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WILTSHIRE & SWINDON USERS' NETWORK

1991 - 2011

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The Wiltshire & Swindon Users' Network (WSUN) and our Members' Response to the "Disability Living Allowance (DLA) Reform" Consultation Questions and WSUN's Strategic Overview

Foreword

The Wiltshire and Swindon Users' Network (WSUN) is a user-controlled organisation that meets the Department of Health "Design Criteria" for an established User Led Organisation (ULO). WSUN supports people who come with the experience of having physical or sensory impairments, using mental health services, being an older person, or having a range of learning difficulties. This also includes those referred to in the 6 equality strands and all are hereafter referred to as 'marginalised groups' Our members are supported to become involved to develop ideas to shape Services, such as Health, Social Care, and Community Partnerships with Wiltshire Police Equality Unit. WSUN has recently been commissioned to set up Focus Groups to undertake Access Audits and scrutinise plans for Disability Access Issues.

We also host a very successful award winning Wiltshire Independent Travel Scheme (WITS).

WSUN has recently taken on, (from the 1st August 2010) the Host responsibility for the Wiltshire LINk (locally known as "Wiltshire Involvement Network – WIN" and now co-produces this function with Age UK Wiltshire.

WSUN believes in, and is totally committed to, the vision and values of social inclusion. We seek to ensure and promote Dignity and Respect for all in our local communities. But all Local Authorities (with Social Care Responsibilities) need to ensure ULOs are supported appropriately with continual funding to ensure this vision becomes a “true reality for all,” not just a few.

Note:
This report has two main sections:-

Part 1 – WSUN’s own organisational Strategic Overview on the “Disability Living Allowance (DLA) Reform” Consultation

Part 1: Relates directly to the sections in the DLA Consultation Paper, for ease of cross-referencing and if there are gaps it means WSUN has no comment to make on those sections:

Department of Work & Pensions (DWP) - Disability Living Allowance (DLA) Reform – Executive Summary

WSUN welcomes the government’s commitment to promoting social justice for disabled people and the focus that has been given to increasing independence, being involved in what is happening in your local area and better job opportunities.

However, we are concerned about how it will happen or what skills and training of the “Decision Makers” will have’ to make decisions on the ability of all disabled people to undertake “daily tasks”? WSUN would recommend service users be involved in and are consulted when there are issues of doubt and also are involved in appeals panels

WSUN believe the government’s proposal needs an urgent reconsideration of the following four areas:-

Residential Care Homes:

WSUN is worried it could be assumed that, for people living in residential care provided by the Local Authority, the LA would provide all the care and mobility requirements for that person. However this is not always the case. The Mobility part of DLA provides a way of giving a person living in residential care an opportunity to cover the additional costs of being able to get out and about.

If the government goes ahead with these changes, it could mean a significant reduction in the “quality of life” of those affected and unable to get out and about; or Social Care could be expected to make up the difference in funding. Given that the Government have said we need to save money in the way services are provided, WSUN think that Local Authorities may not able to do this.

For example WSUN is concerned if the following happens regarding:-

- The removal of the DLA mobility component from people living in residential care is based on the idea the Government have on ‘double funding’. However, evidence shows that most Local Authorities are not currently meeting mobility costs. It also makes clear that rather than removing ‘an overlap of public funds’ as the government has stated, this measure will simply transfer costs to already-stretched local authorities or will leave people without the vital support that they need.

- Many disabled adults (under 65 years of age) living in residential care have all their income taken to pay for their care, and are left with just the £22 per week Personal Expenses Allowance (PEA). This is not intended to cover additional mobility costs. It is intended to cover personal costs such as clothes, toiletries and phone bills. Without the DLA mobility component, the PEA is not enough to cover additional mobility costs and people will be left without the money to meet basic mobility needs.

- The resulting savings of £160 million are relatively small in contrast to the total of £81 billion in spending cuts the government plans to make by 2014/15. Many residential homes think this may affect up to 80,000 disabled people (across the country). If this is right, many people may be left unable to afford to leave their home and denied the independence most people take for granted.

Taking into account aids and adaptations:-

WSUN have said that many disabled people use aids and adaptations to increase their ability to participate in everyday life. Currently, DLA takes account of some adaptations, such as false (prosthetic) limb(s) but not all, for example wheelchairs are not taken into account. WSUN believe the Government should not take into account the use of aids and adaptations as part of the Personal Independence Payment assessment. These are **basic human rights** requirements to enable people to remain as independent as possible and not luxuries as all our members confirm.

