There should be no differentiation. All have needs. Making a decision of this type already puts barriers/discriminatory practice into decision-making and access to services.

ICR13

I'm not sure how you can limit which funding streams can or cannot be included by a disabled person, surely there should be no exclusions, unless very sensitive and private information may be released. Also the "Right to Control" should apply to disabled and carer – especially where the care is a close family member, like me a husband.

ICR14

Only these people who fall under the category as 'disabled' should have access to 'right to control' funding streams. Any funding streams should be included in 'right to control' funding that are accessible to disabled and less able people.

ICR15

I don't really understand this question. Any funds should only be given directly to people who can demonstrate their ability to use money to improve their lives to a reasonable / average standard.

Working together to support disabled people: Question 4

What things would public bodies need to do to make it as easy as possible for disabled people, who are using different funding streams in the trailblazer areas, to use the Right to Control?

ICR02

There must be a single point of contact capable of handling problems experienced throughout the trial. However this may then not reflect the true state of affairs after the trial. Currently from experience with Social Care, following the setting up of a package the allocated social worker steps away from the case and if it is necessary to change the package then this usually means going back to the start again with a full reassessment. If this is the method envisaged for operation under RTC then it must be trialled within the pilots.

ICR03

A key issue here is to have one contact person sufficiently trained and knowledgeable of the system, that RtC users can communicate with, in addition all paperwork returns and forms must be harmonized and rationalized!

A difficult one, all, 'professionals' must be fully committed to RtC, the principles behind it and a genuine desire to make it work.

ICR04

Give them the information as to what is available in a clear and understandable way. This must be accessible to all disabled people. I think there should be life choice guides, a bit like key workers in Social Care. These people are independent and should be disabled so that they can empathise with the customer. A disabled person goes to see them about their aspirations, wants, needs and life-style choices. The life choice guides know what funding streams are available and can help the disabled person

match up to the appropriate ones. The guide can help the disabled person ring or apply for the funding if that is what is required. The guide should know what things are available that the Disabled Person can get with the funding – this should not just be specialist services, but also mainstream solutions eg if you pop down to “X” shop you can pick up a piece of equipment that does what you need at half the price that the specialist service would charge. These guides should be an active part of people’s lives on a long term basis so that the Disabled Person does not constantly have to restart the relationship with a new one, thus having to go through all the information again.

ICR05

1. Bring funding streams together.
2. Pay funding streams together.
3. Review them all together.
4. Self Assessment.
5. Advocacy and ULOs needed.
6. Greater choice e.g. over health care and aids/adaptations available

ICR06

In consultation to LDC I would refer such advocacy to the competence of such bodies in knowledge of the active support given by staff. I would highlight the first hands on experience of LDC and can say only the positive skills of service this private organisation provides and require the support of local authorities who have been very helpful. Key workers could highlight the needs of disadvantaged disabled for the important needs of services.

ICR07

So is the gvmnt also removing incapacity benefit, housing benefit and council tax benefit? Do we now live on the streets? The gvmnt has already removed income support from us. This was a very clever adjustment (and yes, we noticed it). It meant that I could not get my medications for months, until I finally discovered the HC2. Was this good for my health? No. Surely people who are very

seriously ill, have a high need in respect of medications? We need massage (with reiki) and we can't get it. Is this going to be provided for us? We can benefit from homeopathy. Is this going to be provided for us? We already control our own funding and care, via direct payments, so why is the gvmnt interfering with a successful system and making things more difficult for us, when things are already so very difficult for us? Why is the gvmnt about to waste so much money that we desperately need? Many people with M.E. already survive on mounting credit card debt. Is this good for their health? No. Is this situation going to improve under the new care scheme?

ICR08

Provide adequate/appropriate advocacy and information. Give options to choose from – if they are not there, how can they choose them? Accessible formats.

ICR09

- Provide simple, seamless guidance, in partnership with each other and with disabled people.
- Where possible, align systems, e.g. paperwork; timescales; methods of payment etc.
- As this is effectively a use of 'braided funding', ensure complete transparency of assessments, including disaggregating funding amounts assessed for different needs.

ICR11

Well trained up to date assessors who are examined/reviewed and supported to ensure they provide a high level of service, understanding and think laterally. Well piloted schemes and assessments. Don't pilot the Right to Control to all, if there are initial glitches people will become disillusioned, despondent & feel let down. The gov't & local authorities, other agencies will lose integrity. Well piloted media/assessments. Use variety of methods of assessment. Encourage service users to become assessors & provide support in long & short term to do this.

ICR13

Make access easy – via mail – email – internet – phone. Make all forms simple and without JARGON. Wherever possible direct phone contact may prove more useful.

ICR14

To purchase a way of distributing services to organisations or people providing the required level of service required by the end user.

ICR15

Make communication easier. Many local authority bodies are so diffused that it can be difficult to identify which department to approach for help. Then, having found them their areas of expertise do not overlap enough to cover complex difficulties. Particularly noted: DHS, social service/home care; learning disabilities.

How we can overcome barriers to the Right to Control: Question 5

What should public bodies and other service providers do when faced with a situation where some current users of the services want to do new things with their Right to Control, but some want to carry on using current services?

- Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people?
- How could service providers work with disabled people to make sure this type of service could still be provided?
- If a service has to close because not enough people wanted to use it, what plans should a public body make to ensure that people do not become socially isolated and still have choice and control?

ICR01

I think this is extremely difficult - where an individual has the capacity to be creative with a personal budget there isn't an issue but those most vulnerable people who rely on services being pre-organised run a high risk of losing out with communal options likely to become less cost effective for councils. Plans can be made to some extent to mitigate against the risks here but realistically they cannot be eliminated in my view and a certain section will as a result inevitably become more isolated.

ICR02

Under no Circumstances must “right to control” become “obligation to control”. Those who wish to carry on using current services should not be put at a disadvantage. They must also not be bullied into accepting RTC by threat of removal of their current service.

A right to control must go hand in hand with a good Person Centred Plan. Without this outcomes will be unclear. LAs must not be allowed to discontinue a service unless all users have received a good PCP with a clear indication of the way services will be taken forward to their benefit. Similarly these PCPs must be reflected in the Joint Strategic Needs Assessment so that it can be shown that needs are still being met.

Further on PCPs, the good outcomes have been shown to arise after a good PCP, giving a clear idea to user and provider the objectives of the plan. Some of the proposals I have seen for self assessment are mere tick lists and bear little resemblance to the detailed guidance given by In-Control. There is a danger that in the interests of efficiency and faced with the numbers of assessments to be performed the true personalisation is lost.

At present some services, (e.g. Day Services), are used by people who would not qualify for help under RTC or even an assessment. Without them though many would need more help. Also staff in Day Services can often pick up early signs of problems developing which can prevent future problems. In discontinuing a service an LA must consider the needs of all users. It must also consider whether by doing so it is limiting choice which would be against the objectives of RTC.

It is essential that those who go down the RTC route have administration support. At present I know that there are a number of people offering local services with salaries, taxation and bill paying for very low fees. The need for this service will expand rapidly and the existing "voluntary" style of arrangement will not be able to cope with the numbers. LAs must have systems in place which prevent "sharks" from offering support services which rip off the disabled. With expanding numbers this could be big enough to support a new wave of afternoon financial adverts on TV.

A major concern is that the existing qualification standards will apply and that no new money will be available. There will be a rush to get funding approved while it is available, from those in the know and the most able to manipulate the system, because LAs will rapidly run out of money. Once funding is issued the LA has no means of controlling costs other than limiting further supply or removing services from people receiving the old fashioned services. Admin costs are likely to be higher and people on

existing LA services are likely to lose out because these will rapidly become uneconomic to continue.

All policy statements and consultations (see Valuing Employment Now) are encouraging LAs to close or drastically reduce existing services and use the savings in the forms of direct payments for support in work and leisure. Sell off of assets may make the books look good initially. Also contracting out will also initially cost less because of the LAs employment cost problems. (Due entirely to the Government's failure to sort out public labour rates and pensions). However these are only short-term solutions.

The situation rather reminds me of the sell off of council houses with many gaining a cheap asset from the better housing stock. Again in a dogmatic approach to force through a policy, there was no new money or an allowed replacement of the housing stock with a crisis in social housing resulting, which we are only just beginning to sort out.

Without new money this is not an exercise in equality but one that potentially creates a disabled elite and is potentially one of the most dangerous, if well meaning, pieces of legislation for the disabled.

ICR03

It is not possible to please all people all of the time. Remember, the founding principles of Right to Control are choice and control. The harsh reality is that if a service is not providing the customer with what they want to the sufficient standard then they will cease to exist. The public body and service provider must look at what is being provided and gauge satisfaction levels and change if necessary.

Services should not be purchased and run if too few people are using it. The key question is why has it reached this level?

Better communication may be needed, market research user surveys. No service must stay cast in stone otherwise it will wither and die. Any service must evolve and be innovative responding to social changes and differing demands.

The term 'socially isolated' is emotive. Disabled People may need peer or advocacy support to try new activities and ways of doing things.

ICR04

Any service delivery weighs up different people's needs. You may be able to put disabled people in touch with each other so that Seamus et al may be able to buy equipment as a group, so lowering the cost. You might be able to get a Voluntary Organisation or a Commercial Organisation regionally or nationally to provide the service. You may be able to find mainstream equipment at a cheaper price for Seamus and other people so saving in one area may help you save in another. I know this argument is used a lot, but realistically working in Social Services myself I do not see many bulk buy deals going on. Cheap does not always mean better. Could disabled people with similar needs get together and negotiate a discount with the supplier themselves?

Disabled People or Voluntary organisations might be able to run smaller services. The Local Authority needs to think corporately e.g. it might be able to give young people work placements and extend this to providing the service for disabled people, or combine a number of services together in one place e.g. day care plus information giving etc. Change always causes difficulties for someone, but this is not an excuse not to change things for the better.

ICR05

If there is to be real choice and control providers must offer a full range of alternative services to people. Public bodies need to improve the quality e.g. of social care provided. More money must be made available if necessary. Disabled people shouldn't be shunted away into Day Centres etc. to be "out of sight out of mind" more inclusive community options should be offered with transport if needed

ICR06

Having reviewed the website there are a number of alternatives that public service sector should consider for organisations like I have been in contact with. The forum of being an intermediate would allow persons with disabled access to be present at public sector. Therefore I would appreciate feedback to be able to allow organisations to access their regards in Public Bodies. I would hope that activities will increase the public choice and give the awareness to statutory services allowing choice and control for available needs.

ICR07

This question and its content is amazing. I'm really not sure what is going on here. It is clear that the gvmnt is wishing to bully people. That is absolutely crystal clear. What is the gvmnt trying to achieve? Are the disabled now to maintain British industry? The gvmnt should not be allowed to force people to have certain care when that individual may have higher needs. The individual has not asked to be disabled and they must be heard. For example, yes, many disabled people are indeed on the Internet. Good. It is a wonderful global platform where, for example, the deaf are equal. It provides information and social interaction. The gvmnt wishes for 'all' British households to have the Internet service. So why doesn't the gvmnt come up with some work that disabled people can do at home, via the Internet? Having said that, in respect of people with M.E., some have too much brain fog to do that work and others may be able to do it. M.E. symptoms 'move around' the body. The brain is also a muscle and it can also tire. It needs some stimulation but the boundaries of this highly debilitating illness need to be respected. 'We' have no choice in that.

My activity each day includes, not just my hours of work, but 'all' physical activity for that day, i.e. from the moment I begin to move, think or speak. This includes taking a shower, dressing, getting my breakfast etc. I still do not dress, nor shower on my rest days. I am recharging. No help can recharge my limited batteries, sadly; no help can replace my energy and give me ability that is physically not there. If I did not have a car to move me about, I would rarely be able to get outside my front door, so yes, I have a very high need for a car. I have serious difficulties walking some days and

yet I can't get a disability badge for my car because I am not on high level DLA. Not many people with M.E. if any, are. As the gvmnt doesn't understand the seriousness of our problems, of course we are afraid and of course we wish to maintain control. We know far more about M.E. than any physician, at this time in history. We have tried everything and anything we can to get well. We have learnt a great deal and we alone know how to manage ourselves and our condition. We need natural, healthy foods for one thing. Is someone going to shop, cook and wash up for us? Be realistic. And many of us cannot for example, do all of these things in one day, no way! We also need the energy to eat the meal and to recover from that exercise alone. There are few pigeon holes provided by gvmnt into which we fit. We are very isolated indeed with our particular disabilities and in this isolation, we still need to maintain ourselves physically, mentally and emotionally. It would help the gvmnt to view M.E. as a serious heart condition, or that we are post stroke, then it may just have a clue as to the difficulties we are dealing with.

Re this "What plans should a public body make to ensure that people do not become socially isolated and still have choice and control?" This is a clear admittance that the gvmnt intends to bully and isolate people.

Re this "How could service providers work with disabled people to make sure this type of service could still be provided?" In other words, how can the gvmnt force their ignorant opinions onto people who have no choice about what they are having to manage each and every day of their lives? Who's the expert?

Re this "Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people." Of course not. That would be an irresponsible waste of money now wouldn't it? One should research and do so 'realistically', to identify need and provide, with constant review. Providing a service that people do not want because they have higher needs that need to be met, is ridiculous isn't it?

Our world is not your world remember? We have had to accept and adapt to an alternative lifestyle. We have to not view ourselves through the eyes of others/main stream society and we have to

totally re-define our self expectations. It would be very helpful if the gvmnt did not constantly wish to knock us back, below the poverty line for one thing. Why is it that this alternative lifestyle we need to adapt to should be deemed as a lesser-than lifestyle? Why can't we be happy? We have no choice but to embrace our disability and the pain, so why must we be ashamed and miserable with it? I understand that the gvmnt doesn't want the entire population to wish to be sick, but I'm afraid this is 'the reality' of 'our' lives and I want for each and every courageous disabled person to hold their head high and have masses of self esteem. Along with disability comes many qualities and gifts. We develop into very good managers for one thing. I know this because I am qualified in front-line chartered management and I recognise the skills that I see developing in others. Excellent resource management, forward planning, utilising the resources of others for examples. You wont catch me looking around a shop for something, when I can 'ask' and use someone else's brain.

Re this "What should public bodies and other service providers do when faced with a situation where some current users of services want to do new things with their Right to Control, but some want to carry on using current services?" The gvmnt should stop wasting money, dictating, bullying and frightening people. It's as simple as that. What does the gvmnt hope to achieve? At the appropriate time, I will give a clear example of this behaviour and the damage it can cause. I have no idea why it is that the gvmnt thinks it can bully people into being well. It really doesn't help. 'We are ill' and negative behaviour and stress, just makes our health worse. We understand how frustrated the gvmnt feels because we feel the same! The difference is though, that the gvmnt can walk away from disability and pain and we cannot. Really, we've tried! Many times! And we still do our very best each and every day to lead as productive a life as we can. We want to, really we do. We are very, very sorry, to so many people for our gross limitations.

ICR08

There would have to be a way of managing that situation for the interim. Those people in the 60s etc, have known no other system – they may not want change. If there was to be a change the social gatherings they enjoy need to be provided in an alternative way.

ICR09

- Respond positively to these new preferences!
- Work with disabled people to demonstrate the benefits of the Right to Control.
- Provide examples of where the system works well.
- Support a working relationship between successful users of the Right to control and those who are less confident about using it.
- Most importantly, public bodies need to make cost efficient plans to manage a transitional period.
- Public bodies need to ensure that service users are provided with alternatives, where available, and to consider new cost effective ways of working with disabled people who are not ready or unwilling to make the transition.

ICR11

Most local authorities already commission services. The agencies who are commissioned already have to manage referrals/work by being flexible. This is or should be reflected in the cost of their service. There will never be a point when everyone wants to control their own care. This can be for a multitude of reasons such as poor health, lack of confidence/poor self esteem/lack of knowing what is available.

ICR12

I feel that the whole personalization agenda is nothing but a 'cost cutting' agenda. It might be alright for a lot of people who have a physical disability but for people with learning disability, there is such a wide ability mentally from people who can read, have a high mental ability to those who can't understand who will acquiesce to almost anything to the profound and multiply handicapped who not only need someone to care for them mentally and physically have no comprehension. As a carer of someone who lives at home is 42 I'm extremely anxious. The present facilities are exemplary. Why change what is good.

ICR13

When service provision becomes a question it usually means someone is looking to CUT COSTS. If you cut services, then even though a greater burden will fall on carers shoulders and somehow they will cope but not be grateful. Great care and thorough consultation must occur before any services are cut.

ICR14

Value for money should not be a requirement of right to control. Value for money is usually associated with the economies of size that cannot be achieved by right to control. Service providers should discuss provisions with service users to ensure that provisions meet demands. Small demands for services may need to be met by statutory agencies using public funding.

ICR15

Public bodies should not be using profit making service providers. It is morally wrong and open to many areas of abuse. Service providers should be non- profit making. Involve charitable organisations.

How we can overcome barriers to the Right to Control: Question 6

What should the public body do in the situation where it costs more for one individual to use their budget to buy equipment or a service than for a public body to buy it?

- Should they stop an individual from buying equipment himself if it means there is less money for other people?
- Should they allow him to buy equipment himself only if he can show that he needs different equipment from what the public body already offers?
- Is there anything else that an individual or the public body could do? For example:
 - Could the public body agree discounts with providers which cover purchases by local disabled people buying equipment for themselves?
 - Could disabled people with similar needs get together and negotiate a discount with suppliers themselves?

ICR01

This issue is already cropping up-we have individuals who are asking to buy what they perceive as the powered wheelchair they want, rather than the range that the council provide and are able to negotiate large discounts for because they bulk buy. The reasons individuals want a different sort are varied-sometimes it is as simple as they want a different colour. Sometimes there may be a dispute between professional and individual as to whether it will meet their need – e.g. the individual who wanted a step in shower because it looked nicer than the wet room that would be more suitable for her degenerative condition- essentially where someone doesn't make a wise decision or decides to spend on something entirely outside the remit but particularly pressing such as a gas bill. The problem in agreeing some of these is it leads to vastly increased costs which then leads to authorities tightening up the circumstances in which they will provide which ultimately leads to

certain people benefiting from choice at the expense of those who no longer have any choices.

Another issue is that once the money has been spent unwisely but the person still has the need the authority is still legally required to meet the need-albeit in those circumstances a personal budget would be unlikely to be reissued-the council would just take over-however it still ends up paying twice. I therefore feel that individuals should be stopped where it means less for others. Choice is only good if it doesn't eliminate others in need.

ICR02

The purpose of this legislation is equality. Money needs to be spent to enable disabled people to be equal to their non-disabled counterparts. But spending more on one than another with similar needs actually creates a disabled elite.

The assessment made is supposedly based on need and not on cost. Hence spending more money on an item bought personally via an RTC payment than for someone provided via an LA service would be against the spirit of the legislation.

All payments must be on known cost to the public body.

ICR03

A 'notional' amount for equipment is required. The question, of course, is how much this sum is. Life is all about choices, priorities and preferences Disabled People should take this responsibility like anyone else. In no way, should a Public Body dictate to an RtC user on what equipment they should buy or indeed stop them buying what they choose.

The two ideas sound interesting and could be administered through the local centre for Independent Living.

ICR04

As someone who works in social care, I often wonder if organisations keep their prices high because they know Social Services will pay it. Ultimately, of course, there will always be boundaries and limits to the budgets that Disabled People have to work with.

Local Authorities or groups of Disabled People could do deals with organisations. When the information is given out to disabled people about how or where to get equipment from, the deals can be publicised so that the provider can be assured that they are being more highly advertised. However, again the life choice guides or wherever the information came from must be open and honest and not push people into paying for goods and services just because they have done a deal or something is cheaper.

ICR05

There must be a much wider range of equipment and continence aids available for people to choose from. Discounts could be negotiated by public bodies but service user purchases this themselves from the wider choice available. Link discounts to ongoing contracts for servicing.

ICR06

The needs of persons with requirement to obtain supplies is needed to be followed up by helpful development to ensure that maintenance is kept up for best working standards. Such equipment is required for every day activity and public bodies and suppliers would be promoting long term cost advantages both to the individual and public body.

ICR07

Well if it's the same equipment, the individual concerned needs to stop being silly and instead, be thankful. If they need different equipment, let them have it of course. I can imagine just how difficult it will be for the individual to prove to a body that they need different equipment however. How stressful is that? It doesn't

sound at all 'simple' to me. It is clear that the gvmnt has absolutely no idea of what it feels like to explain the depths of one's disability and needs, to justify these and to beg for help. This is also very difficult for us because we cannot afford self pity, so to engage this mode is quite painful for us. Again, this is all very confusing and one could wonder what the gvmnt is up to. Just use the power available to try to control prices. You really do not have control over 'everything'. We disabled certainly don't! It looks clear to me that this is just an excuse to penalise people who wish to receive direct payments and nothing more than that. And why do manufacturers/distributors of aids to the disabled make such a huge profit? Have they no morals? Isn't it exactly this 'greed' that ruins our country? It's certainly not the disabled, many of whom used to do a bit of voluntary work for the community, until that was banned by the gvmnt.