The mobility part of DLA needs to remain in place in order to:

- enable disabled people to properly service and maintain their equipment and insure for “public liability” and to cover the cost of “wear and tear” and therefore save for inevitable replacement. It should be recognised that some aids and adaptations are provided by government and will be returned for other’s to use when no longer required.
- allow disabled people(having had a Local Authority/NHS Assessment)to maintain privately purchased equipment. This principle enables social inclusion as citizens and is at the heart of 'putting people and patients’ first and increases disabled peoples’ “Choice and Control” (As per the principles’ in “Liberating the NHS”.)

Structure of the new benefit

The restructure of the proposed benefit includes changing the current system of being assessed as having either low, medium or high support needs will change to a two part system. People’s needs will be ranked by using an assessed list of tasks that can be completed in order to qualify for the ‘daily living’ part. A ‘tick’ list would not identify the difficulties someone might face when completing the task and factors such as skill, confidence, fatigue and risk of injury needs to be taken into account.

WSUN members can give evidence of their particular difficulties that would not fit the proposed ‘tick’ system as this will not reflect the existing complexities for individuals.

A passport to other support

It is important that the passport to other benefits is maintained. Otherwise people will have to evidence the level of their impairments and the level of support required time and time again and this leads to a duplication of assessment and bureaucracy and further stress for those with impairments or disabilities. There is a huge difference between someone recovering from an accident and those who have diagnosed and progressive conditions.

It is fundamentally important there is a “top up” mechanism that reflects the hidden costs for disabled people, on this long journey to becoming “full citizens” in the “Big Society.” Therefore if these passports were removed it would put people on, or under, the poverty-line.

It is currently passports that lead to the following benefits, (but not extensively or exclusively). Giving entitlement to:-

- Council Tax – reduction of band
- Bus passes
- Blue badges
- Incapacity Benefit premium or (Employment Support Allowance premium)
- Jobseekers allowance premium
- Independent Living Fund (ILF)

Part 2 – What WSUN's members' said to the "Disability Living Allowance (DLA) Reform" - Consultation Questions

Foreword

Whilst WSUN actively promotes, supports and believes in the Social Model of Disability, we have circulated and asked our members to respond. There may well be some medical model views in this report. WSUN has compiled this report to reflect the diverse and cultural views of the individuals who were consulted.

The views expressed by individuals in this report do not necessarily reflect the views of WSUN.

The process by which WSUN consulted with our valued members';

WSUN used the "Disability Living Allowance Reform" and developed a questionnaire, using the questions in the consultation document. We have also independently supported people to complete the questionnaire. We have outreached to a number of WSUN members who would otherwise have lacked confidence or skills and also written letters to the Editors of our local press, raising awareness of the consultation and WSUN's wish to pass on their views. WSUN gave members and service users the contact details of the Department of Work and Pensions Website and address so that people could reply directly back to you if they so wished.

Issues relating to people who have hidden impairments (disabilities)

WSUN has used extracts of an event, in January's 2011 "Our Time To Talk (OTTT)" WSUN supports and facilitates OTTT. This group covers the entire spectrum of people with Mental Health experiences including many people who have experiences of being sectioned under the Mental Health (MH) Act. (WSUN also supports people who have previous experience of detention under "Section 136 of the Mental Health Act")

Some people who have experiences of; MH, Dementia and Learning Difficulties have said although they can physically undertake the ‘’Daily Tasks” they need to be supported/actively encouraged or reminded to undertake those tasks. Some people have also said they can get dis-orientated mid task, sometimes due to the level of medication they take, “It’s like trying to concentrate in a fog!”
Extracts: from OTTT and their concerns, relating to PIP and their support needed to live more independent lives:-

A group discussion ensued highlighting the following points:

- The importance of small, local groups which help people to ‘recover’
- How life is hard for everyone but the lack of support impacts on ‘wellness’ with one attendee emphasising the importance of not giving up support during times of ‘wellness’. Gave an example of being able to volunteer on an ad hoc basis is not the same as being fit or able to work.
- Stigma and negative perception of people with MH conditions as it is a ‘hidden’ disability.
- The need to provide continuity of service – possible cuts in funding may mean a loss of social support from groups.
- Improving Access to Physiological Therapies (IAPT) and Cognitive Behavioural Therapy (CBT) are available through GPs. However, it was pointed out that only GPs or the Police could make a referral to MH services.