I'm more concerned about the bullying of individuals by gvmnt more than anything else, here. We disabled/seriously ill can't take stress, as the gvmnt knows. It should stop exploiting this 'fact'. And I could give you a very good example of it having happened, to me, already. Care to listen? Care to 'know'? I shall: I am on low level care, DLA for life, because I couldn't keep going through the review system and cope with the stress of an appeal, which stress literally put me in bed. I am not 'able' to cope with it at all. So, DWP bought me off and I had to accept low level DLA, care component, nothing for mobility, even though I can barely walk at times and thus no disabled badge for my car, because I am so ill. I was 'bullied'. So yes, I know about bullying by the gvmnt and I can see it here, glaring out of this document.

Re this: 'Could disabled people with similar needs get together and negotiate a discount with the supplier themselves?' No, people with M.E. are generally far too ill, to co-ordinate such an exercise. They struggle with the simplest of things at times. Imagine a stroke victim? You may then have some idea of the brain fog and confusion, experienced by many who suffer M.E. Please do not underestimate the serious nature of this condition, which renders its victims helpless in many areas and very isolated due to the lack of professional knowledge in respect of this illness.

ICR08

There could be a voucher system to provide basic equipment that all society has access to – but funding may be able to provide the difference if better items are preferred.

ICR09

- Cost effectiveness indicates that choosing a service or equipment at a lower price, as long as it is fit for purpose, makes sense. If this allows financial latitude for disabled people in choosing their supplier, so much the better. However, Right to Control implies just that - that a person can choose who supplies what as long as it's within their personal budget.
- It should be possible for public bodies to negotiate discounts with service or equipment providers if they know the level of service required and therefore are able to negotiate an effective bulk discount. This is likely to be more reliable in the first instance than individual disabled people 'federating', although some would be both willing and able to do this. There could, in some circumstances, be a role for local Centres for Independent Living taking a lead in any approach to 'federating' as enablers, if there is sufficient local interest.

ICR11

Use voucher codes. Give a voucher code for individuals to use when purchasing in order to get discounts. Local authorities might gain income by tapping into a bonus for the number of referrals for equipment. There would need to be clear guidelines for staff recommending organisations providing equipment & what any bonus money might be spent on.

ICR12

If they require the equipment to enable to give quality of life its too much to expect them to go through all these options to acquire the necessary equipment. Let the public body purchase it, they have amongst other things the knowledge and skills.

ICR13

There must be careful consideration before any intervention is actioned, as disabled and carers may see a need for equipment that has not been recognised before.

ICR14

Where this occurs; the public body should cut out the purchasing agent to deliver better value for the service users.

ICR15

Public body should provide; perhaps deduct from allowance. Yes, if it is 'public' money being used. N/A public body already provides adaptation where necessary. Already done / could be extended.

How we can overcome barriers to the Right to Control: Question 7

When might service providers and public authorities decide that commissioning the Right to Control is unaffordable, for example taking into account costs such as set up, advocacy, and other running costs? How should they consult on this with service users?

ICR01

We are already facing some real and difficult issues about affordability. In my authority we continue to place people in residential care due to very limited options for 24/7 supported care in the community. I am trying to set up new schemes as alternatives to this which will for example also address the unmet needs of disabled adults in the community living with carers but who would like their own place. Economically there are too many financial risks for me to persuade either providers or our accountants to go ahead and develop these schemes on a personalised basis (i.e. where at any moment they could lose a particular individual who choose to spend elsewhere) as block contract/group arrangements do not fit in well with the new regime of personal budgets.

The fact that group living in a more institutional residential environment is markedly less expensive even compared to living in a shared tenancy or a scheme where you have your own front door but within a scheme which is covered 24/7 by one provider who has tendered and has to re-tender every 3 years (giving potential for choice) and certainly where everyone could potentially have different providers makes it likely in my opinion that people are more not less likely to go into residential care where in theory personalisation does not seem to apply? I am certainly very concerned by the recent approach of ILF in our area which is now approaching any group scheme – e.g. where 2-4 tenants share staffing in an ordinary rented house in the community-to now withdraw its funding on the basis we are not offering choice. We are not offering unlimited choice that is correct but its a much better choice than long term residential care sharing with 30/40 individuals or long term hospital.

Trying to make this real-if say 4 out of 8 tenants in a 24/7 supported housing scheme opted to make their own arrangements-say these were the less vulnerable in the group - who didn't really need the expense of the overnight service-nightsitting- then we might be in the position of having to consult with the remaining 4 who needed help at night about the viability of keeping this going

ICR02

Surely the key is the JSNA created from the PCPs of the service users. This gives an indication of the total need of the community. Limitation of cost will continue to be done as at present by creating a threshold at which need is served. For those that meet the threshold it is their choice as to whether they take up RTC or not. The only question is how many get served. The likely end game is that the limited services available to those who don't make the threshold will disappear.

ICR03

This question is the key to the whole exercise. If the whole RtC exercise is to be judged purely on monetary terms it will never work. How can one equate monetary value to concepts of 'choice' and 'control' supporting and enabling Disabled People to reach their full potential and lead 'ordinary' lives? The whole question goes back to what I said earlier the necessity of total and genuine commitment to the principles of RtC and to making it work. Local Authorities should be well underway in understanding the costs involved through Direct Payment schemes, other Public Sector agencies may need 'educating' to the RtC principle and 'release or give' money to make the scheme work properly.

The quality of the service to be provided will need to be agreed locally and costs agreed accordingly. The specification and options thereof must be consulted on locally with all potential users. It is a political issue, which must be debated. In a civilized democracy Disabled People must be supported, the question is how and in what way. The principles and value of RtC have been recognised and accepted, now is the time to make it work.

ICR04

It would be best to use independent Disabled People from another area, acting in the role of critical friend.

ICR05

This should not be an option available to public authorities. Disabled people in the 21st century must have a legal right to control

ICR06

I would like to forum workers present cases to the service provider or public body merking out the consultancy effectiveness. This could be by the appropriate persons appointing the decision to disabled persons via the Right to Control in remitting the services circumstance. The example of this is a person deciding his ability to participate in work and freedom with the resource of Forum allowances.

ICR07

The gvmnt should not be even thinking about setting up such a scheme. It is clearly highlighted in this question about the costs. This is money that is desperately needed by the disabled individuals themselves. The money to be used will be 'stolen' by the gvmnt, from the most poor and vulnerable members of our society and 'wasted'. We need it. Please don't steal and waste our money and please don't bully us. We are afraid. We only ask to 'survive' and many of us are in debt already, doing just that. If an individual is well enough to argue their care needs, they are well enough to control their own budget and the other support is not required. So what's the problem and why is the gvmnt causing problems and wasting vitally needed financial resources?

ICR08

Consult from the beginning – in a way they can understand using existing set ups. BE HONEST OPEN & UNDERSTANDABLE.

ICR09

- The main role would be keeping service users involved and informed. Solutions could well be found by working together on this.
- The public bodies need to determine what the 'critical mass' would be for services to be efficient and cost effective, and what the 'tipping point' would be to terminate the Right to Control approach. This implies a high level of co-ordination which may not, in some areas, be available, or may not be working effectively.

ICR11

The reference group would be in place to review the implementation and amend as necessary. Feedback for the smaller decision making group would effect change. A clear and regularly reviewed workplan/review & evaluation programmes should be in place prior to starting, with times & who will carry out the review & evaluation. Preferably an objective organisation such as a university.

ICR12

This is exactly one of the issues carers and users who can comprehend are very anxious about. The cost! So if it's consulted there will be no solution because they just won't have the finance to do anything.

ICR13

Cost provision for above mentioned services must be supported in full by NATIONAL GOVERNMENT. For too long the rest of the nation have enjoyed a badly funded service underwritten by the disabled and there HARD WORKING CARERS

ICR14

Where right to control proves unaffordable, the service user needs to be involved at an early stage. It should not occur, because each user will have a budget that can't be exceeded.

ICR15

Right to control has not been clearly defined in this paper. A policy is unaffordable if it doesn't work. Is this current questionnaire good? If so continue along these lines but simplify.

How we can overcome barriers to the Right to Control: Question 8

Is there any legislation or are there any rules about how support is provided which might get in the way of the Right to Control, and how can we overcome such barriers?

ICR03

I am unaware of any legislation preventing the successful roll out of RtC, if there is, it must be repealed or changed to enable RtC to work. Similarly, if any local authority bureaucratic 'rules' are preventing it they must be stopped and streamlined. Any internal system of an organisation must work for the benefit of both the organisation and customer not just as has been the case in many Direct Payment schemes, the local authority.

ICR04

Please see answer re life choice guides to question 4.

As an individual I can only comment from my own life. Social Services had put a lot of rules in, in the Local Authority where I used to live their rules stop direct payments being used to go out shopping, for social activities and only allow 1 hour a fortnight for washing and ironing. As a parent I feel that these activities are not only good for my psychological well-being, nutrition and physical health e.g. regular movement, but also to stimulate my son, teach him life skills, help promote his mental and physical health, promote his social well-being and encourage his social participation. Social Services do not assess my needs as a parent, purely as a disabled individual. These rules create barriers and I have known other disabled parents potentially being left in dangerous situations with their children because their needs and aspirations are not seen holistically.

There are many restrictive practices across all funding streams. This is because they are set up on the basis of the Medical Model of Disability, making assumptions about what people can or cannot do. The systems are based on the fact that if you are as disabled as I am you will not be working e.g. it does not matter how many

times I tell the service that comes to service my hoists that I work full-time and that I need to know when they are coming, they still always call unannounced and during working hours. Also, if you are working there is an assumption that you do not need 24 hour support and the charging regime therefore penalises working Disabled People with large support needs. To keep my joints moving hydrotherapy is a key, but as the Hospital pools are only open for restricted hours in the daytime I have to take a lot of time off work for a session as I have to travel 14 miles to the pool. Also, as Disabled People go through their lives there are rules that mean they cannot always maintain or get what they need. Working in Social Services I see young Disabled People being forced to stop going to a service because of their age. Whilst I agree that they should be treated as an adult these “transitions” are not always managed well, and it is still about what services already exist (which are often nothing like what they have previously had) rather than creatively help them do things that other adults do, but which also meet their needs as a Disabled Person.

Another example of where control was removed from me was when I wished to move with my family from one Local Authority area to an adjacent one. All I wished to know was what direct payment package I was likely to get from the Authority I was moving to. This was because without significant help (I was receiving 24 hour support) I would not be able to live. I was told that no assessment could be done until I lived in the new Authority. The consequence of this intransigence was that my husband and I had to decide whether to continue with our house move without knowing that my direct payment package would meet my needs, and that my 4 employees (my Helpers) did not know whether they would still be employed. I was not asking for a definitive answer, just an assessment to see, whether in principle, the new Authority would have given me the support I need. Despite lots of begging they would not give in so I had to risk buying a house and moving in before they would fully assess me. The same policy was carried out when looking at physical access i.e. I needed hoists etc, that unless I was in the house they would not assess me. They wavered a little bit on this, but only at the very last moment. I only found out on the day that my previous house was being sold that they would give me the package that I needed for my helpers. I did not get the hoists I needed until I had been in my new house for 2 weeks, luckily I had quietly taken my mobile hoist from my previous house and as it was so old that Local Authority did not

chase me for it, otherwise I would have had to go into temporary emergency care, because I could not get to bed or the toilet. I did not get my bath hoist for 3 months despite it being medically important that I have a bath every morning.

My Helpers also had to take a leap of faith with me. Some of them could not wait to find out if I had a job for them, but luckily some of them did stay with me. If they had not, again I would have gone into emergency care until I had recruited my own Helpers which, as I have a very thorough recruitment process can take 2 or 3 months, to find 1 right Helper, and in this scenario it would have been 4 Helpers.

All of this was ridiculous as I had started enquiring a year and a half before moving from Kirklees to Leeds to ask Leeds what my prospects of support were, so it was not as though I dropped it on them at the last moment. The 2 Authorities did not co-operate with each other either so I was constantly having to act as go-between to try and get one or the other to move their position. For instance, Leeds suggested that Kirklees could carry on paying my Helpers, until Leeds had sorted my package out after I had moved. Kirklees quite rightly felt that Leeds had had long enough to think about it and if they carried on paying Leeds would never get their act together. However, I was stuck in the middle with both of them not agreeing to help me and being sick with worry, having been forced to commit myself to a life in a new place without any idea of what this would entail and whether my life was going to fall apart. No able-bodied person would ever be expected to live like this.

Twice I have been in the situation when I have had to get a hoist for work. The first time was 4 years ago and because I was pregnant I thought that I might become too big and heavy for my Support Worker to lift me. My manager was in agreement that I needed a hoist and asked me to find out how I could get one. I asked Personnel and Employee Health Care who said they did not know, Access to Work who help assess for and fund equipment for work, but they said they did not cover hoists, and the Occupational Therapists who said that they provide hoists for people in their own homes, but not for people at work. My manager then suggested contacting Social Services Equipment Service, as they loaned out hoists, but again they would not do it for employees. Luckily, I was so ill during my pregnancy that I actually lost weight, rather than putting it on, so the fact that my many weeks of ringing around and

internet searches did not come to anything, was not a problem! My second attempt at finding a hoist was last year when my Support Worker got a hernia. As well as reducing lifting before he went off for his operation, it was crucial that I got a hoist so that I could get temporary Support Workers to help me, during his 3 months sick leave. His Consultant also made it clear that even when he was back at work he would have to be careful for another 3 months. I explained to my new line manager the difficulties that I had had last time I tried to get a hoist. He asked me to try again on the basis that my query raised with Personnel and Employee Health Care may have triggered an improvement in the system. I rang the same people that I had done before, again with no success. I also rang Social Services Equipment Shop and Crossroads for ideas, but with no success. Eventually, my line manager contacted the manager of the Disabled Children's Service in Safeguarding who is responsible for the budget which is used to train Council employees on lifting and movement issues and provide equipment for the residential homes. They then asked Training to get an external consultant to come and assess me. I worked in Children's Services at the time and my manager was senior manager in that service, if I had worked in another part of the Council I don't think they would have been willing to use their budget. As a result the Council bought the equipment I needs so I now have a very good mobile hoist and comfortable slings.

As a blind person I, of course, cannot drive. I do, however, have to use my car to get to work, do the normal parental taxiing and general everyday driving about. To be able to do what I want I need to be able to insure my car so that all my Helpers can drive it. As I am not a driver no insurance company would countenance my application, and the only way I could get any insurance that went some way to meeting my needs was to have my husband as the main driver and have 4 named drivers. Each driver I add makes the premium more and more prohibitive. This weekend, for example, I have a temporary Helper and should be taking my son to his gymnastics lesson, which I can only now do by getting a very expensive taxi. I used to have a Motability car where I could have an open policy for any driver, but it was not cost effective to use all my mobility DLA for this. I have tried all the insurers who say they specialise in insurance for Disabled People and apart from not being able to supply the insurance I wanted, what they could offer me was considerably more expensive than Motability or having my

husband as the main driver. Thus, this service makes my life more restrictive and expensive.

ICR05

No artificial ceilings on care costs. Reform ILF criteria for funding (or scrap ILF as a separate bureaucracy and merge it with social services). Must accept that there may need risks involved for disabled people but these have to be allowed. Care Agencies may need to be forced to change their attitudes e.g. not able hoist without 2 people, carers not able to travel without service users outside home town etc.

ICR06

Under the Freedom of Information the allowance of budget would be brought forward if all service providers are allowed give the freedom of choice the respect cooperation to allowing the ability to compensate the service and thus expanding services but not allowing the ability to compensate the service and thus expanding services but not duplicating and reallocating for other needed criteria in such things as blue badge allocation or freedom pass.

ICR07

Yes, I need massage (with reiki) really badly. It really, really helps me and others with M.E. It is probably our most powerful therapy and we can't get it here in Walsall without paying for it, from our limited resources. Regular massage (with reiki) would definitely help people with M.E. to cope and also to get well. I do wish someone would listen please as I do know what I am talking about. In fact, there is a theory about a build up of toxins in the spinal fluid in research at the moment. Apparently and I would agree, massage distributes the toxins so that they drain off via the lymph glands. I would agree that it is likely this may be the case. 1) We are very toxic and we can take few medications 2) Our pain is may be caused by this build up of toxins 3) Our muscle tension/spasms (which I certainly get and ouch) may be caused by this – which definitely contribute to the pain 4) Some people have died from M.E. now and their spine – sent off for research has shown signs

of serious disease 5) We have to avoid alcohol, caffeine and anything that may be toxic in our system 6) We have to drink a lot of water 7) When the pain actually goes to our back and some of us have this all the time, it's hell 8) We frequently feel as though we have been injected by a thousand bugs, which is a very horrid, fuzzy feeling all over – suggesting toxicity 8) It may also account for some people's brain fog, which is usual when first ill with M.E. and when doing a lot of work with the brain, like this!

Yes, homeopathy which works very gently and it does help but again, we are not allowed this in the Walsall area and it is way too expensive for us to buy. Barriers could be overcome if we were 'heard'. No-one else knows anything about our condition, so why do you not listen to us, the ones who are suffering and I really do mean suffering.

ICR08

Data protection Act – could be an opt out consent form. It could contain consent and you could tick the boxes of people you do not want to share info with.

ICR09

- A key legal issue would be what happens when a public body wants to withdraw a service because it is no longer economically viable to provide it. It may be that the public body would find itself accountable under law for this service provision if it did not consult adequately on the withdrawal of the provision, or make adequate alternative provision. The recent Southall Black Sisters case illustrates this issue.
- A disabled person needing to become an employer is likely to be a nightmare for many and could easily put them off taking this route! For instance, have you read the regulations on Sick Pay for an employee??? Effectively being an employer, even a small employer, is not a simple or easy process!

ICR11

With regard to accessing ILF. Individuals who are unable to sign for themselves such as those with dementia or learning disabilities cannot access ILF thru Direct Payments even though their spouse/parent/guardian has Power of Attorney, even when P of A has been granted when the service user been fully aware of their circumstances. This then creates inequality of access to personal choice/meet individual need.

ICR12

Yes we keep hearing that people with L.D. must find jobs. But their benefits will be in jeopardy. For someone who has never been able to work because of their mental capacity, any benefit reduction would be serious.

ICR13

I do not know.

ICR15

Much more consultation with carers is needed. Authorities seem to distrust carers but it should be self evident where care is working effectively for the individual, especially where it has been working for some time.

Support to exercise the Right to Control: Question 9

What information and support will disabled people need in order to enable them to exercise their Right to Control?

- Support needs
 - Who is likely to need this support, and how can they be supported to make the right choice for them?
 - What types of support do you think will be needed?
 - How do we ensure the inclusion of those disabled people who have, or are seen to have, limited capacity to take decisions?
- Support provision
 - What is the best way of providing this support?
 - What agencies are best placed to provide that support?
- Cost of support
 - Should the costs of supporting people to use their budget be met from within a person's individual budget or be paid for by public bodies centrally from their overall funds available?
- Information, advice and support
 - How important is information about the range of services/equipment and support in ensuring the Right to Control?
 - How important is information about the cost of services/equipment and support in ensuring the Right to Control?
 - How important is advice and support to disabled people in choosing and setting up support?
 - What are the best ways to make sure that people know this support is available?

ICR03

Any information provided must be seen in terms of 'hard' and 'soft'. Both are important for RtC. Hard info is that found in leaflets, pamphlets and the Internet, soft info is that gained from talking to people with similar services or are in a similar situation. One will never get this sort of info from written literature. Indeed, personal recommendations from people who have a real experience of an issue - the pluses and minuses and things to be looked out for is invaluable in order to reach a final decision as well as to discuss and debate ideas and ways forward.

As RtC is potentially 'big' and 'confusing' for some Disabled People advocacy may be needed to support someone through the system. Centres for Independent Living staffed, controlled and run by Disabled People in each area as advocated by the Life Chances Report would be ideally placed to offer this type of service.

All Disabled People will need hard and soft info and Local Authorities should enable and support this to take place particularly the 'soft' by supporting user groups to form and develop. Older people and people with a learning difficulty may need more support.

Most Disabled People, even with a high level of impairment can express in some way preferences if alternatives are presented in an appropriate way. Effort must be made to include this group of Disabled People.

By giving Disabled People an amount in their individual budget to buy in this service is surely in line with the spirit of the principles of RtC - choice and control. The 'notional' amount provided for this must be realistic; it is then up to the individual Disabled Person, bearing in mind agreed outputs, how and where the money is spent.

The quality of info is vital in order for the person to reach an informed decision. A lot of info exists already on many things, although not in one place. An independent third sector agency is important here, ILC again, which could not only provide info, the

range, quality and cost but also provide special advice. The National Audit Office, a few years ago, in a report on the process of involvement and the third sector were very clear. They stated that Local Authorities could not just 'dip in and out of a third sector organisation expecting a contribution to an involvement exercise without building up a relationship and providing on going support. In the context of RtC this is vital as Independent Living Centres would be ideally placed for this work.

ICR04

Please see response to question 4 re life choice guides. In my situation I want to be as independent as possible and I hate the fact that my husband is labelled by Social Services as "a carer". He helps me do some things and I help him do things as any couple would. I have able-bodied friends where one person in the couple always does the finances, but you would not call them a carer, so why automatically label people when one person has a disability. I therefore object to assumptions that are made about him and what Social Services decides he should or should not do. If my needs are met through my Helpers I am then not "a burden" to my husband and I can take a full part in my role as a partner, mother, employer and employee. However, I acknowledge that there are some people who would want "a carer" or advocate to help them and so these services need to be available to them. Whatever happens independent people need to help disabled people to make the right choices because any team or department in a statutory organisation will have their own slant on what they think is available or necessary for the Disabled Person. Having worked In Social Care for years I find that people find it very difficult to see someone holistically and make creative solutions. The life choice guides or whoever helps the Disabled People need to be given some power so that they can help make things happen otherwise the so called professionals In Social Care, Health, Education etc will not respond as quickly and flexibly as they should. There is a lot of snobbery amongst "professionals" and therefore the life choice guides need to be given high status and be seen as professionals in their own right. They should not be voluntary or low paid. After all, to use the life choice guide properly you need to understand how the different organisations work so you can help the Disabled Person achieve what they want to, this includes influencing mainstream organisations eg to get

local services to sell disability equipment as ASDA have started to do.

Anyone giving support needs to be seen to be very careful about how they do it so they must truly listen to what the disabled person wants. However, I have to acknowledge that a lot of disabled people have not had the chances that I have and, therefore, will only ask for what they have already got. The guide or facilitator must help to stretch the Disabled Person's imagination without being patronising. Lots of people know what methods can be used to hear what Disabled People when they have communication problems, but a lot of people may not have the time or the ability to truly listen so supporters need to be chosen very carefully.

A person's budget should include on-costs as you would have when you set up a post in any organisation. For instance, I employ my own Helpers by using direct payments. I cost a lot of money in terms of my personal care, but save the Local Authority a lot of money in terms of recruiting and managing my Helpers. I should be given money for advertising, postage etc in addition to what my care costs as realistically these are all out of pocket expenses. As it is my household bills are higher as I have Helpers in my house e.g. electricity, gas, toilet rolls etc, so I should not have not to pay for things that the Council would provide if they were directly providing my care e.g. phone calls to prospective Helpers. Whilst this may look like a lot of money the Council would be paying it otherwise, they just don't specifically identify it. Disabled People often have less money and higher bill so they should not be more penalised for wanting to control their own lives. Cost can often be improved by, for example, passing on to other Disabled People unsuccessful, but good Helpers after the recruitment process. Full details which are concise and plainly written should be available to Disabled People using different formats, media, venues and settings. If you are truly wanting to see what is available you do not want to read through hundreds of leaflets. Technological and human resources must be available to help find the right information.

ICR05

Costs - there should be extra in peoples budgets for this, thus increasing Choice and Control. Information - is very important - there is little now. Social Care/equipment should be free. Advice

and Support is very important. Best way to make sure people know about support is via ULOs and advocacy services Support Needs - Self Assessment with Independent Advocate - essential for those with "limited capacity" especially. Provision - Individual Budgets (personalisation of care - User Led organisations) Disabled People's Organisation best placed to provide support.

ICR06

I found this question a little bit drawn out - even off putting because it only allows the individual to promote a non community based perspective. This would not be in relation to those who have limited functions to further activities that would in fact promote a community endeavour to share experience and ability to the knowledge of these available to contribute the help forwarding the promotions that equality is to be enjoyed by both helping and voluntary contribution to needs that result in positive reimbursement of fulfilment in many concerns such as mundane to broader applications. The advice therefore is to bring a full and enjoyable dialogue to endeavours that may not be highlighted but often prove most essential. I myself do appreciate the outcome of noting that even from my experience I have been seen to note the persons who have given positive contribution to up build in community the outlets of social help to allow all to progress in the own endeavour in service to others that require the full hands on development to share the path that trail blazers sets a shared standard of success.

ICR07

Well it would be really nice for a single person, living alone to have someone to help them when they are first ill with M.E. when it is in acute flare up and the individual (as well as their family if they are fortunate to have one) has no idea of what is happening to them. It is 'the' most isolating condition and to be rendered as useless as a 96 year old, at the age of 24, or 32 or whatever, is absolutely devastating. Pardon me, 96 year olds and I love you very much.

For the rest of us, who've already educated 'ourselves' and learnt to cope, we'd really like to be left in peace please, with our direct payments intact, to continue to look after 'ourselves'. We really

don't fit into your world, nor your categories and not even your thinking. I now see the world of disability as normal and the rest of the world as a temporary state of something unreal that is not likely to last. Personally I have a social network, so I am ok. Others may need more support. I know one now, on facebook. She's 29, she has a couple of £thousand debt and her M.E. is flaring up out of all proportion. She is trying to come to terms with stopping full time work, to avoid a wheelchair situation. She is in pain and physically wasted. She is very afraid and she feels, very, very alone. Her relationships are suffering (which is what happens) and people are not there for her. They don't 'understand' her condition and just how very seriously ill she is

I realise that this question is very much relevant in respect of people with Alzheimer's. The only way for me to get through this document with my limited ability is to remain focused on my own condition and what I know about that. I can't comment on other conditions right now. I'm having to remain very focussed and concentrate really hard. I realise that it is difficult and that a lot of people with Alzheimer's need a lot more care than they receive right now. This is correct.

ICR08

Advocacy availability. No where in this document are family carers mentioned – the majority who are able will be taking on yet another unpaid role. INVOLVE & EDUCATE FAMILY CARERS.

ICR11

Info is power. Sustainability & inform choice. Essential for most who will be inexperienced. Essential for most who will be inexperienced. Have strategy for comms & 10 year plan. All should be able to access clear and concise up to date information from a variety of sources. Support:- equipment where necessary to read info. These people should already be known by agencies.

ICR13

Information – range of services access – all of these issues may be solved by a simple approach. Put the information simply/without JARGON on a DVD, and/or by e-mail etc.

ICR14

At all stages, the service user should be involved at an early stage in the process.

ICR15

All, make sure they have all the information; Simple access to information / support; Listen to their carers. Ensure carers are will trained and supervised.; Telephone to person not machine; Social services, employment department, health care agencies, education department.; Services should be free at point of need ; People capable of making relevant choices will see relevant help / info / support; TV radio press.

ICR20

When you talk about disabled people with similar needs getting together to purchase services with a discount - for many groups that would need to be the carers taking on an extra role.

Individual arrangements can work very well until they breakdown and then its back on the carers to re-arrange and cover in the interim - if a support worker at a day care service calls in sick the day care centre has to cover but if its through a direct payment its often the carer making new arrangements.

Support to exercise the Right to Control: Question 10

What additional support will existing information and advice, independent advocacy, support brokerage and other support services need in order to meet the needs of disabled people using the Right to Control in the trailblazers?

ICR03

The support any 'fledgling' organization needs in the voluntary sector must be routed on firm foundations, e.g. constitutions, committee structures and financial systems. A degree of 'entrepreneurial' savvy and departmental skills will also be required by the organization so as to ensure sustainability. Local Councils for voluntary service are tasked with the responsibility of supporting voluntary sector groups in a particular area but the standard of support and advice is very patchy and variable in quality. In my experience few have a real understanding of a Disability Equality principles, let alone practice them.

A project run in the West Midlands call the Regional Disability Network is a good example of the way forward. Simply put the roll of the RDN is to support the capacity and sustainability of disability voluntary groups in the West Midlands. Other Disability Networks exist in the country with similar aims. The key question is how these networks are funded and what outputs are expected. However to have a robust, thriving and healthy Disability Group Voluntary Sector it would be a good model to adopt.

ICR04

There needs to be a clear instruction that independent support eg life choice guides, needs to be put in place. Resources will need diverting into this, or initial funds be made available to set them up, Local Authorities must not let information and advice services eg the guides, dwindle just because initial funding has stopped

ICR05

Funding especially independent from Social Services etc. Access to legal advice and funding for court challenge

ICR06

I would suggest that a hands on practical report whom helpful advocates will put importance to the trailblazers. In as much the required help is achieved and allows the persons personal perspective to involve the support required. I hope the ability to advance trailblazers to appropriate public bodies include the legislation of local groups and local public bodies.

ICR07

Well thinking now, that if all benefits become one and are paid out in one lump sum, I guess some people are really going to struggle to manage their finances, if they are not used to doing so. Is that one of the intentions, that people learn this skill? There could be a website for people to swap tips/skills trade/share. I don't envisage anyone swapping gardening skills though. Sorry, my humour is kicking in, it helps me cope J. I've a deadline to meet and I've only just received this document, so really, I'm actually stressed. You may not listen to much that I have to say, I know I'm not 'an agency' but hopefully and maybe 'something' will get through to someone?

ICR08

Person centred thinking skills to work around & focus on the needs of the person. Available choices to signpost individuals to. Money management and how to use it efficiently. Flexibility.

ICR09

- Full knowledge of how Right to control works, training in disability equality and equalities generally, and an understanding of human rights.
- Readily available contacts if difficulties arise in individual cases.

- Knowledge about signposting if this is required.
- More experienced people mentoring and supporting those who aren't.

ICR11

Quality training & networking for sharing practice. Monitoring & evaluation methods. Mechanisms for being a part of a reference/decision making group & ways to feedback & influence decisions.

ICR12

Brokerage is going to cause a huge worry, disable people and their carers could be open to all manner of mal brokerage.

ICR13

Needs for additional support may not become evident, until the system has been up and running for some time. Again consultation with the disabled and carers is **CRITICAL!**

ICR15

? If they are already doing their job further money/support should not be necessary.

Challenging a Right to Control Decision: Question 11

Thinking about the current processes in place that enable someone to complain now, what kinds of help and information do you think people might need to:

- Challenge a decision that they are not happy about
- Request and take part in a review of a decision?

ICR03

It would be fair to say that quite a few Disabled People do not have the confidence or self esteem to make complaints, particularly when the service in question is vital to them leading some sort of 'normal' life this may begin to change when they themselves are responsible for using money to buy in a service. However the help and info a person may need to challenge a decision is to have all the facts of the case in writing and reasons why a decision has been made. Advocacy support may be crucial here particularly for someone with mental health concerns or a learning difficulty. Negotiation and communication skills are vital which are bound up with education levels and experience. Centres for Independent Living could run courses on these issues giving participants the tools and no how to challenge decisions, outlining different methods and processes and possible ways around the problems.

Any reviews that take place the Disabled Person must be present together with advocate or supporter.

ICR04

There needs to be a responsibility on workers that they have to show very clearly why they have made the decisions that they have. Complaints procedures in Councils and Health etc need to take Disabled Peoples needs seriously, and just because someone has made a complaint before they must not be seen as "awkward or trouble-makers" as this can adversely affect the outcome. There needs to be clear independence when investigating complaints and it must be an explicit responsibility

that anyone investigating these complaints should have direct experience of Disability, of being a service user, or the investigator must work closely with someone who has. In both the complaint and review processes legal advice should be available to the Disabled Person. It is very stressful every year to have to constantly prove your needs over and over again. It always feels like Social Services is trying to catch you out or get out of helping you, or constantly trying to argue that Health should help you instead. Reviews should be more positive and friendly and should be seen as a time to check out everything is OK rather than the pressure constantly being on the Disabled Person. If this Right to Control legislation is done properly it must ensure that assessments are holistic and therefore, regular reviews look at everything in one go rather than different bits of the service having a review of the Disabled Person at different times of the year. A Disabled Person must be allowed to have a friend or supporter with them during any review or complaint process. They must not automatically be seen as advocates, but rather as supporters who will advocate if the Disabled Person needs them to.

ICR05

Process must be fast and simple. One process not several as now. Simple and easy complaints procedure and independent review process. Simple leaflets, sign posting on how to do this should be told how to complain when assessed.

ICR06

In my understanding a suitable website that allows direct contact would be useful with helpful advice and guidance. The time allocated to a call advice line could prove useful.

ICR07

The gvmnt knows full well, well it should do and I'm sure it does that people who are coping with disability/serious illness are simply too sick to appeal. This is all 'very' cruel.

ICR08

Always inform individuals they can challenge decisions – in a way they understand. Don't make them feel guilty if they feel they want to – as some people have in the past.

ICR09

- Most people don't complain, so this is an issue. Systems would work much better if they did.
- People need full, clear, accessible and transparent information about each part of a decision. For instance, if someone's claiming funding for a range of needs, and is given a lump sum in response, it's impossible to challenge the decision effectively because there's no information about what amount has been assessed for each category of need.
- Free legal support and advocacy.
- Case law operating at an early stage to test and modify the system would be helpful!

ICR11

Well trained, skilled quality marked advocate not paid for by the organisation/agency at the centre of the complaint. Skill in management, organisations, delivering into in a no. of ways. Keep up to date with law & policy & procedure.

ICR12

Very difficulty, most disabled people and their carers 'give up' their complaints once the issue has passed because its all to much and probably have that sense of feeling that they are wrong.

ICR13

An advocate and service for those with hearing – speech and learning disabilities etc. a DVD or CD with a simple explanation on how to complain. Try to use less jargon and more simple English explanations.

ICR15

Very difficult to complain as people are mostly dependant on the people / bodies they wish to complain about. Perhaps an independent phone help line direct to a person (not a machine) might work for people who can communicate verbally.

Working together to develop the trailblazer sites: Question 12

What do we need to do to ensure that disabled people and their organisations play a full part in the trailblazers?

ICR01

I think there needs to be an honesty about the possibility that some disabled people may benefit from this but others may not. If you are a creative person with good understanding you will be far better placed to benefit than if you lack this. I think everyone automatically expects to be better off-I do not see how this will be possible. Clearly devolving money to the person using it should unleash a potential to free things up but not necessarily how everyone expects.

ICR03

It is hoped that there are sufficiently robust Disability Organisations in each area to play an active part in the Trailblazers. There probably is not, one has to ask why. It is important that any Disability Group is pan impairment so it represents a broad range of experiences and outlooks and Disabled People themselves must be fully immersed in the activity. Maybe a new group needs to be formed, 'pump primed' from the Local Authority and CVS clearly setting out its intentions. This all goes back to what I intimated early with regard to Centres for Independent Living.

ICR04

Make sure that Disabled People and user-led organisations are the leads in all meetings, or at least have a professional Disabled Person facilitating them who can challenge public bodies, can work through plans with Disabled People, and give meaningful and realistic feedback. Ensure that a variety of Disabled People's opinions are included. Make sure that Local Authorities speak to Disabled People getting services from other Authorities for some honest ideas of what can go right and what can go wrong.

ICR05

Work with NCIL and other DPOs to capacity build. Provide more independent funding. Fine Local Authorities without a ULO in place by 2010.

ICR06

The importance of successful liaisons would give helpful organisations a full part in the trailblazers by their respectful insight to the disabled persons needs. This should allow long term discovery of the active role that individuals require and fulfil the needs of organisations to plan effectively in cooperation towards achievements and aspirations that inspire others.

ICR07

What? We do not wish to 'play'. We'd just like to 'survive' if that's ok with the gvmnt? Or does the gvmnt really want us to die? There is already a high suicide rate for people who have M.E. It is the disability system that finishes them off in fact. There is going to be an alarming increase in suicides I fear. I may be one of them, if I really can't survive, or my self esteem is ground down too low by all of this. When one is disabled/seriously ill, maintaining one's self esteem is such a crucial factor. This matter is not just about money. What is the 'message' being given to the disabled/seriously ill? 'You are a burden.'

ICR08

Consult widely – try to reach all people, especially those who don't always have a voice. Be open/transparent & engaging. Involve from day 1. INVOLVE FAMILY CARERS – they will be providing most of the support – alienate them and the system will never work. I thought the personalisation agenda values carers – I don't see any evidence in this document.

ICR09

- Simple, straightforward information.

- Opportunities for disabled people, public bodies and service providers to meet in an open forum to express their local concerns and possible solutions.

ICR11

Treat those with a disability the same as everyone else. Ensure there are no barriers to accessing services. With choice comes responsibility. Ensure training and networking events keep key individuals up to date. Cascade information. Measure performance & act on poor performers. Enable service users to inform decision making thru groups/phone/video conferencing etc.

ICR13

Write – phone – email - disabled groups – carers groups – known individuals who are disabled and carers. Make any communication as personal and jargon free as possible.

ICR14

Involve them at an early a stage as possible.

ICR15

Home care: Commissioners must make frequent physical (not paper) checks direct to users of contracted service providers. They should also speak as often as possible in confidence to the 'front line' carers many of whom have grave concerns and sadness because they are prevented from giving all the care needed (and promised) by the short comings of office management.

Transport: How do we influence road makers to care for disabled people? Most wheelchair users are also in pain. 50% of dropped curbs are not flush with road surfaces. Pavements in Gloucester are in such poor condition that it feels as if were travelling over cobblestones! Could traffic-calming humps be extended to paths to provide flat crossings? Invite all disabled people, carers, doctors, local councillors, teachers to take part in meetings such as organised by LINK.

Implications for service providers and commissioners: Question 13

What are the implications for service providers and how can they be assisted to play their part in promoting choice and control in the Right to Control trailblazers?

ICR01

It does make service providers more vulnerable/accountable. As above I am concerned at the individualism of the approach if implemented inflexibly which seems likely will be at the expense of good collective arrangements that have served many disabled people -especially the most vulnerable well.

ICR03

The implications for service providers are clear. Do they provide the RtC user with what they want? Can they offer choice with any service provided? The issue of control rest with the Disabled Person who may themselves need a degree of support in any decision making process. There may well be a need for cultural change (very difficult) in Local Authority Service Provision. The need for reliability in any service is paramount.

ICR04

See answer to question eleven.

ICR05

Service Providers need to change their attitude towards disabled people. Must accept that they are not in control - service user is. May need re-educating and retraining

ICR06

The duplication of services is a main concerning relation to budgeting allowance. Therefore I would encourage a transparent

review to allow achievable aims to be developed and that would give the ability of some service providers to adapt to the needs of their structure and allow assistance to play.

ICR07

Tell them to go away and get a proper job? Sorry, I'm very tired now (and I can't read up any more).

ICR08

Fear – whilst some people will welcome the right to be involved & control their lives, many will find it a scary thought and don't like a lot of choice – it will give them more to worry over. My son with Autism would worry about having to make more choices.

ICR09

- Huge implications! This could be one of the most difficult transitions in recent history. Clear information about Right to Control is, once again, a key element of enabling service providers to respond. They need to be fully aware of the opportunities and also of their responsibilities.
- Service providers may well need to link with public bodies to consider implications and to plan how to manage this change.
- Service providers also, and most importantly, need to work with disabled people to understand the likely needs and issues.
- Again, openness and the willingness to adopt new ways of working will be an advantage.

ICR11

Death by consultation. Being given expectation of what might be and then be let down. Remove barriers of idiosyncracies where e.g. on benefit might be gained means a reduction in the whole. Sustainability. Review & evaluate to ensure it works.

ICR13

In previous questions I have highlighted the need for the personal approach, but also the service providers must be prepared for sometimes harsh criticisms for past performance. The disabled and carers are now being empowered by national and local government and they are not afraid to use their new freedoms. Watchwords for any service providers are:- LISTEN and LEARN!

ICR14

Service providers will need to be empowered to provide the services needed by service users.

ICR15

Service providers will need to monitor more closely the care they are providing. Often more is promised than is delivered. Usually the fault of poor organisation of time and resources by middle management. Shortcomings are not often (in my experience) the fault of direct carers who are pressured to do more than is possible (eg rota requires them to be in two places at once. No time allowed between home calls). More supervision – direct contact with users by contracting bodies.

Implications for service providers and commissioners: Question 14

How can public authorities and service providers best work together with the service user to agree an individual's support plan and support them to achieve agreed outcomes?

- Who should have lead responsibility?
- How should reviews of the support plan work?

ICR01

I would opt for local authority social service depts as being in the best place to implement/coordinate locally. My experience of organisations such as ILF/Access to work are that whilst sometime excellent they are unpredictable/rule bound and inflexible and they are often not there for the long term- i.e. they pop in and out but are not there quickly when problems arise-it isn't as easy for social work staff to disappear-they are locally accountable to councillors etc

ICR03

There must be full clarity and understanding amongst all the Public Bodies responsible for the funding streams, which are to be used in an RtC Scheme. Full commitment amongst practitioners of RtC would also be welcome but could be difficult amongst some people. This goes back to what I said earlier, i.e. a culture change for some – the Disabled Person in the driving seat making decisions for themselves and not beholden to others having to accept what they are given. Extreme views but elements of this way of thinking in the health and social care sector still persist. Any 'giving up' of resources to make RtC work must be strategically agreed and come from senior management and their needs to be parity across the country.

Working together is crucial amongst everyone with a 'can do' approach. Clearly, some Disabled People may need support e.g. what RtC means and is undoubted benefits but by the same token

concepts of responsibility and budgeting may need explaining particularly in the context of agreed outputs. One person should be identified as the communication channel for the Public Body RtC money and the Disabled Person have the lead responsibility and control i.e. how the money is spent of the RtC amount.

ICR04

See answer to question 11.

If there is such a role as the life choice guide they could be key in this process.

ICR05

Lead Responsibility 1 Service User and Advocate 2. Service Provider 3. Overseen by public authority. At request of service users and advocate at any time. Otherwise annually during pilot process - less often otherwise. All emphasis must be on agreed outcomes being met.

ICR06

I have hope that the many who enjoy the needed structures will follow up on recommendations by those who represent the persons to forget for the needed encouragement and deliverance of a shared support plan

ICR07

Well it's taken me all this time to realise. We're going to save a lot of money, when you make all of those lazy civil servants redundant. Bye bye council tax and housing benefit people. I get it now. Ok, it sounds good. Then I hope you will use that money, to make sure it reaches those in need. Good. Sorry about the job losses though, seriously. This is interesting because here the gvmnt admits that other people will dictate care. But you haven't a clue what I need, so how can you? Which outcomes? Ok, if I have someone in to do all of my shopping, cooking, cleaning and ironing, I may be able to work 4 afternoons per week. Is it worth it, realistically? I should have the lead responsibility for my care.

They should work, in my favour. I am the sick and disabled, vulnerable person and not through choice.

ICR08

Whoever the individual chooses, should be the key worker, the person they trust.

ICR09

- Seamlessly.
- For the moment, the public authority should have lead responsibility.
- Reviews would work best through a single-contact co-ordinated response.

ICR11

Decision about care should be joint agency. Improve communication breakdown barriers between organisations. Have champions of good practice. Review should be agreed & timing & method at same time as plans rolled out. To include all involved. Train staff & review their practice regularly. Provide quality supervision. Provide up to date procedures. Use service users to review & evolve policy & procedures. Have regular networking events with examples of good practice for workers & s. users.

ICR13

Basically, listen not only to the individual who needs the support, but also the carer. Often in the past carers have been totally ignored. Carers – they are a valuable source of information help and co-operation.

ICR14

Lead responsibility should go to the Social Services Team.

ICR15

More supervision is needed re actual care provided. Example: Homecare – Personal & domestic; Public Authority – Glos social services contracts out care to local care providers. Setting up very good. Interaction SS, self and GP to agree homecare package. But in practice not so satisfactory. Lead responsibility should be with care users and remain so. Reviews of support plan do not really work at all. Questionnaires are conducted in such a way that ordinary dissatisfaction are not really dealt with. Complaints made to public authorities and care providers are met with ‘we will look into it and rectify the situation’ but things are not put right and no feedback is given. Front line carers (who come to the home) are mostly excellent but unsatisfactory workers are not checked on or dismissed merely moved to people less able to complain. Good carers have their dedication abused by given impossible tasks – booked to be in two places at once, no travel time between clients. This leads to many users having their due time curtailed. Carers and users are unhappy. Care should not be contracted out to profit making bodies.

Implications for service providers and commissioners: Question 15

Are there particular implications for third sector organisations and how can they be addressed in the Right to Control trailblazers?

ICR03

This will depend on how well developed the third sector organisation is, its constitution and whether the board of trustees choose to take the organisation down this path. If so there will be implications of delivering outputs for a service contract. Obviously how these are drawn up, what goes in them, what quality can be expected and crucially at what cost. The cheapest option may well not be the best service.

ICR04

There might be in that some of the independent work might go to them. However, it is important that they are not set up as an extension of or act in the same way as Social Services. Disabled People themselves must be the key focus. Having worked on Family Support issues in the Council I have found that third sector groups do not have the knowledge and training and power to take on the guide role without some clear support.

ICR05

To fully support disabled people 3rd sector organisations need to fully develop their capacities. Need more independent and reliable funding sources in order to plan and implement service delivery.

ICR06

This would not be a needed sector of organisations if the person who are the remit decisions makers had first experience of clients that voluntary groups agreed to their own coverage of the assessments base discussions implemented by the commission.

However, it would allow more rigid allocations of voluntary groups to assess their experience to be highlighted to ensure the effectiveness of persons control outlined in trailblazers to be implemented. I am sure this would lead to positive to excellent feed back. For the commission, voluntary groups and the persons at resulting end of cooperative control in service and community functions it would a successful outcome.

ICR07

This is over my head again, but I understand from them that they are not at all happy about what's going on. I'm sure they've given you their reasons.

ICR08

They will need to think 'outside the box' and adjust the way they deliver their services. They still have a vital role to play and could look at it very positively.

ICR11

There appears to be a move by local authorities towards collective service level agreements where several small groups or branches of large organisation must get together to bid for funds. This often means mergers. The implications of mergers are not being thought thru such as the cost of a universal IT system. Only the cost saving such as management/capital expenditure/oncosts seem to be considered. There are risks regarding loss of organisational identity and reduction in meeting local need as services become centralised. Exit strategies are non existent. Deadlines can be too short for already stretched small groups. The time away from delivering services to service level agreements/mergers is huge & not costed.

ICR13

I am not sure by what you mean when referring to "third sector organisations" If you mean private companies and businesses, great care must be taken so that no exploitation takes place. No

company or individual must be allowed to acquire financial reward from co-operating in the provision of services.

ICR14

I am not sure by what you mean when referring to “third sector organisations” If you mean private companies and businesses, great care must be taken so that no exploitation takes place. No company or individual must be allowed to acquire financial reward from co-operating in the provision of services.

ICR15

More consultation direct with service users.

Implications for service providers and commissioners: Question 16

What are the implications of the Right to Control for the commissioning of services and how can commissioners be assisted to play their part in the right to Control trailblazers?

ICR03

Any commissioners involved in RtC must clearly demonstrate an understanding of a Disability Equality philosophy and be able to demonstrate this in their practice. This could be difficult as I have already intimated as the whole ethos of RtC is 'giving' Disabled People the power to choose and decide what services are right for them within agreed outputs. This means commissioners having to 'give up' some of their control. Can this be achieved in all cases?

In the Trailblazer sites a template could be developed on how RtC should work incorporating training support programmes for Disabled People and commissioners.

ICR04

Commissioners need to be much more co-operative and flexible in their approach. In fact the Disabled People should become the commissioners and will have to learn to work with the organisational ones so that they can help Local Authorities and Health etc to plan ahead whilst keeping these plans flexible enough to meet changes as they arise e.g. how are they going to react to a request from a group of disabled people to use their respite budget to go on holiday to Spain. Disabled People will need to learn skills of negotiation etc.

ICR05

Need to commission a wider range of services, reduce block purchasing to enhance choice. Must monitor quality of services commissioned. Must be more flexible in their approach to what/who they commission.

ICR06

In the bodies set to organise the implementation of the needed response of governing the require level of support each component must adhere to the required need of others this primarily being the set up of over reviewing the local support activity. The organisations I have reviewed would be assisted if the individuals would contribute to their endeavour of development. Therefore ensuring that duplication is subject to the requirements of each person and overseen by the accredited ombudsman to draw the correct amount of deliverance of public service protocol for those who require the ongoing interests and thus ensuring a full and fair assessment to ensure full support.

ICR07

This is over my head and I can't read any further, nor take in any more information. I am tired now and I lack ability. I have done my best, more so for the people who are more ill than I am, in respect of brain fog and who 'cannot' speak for themselves, bless them.

ICR08

Many block purchases will change but they can adjust their service to suit demand. They will need help to do so and that will be key to transition of service.

ICR09

The big issue for commissioners is how to manage the transition and still achieve fitness for purpose and value for money in a rapidly changing environment.

ICR11

If Right to Control is a failure commissioners will lose integrity and the confidence of service users & carers. This is already at an all time low with threats of cuts, consultations which lead nowhere &

overpublicised mistakes. Look at others good practice, listen to customers. Train staff to provide “rolls royce” customer service. Keep up to date. Be sustainable. Don’t promise what you can’t do. Protect against political influence where possible. Don’t be reactive but proactive.

ICR13

The main implication for “commissioning of services” and “commissioners” is they should never forget the individual at the end of the lines and the carers who will receive the benefits from the “Right to Control”

ICR14

By making sure that they have all relevant facts about a service user and their needs.

ICR15

Same as 15, more direct consultation with service users.

Any other issues: Question 17

Are there any issues or concerns not addressed above about the Right to Control that you would like to comment on?

ICR02

This response is written from someone who has been a family carer of both elderly members of my family and also a person with learning disability for many years. I have also taken an active part in consultations and local activities in these areas. From this experience the Right to Control is welcome as one of the means by which disabled people can be helped to achieve a better quality of life. I have no doubt, as the examples show that a large number of people will be helped by this legislation.

Equally throughout the years of caring for different people it has become obvious that one solution does not fit all cases. Research shows that RTC is not right for everyone and can be detrimental for a large group. Hence LAs cannot be allowed to have procedures which see RTC as the only or even the main approach to supplying services to the detriment of all others. I would therefore raise the following concerns and comments: -

As stated earlier "Right to Control" must never become an "Obligation to Control", whereby there is only one way that clients can be assured service. Equally carers must never feel under pressure to exercise "Right to Control" if it is not right for either the service user or themselves.

Service users and carers must have a safety mechanism by which they can revert to old services from RTC if they find the new arrangements are detrimental or there is a change in existing services which could be beneficial to them. Recently a number of service users who were people with learning difficulties reverted to Day Services following improvements in their area.

Low cost support must be given to service users and their carers to manage the "personnel issues" of RTC. This is particularly the case for carers who, as seen in 1 above, may feel under an

obligation to take on RTC to achieve the best outcomes for their loved ones.

The case studies throughout shows that the main problem for many is the multiple payments: from different funds; on different days; with different reporting requirements and different review periods. All reports put this forward as the major problem. The personal example quoted above shows that this is still continuing and getting worse. RTC does little to sort this out.

Much is being made of cross government strategy and inclusion in the numerous strategies and papers of different colour. However they all seem to be aimed at particular groups.

a) The green paper on social care “Shaping the future of Care together” offers the prospect of a right to assessment for all but concentrates on the elderly where RTC already exists to some extent.

b) RTC concentrates on the severe and critical cases of disability. Much of the thinking seems to be about finding a single solution, forgetting that most individuals have individual problems. To many it would appear that there is a piecemeal approach at tackling “hot spots” of public spending.

This is carried on under a gloss of personalisation for those who qualify. For true personalisation, professionals should be allowed to find best solutions for individuals’ problems from a wide range of solutions in their toolkit, without preference to one particular method.

The document states:

“The Government wants to shift the balance of power from the State to the individual; assisting disabled people to achieve better outcomes from the support and services they currently receive. “ The balance of power is not shifted as the purse strings are still tightly held by the State by limiting and deciding the level of need at which help is given. It is still a lottery as to whether a service user falls in a particular category to receive help. Without new money major improvements will not be made.

ICR04

I am a wheel chair user and blind, I have no independent mobility. I have 24 hour support through Direct Payments and my employment (my employer employs a Support Worker for me). I am married and live in my own home with my husband and 4 year old son. I work full time. The comments below are based on my experience as a Disabled Person who has been directly in charge of their support budget since 1988 (obviously the first few years of this arrangement were kindly done unofficially by the Local Authority).

One example of where services did not work together for me was a dispute between me and Adult Social Care when I was being assessed for my current direct payment package. I was asking for overnight support as I need to be turned during the night which Adult Social Care said was a Health issue as they would deal with bed sores. My argument was that it was not a Health issue as so long as I was turned I would not get bed sores. I drew the analogy with eating which my Helpers have to help me with. As long as I get help with eating I will not be underfed, but if I did not have this support then I would not be able to eat and so would become unwell, at which point I would be in need of Health's input. Eventually, I got my way, but the argument was unnecessary and comes up every year at my annual review. I know that Adult Social Care wants to get funding from Health if it can, but whilst they are arguing I am having to see extra people and talk about my needs over and over again whilst worrying that they are going to make me have a nurses visit during the night which will disturb me and my family and which will take away my independence as I will not be able to decide when I want to move which I can when my Helpers are with me overnight.

As I believe that all payments should be part of the Right to Control legislation this would be a good time to re-examine the Fairer Charging Policy which does not assist Disabled People to live as their non-disabled peers. Although, income is ignored within Fairer Charging the rules regarding savings penalise Disabled People. I have since starting work saved assiduously as I know that my working life might not be as long as others and also so that I have plenty of money for my retirement and to ensure that my son will not be burdened with debt when he finishes his education. As a result of having saved I now have to pay the maximum charge for

my direct payments from taxed income which means that I am at present paying £468.00 a month just to live independently in the community where I have all the other expenses that my non-disabled peers have e.g. Community Charge, Mortgage etc. The premise behind savings being taken into account for Fairer Charging was that a Disabled Person would earn interest on their savings to pay their contribution. To earn interest of £468.00 a month, should I be able to get a savings account which paid 3% interest per annum, allowing for tax to be taken off, I would have to have savings of about £225000.00. Thus I either have to reduce my living standard by paying from taxed income or reduce my savings. The means testing rules also impact on people who have ILF funding which I used to get until my savings reached their upper limit. Saving has been advocated as something that prudent people should do and yet as a Disabled Person I am penalised for following the advice of Government.

Where there is a problem is that to get services, especially care, you have to sell yourself as a burden. What Adult Social Care need to do is to look at Disabled People holistically. In my case it is expensive to fund my support to live in my own home. However, because I have my support package I am able to work full-time and pay taxes, National Insurance etc, I employ 4 people who also pay taxes etc, and am able to look after my son properly so that there is no need for any intervention from Children's Services. Therefore, what looks on paper as a large expense for Adult Social Care is, in fact, saving a lot of money as I do not use residential provision, my son is not involved with statutory services and I am enabling 4 people to earn a living.

I have been working on something recently and I disagreed with them using DLA as a criterion for a service. They assumed that if you have DLA you have substantive needs and therefore fall into a higher tier of need. However, I did point out that as a 10 year old wheel chair user I was much easier to deal with than a toddler who is running round getting into everything or someone with a behavioural disability because you could just stick me in one room and leave me there. However, I am blind and use a wheel chair and am seen as having multiple disabilities and am thus put into a higher tier of need. You have to change society's attitudes so that they think about people's real needs not what they are assuming they are.

Note - I have just read the case studies in Annex B and really like them. However, I have a number of problems with them. First of all they all start by saying how much money the person is going to get and then go on to say how the person identifies their desired outcomes or identified goals which are then put into a support plan. This seems to be the wrong way round. Surely, until you have identified your needs how can you know how much money you are entitled to? Secondly, I do not like the idea that these plans have to be agreed by the funding agencies in Kerry and Jerome's case. This seems to take the control away from the Disabled Person again and would take forever for them all to agree. It would be like a shop giving me some money for me to choose a T-shirt to buy from them which they then say "no this one would be better". This is why all my comments say there should be an independent body which assesses and allocates money and which then helps you go to a provider, mainstream or otherwise to get what you require. Thirdly, a lot of the equipment or services that the examples imply that you can have would not be allowed by Social Care etc, e.g. social activities, going to the gym, paying bus fare to see your son, and mainstream tools. Therefore, their criteria would have to change dramatically. A lot of pressure would have to be put on them to do this as over the last few years they have become more and more restrictive in what they will allow money to be spent on, so I can see Disabled People's support plans being squabbled over a lot.

ICR05

Equality by 2015 not 2025 - most of us will be dead by then.

ICR06

In the review of the cases that has brought forward this awaited development the persons who have experience both the bureaucracy and failure to implement their social needs have often been subject to a consultation which has not been the focus of their needs. Nevertheless it would not surprise a noted lapse of individual assessments to allow all concerns to be address and therefore allow duplication to be minimised to the clients full and statutory concerns promoted to the real activity of all groups to be a answer(s) for all that are their in realisation to the need of

support and care their in realisation to the need of support and care to allow effective control of help in human dignity.

ICR07

I comment again that this document and this new system does not, anywhere that I have seen, have any consideration for protecting people's health from deteriorating any further, which was the main purpose of the disability system. People with M.E. must NOT be allowed to work full time, for even several years after they feel they are well, should they be fortunate enough to reach this recovery. I spent 6 months in bed, went back to work and became ill again. I spent another 6 months in bed and since then I haven't been able to get it out of my system. This is a very serious and debilitating illness that does major damage unless acted upon immediately, with total rest (at that initial stage). Graded exercise is harmful. The brain needs some slight stimulation and rest needs to be balanced with a small amount of exercise. The patient must lead. It is good to push forward at times, which is painful and then take a few steps back again, to a comfy place. But certainly not for a couple of years, following initial onset of symptoms. I feel it is important to mention the damage caused by gvmnt bullying already. This information is of course, unknown to our full-time workers, in full health. Every bully isolates its victim.

DWP lowered my benefits. This caused to me incredible distress, because it meant that I was no longer able to survive, but still far too ill to work over 16 hours per week. Six months of stress and all of the damage that caused to my health later, I discovered that I was allowed to do a little work, a little work being all I am 'able' to do. Further to this, I found a job that I felt I could manage. I worked 8 hours per week, which meant that I could once again survive. A year later, my hours were cut to 8 hours per 'month' by the gvmnt. With an extremely condescending tone, as if I am personally responsible not for my tenacity and determination, but for my disabilities, I was told that I could "try again" (to manage over 16 hours work per week) "next year". This is when I started to really 'hate' this gvmnt. I ploughed on, relying on credit cards. Had I not worked for local gvmnt, I would have lost my job altogether. Such negative and destructive behaviour by the gvmnt. As it is now, each alternate year, I am only able to regain 4 hours of work per week. Taking from me these few hours of work, which means

the difference between my survival or not, equates to removing £100,000 or more from an M.P.'s salary. It is the most disgraceful bullying and it may even be called murder, because some people do die on the receiving end of such gvmnt bullying. So, I am once more kicked down, below the poverty line, by my own gvmnt. What does this behaviour achieve? Does it motivate? No. Does it kill? At times it does, yes. Some people do actually die because of this sort of gvmnt behaviour. Does the gvmnt really believe it can bully, seriously ill people into being well? This is a ridiculous notion. I am absolutely as well as I can possibly be, with the resources I have available to me and I have the greatest respect for any seriously ill/disabled person who despite their pain and lack of ability, manages to lead a fulfilling life and make some contribution to society, whether the gvmnt allows/supports this or not. The well, take their health for granted. We do not have this privilege.

ICR08

Nowhere in this paper are family carers mentioned. We all know many people with learning disabilities live at home. Many families will be taking on the role the advocacy etc. – but you've not consulted them. Very poor considering the personalisation Agenda feels supporting carers as vital.

ICR09

Right to Control sounds like a great opportunity for disabled people. However, I have a fear that, particularly in the early stages, the attendant responsibilities for some disabled people might outweigh the apparent benefits. For instance, if a supplier fails or if an employee discriminates or behaves otherwise inappropriately, the sometimes considerable weight of taking remedial action lies entirely with the individual, who is operating in a personal capacity. At least organisations are usually geared up and have the capacity to address these sorts of issues.

ICR11

Getting over the service users feeling of dejavu. Surmounting agency boundaries/barriers. Recession/cuts in services. Move back to centralised delivery of services. Closing one stop shops in some areas. Closing local post offices. IT training, access to IT support.

ICR12

Yes, as a carer of 42 yrs of our son with L.D. I feel utterly disoluted with the whole issue. We live in a world of L.D. have put up with the closure of big hospitals people going into small homes and becoming insulated. Closure of big day centres, fragmented the whole service. Not enough room in the small centres for younger users and now this! Its just privatization – and we will end up with many agents making a quick “buck” at the expense of some of the loveliest people, the leaning disabled and their carers will have their lives ruined again.

ICR13

My only real concern is the way this document uses jargon, long words and repetitive questions. Questionnaires and form filling can often be a BIG NIGHTMARE for the disabled and there carers. Please could you in future amend your documents so they are more user friendly!

ICR15

Grass root control from government to local authorities need to be put back into place to ensure fair distribution of resources countrywide.

ICR19

Right to control will end up being a post code lottery. It may work for people in a town or city: but it is highly unlikely to work in a village or rural community. In a village of a 1000 people

in Dorset for instance in an area full of care homes for the elderly there are so many jobs for carers and not enough carers!
It is difficult enough to find some one to clean.
So right to control in a village will only work for if a person has friends or family.

In Dorset the local authority charge a minimum of £15 an hour so if a person is accessed for 15 hours care a week they would need £225 a week to pay for their care. The local authority though do not do care for people who are payed for instance a lump sum of £150 to pay for their care, though they do access an individuals cares needs in the 'fair access to care' criteria which I have to say is not fair for people who do not fit into rigid criteria, being long term sick or disabled are not suitable for putting in box's that one can tick, each person is individual and sometimes their needs are not allowed or accounted for. The local authority do though find agency's to do care paid for with a weekly lump sum yet the quality of care delivered by the agency's are inferior to those that the local authority provides.

I have been told by a social worker that clients often say that agency care is not Up to scratch.

I was told by another social worker that the 'fair access to care' criteria is open for interpretation but only by the local authority.

Please think of have regard and respect for the individual.