- People said that MH is a complex area and people need time to understand their own medical condition and the impact it has on them so they can explain it to medical professionals. Time is needed to get the right medication and strategies to manage their own MH. It is important for GP’s to take other symptoms seriously and not just say it is part of the MH condition.

Part 2 - Findings: What WSUNs' members said and their individual answers to the consultation questions and will include general comments or views

As these are individuals' views some of the comments may be contradictory, or show different levels of understanding of some of the potential implications for some people.

Question One

What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

Answers:

- Inability to walk further than very short distances with aids
- Can be access. Attitude of others. Finance. But these do not apply in all cases
- As a blind person without sight I find it hard to get about without transport or sighted help being provided
- Lack of money. Unable to access local shops. Unable to access public transport especially when you travel alone. If I didn't have my mobility car the only option is to use Taxis! Expensive
- Stigma "mental people are mad" nothing to show you are ill, not like a leg or arm missing
- Access, equality, support, finances, informative, Ignorance, bias, prejudice
- Mobility and access to facilities, Meeting the additional cost of living with a disability, Access to social care and carers
- Unable to board buses, living in the county where the pavements are no longer there, unable to ride scooters on the road
- Due to health and safety to employers and employees, some employers don't want to employ disabled people with their lack of confidence and

experience. Job interviews and job rejections put them off from seeking employment

- Attitudes and accessibility to information, on aids and adaptions. to ongoing support, the workplace is hard on those who are 'able' to negotiate the pavements, the environment, the attitudes of others not to mention that, those of us with physical restrictions have emotional limitations as well, and tiredness and fatigue plays a large part in many conditions, including my own, and needing to take medication in itself can be an irritation for anyone else about, when my alarm goes off every 4 hours its hard enough to deal with it myself, without having other people have to put up with it. The issues are numerous!!!

- For physically disabled, lack of adequate transport and poor contact with their community. People who experience mental health need extra rather than specified care.

Question Two

Is there anything else about Disability Living Allowance (DLA) that should stay the same?

Answers:

- If you drive a car or need to book transport, the mobility component. As a low income person I really value DLA

- The mobility part of DLA should not change. Without it, people like myself would have no independence without the care part of DLA. I could not buy the disability equipment I need.
- DLA is for help to live a worthwhile life. Not for paying bills like gas and electric

- I see no reason for any change other than to make the system more user friendly

- The trouble again is getting to the surgery, although LINK are good, they cannot get to the doctor for the disability at short notice. (LINK is a local Wiltshire system to provide transport to hospital.)

- Yes, the payment of the benefit should stay the same, so they would get by

- Having a Mobility component is good, and being able to use it to pay for a Motability car is fantastic, however the car issue is also difficult because I can’t use public transport (I’m not confident or feel safe enough, and its not reliable enough to ensure I can get home or back from somewhere) so I need both a car and an electric wheelchair but it’s not possible to get both on the scheme which could be addressed maybe? It would cost more but maybe it’s possible to incorporate both issues and needs, I also need a stair-lift but because I own part of my house it’s no longer covered by Social Services servicing which leaves me having to find funding every time it goes wrong and having to suffer a backward slide in my health because of the lack of stair lift, it’s those things that are not considered in the overall offer of support.

- Many people have been forced to sell their home are the potential victims of further cuts

Question Three
What are the main extra costs that disabled people face?

Answers:

- Electronic outdoor buggies
- Electronic indoor chairs
- Purchase of quick frozen meals as inability to cook
- Payment of regular cleaner as cannot lift hoover or make bed
- Payment of regular gardener as cannot take recycling or mow the lawn

- Petrol for short journeys. Cost of aids and appliances

- Transport costs and carer costs

- I have to buy my own electric wheelchair. They start at £4,500 and last around 6 years. I’ve been refused one by NHS Wiltshire as I am able to use a manual chair in my home. I have to pay a carer to take me to hospital appointments at £10 per hour, 4 hours minimum

- Cleaner once a week, purchase of a second hand bed and second hand scooter

- Help for travel to get you out of the house. Money to buy clothes etc to make you feel good (mainly from charity shops)

- Adaptations, gizmo's and gadgets. Paying for someone to do things they can't

- Mobility aids, wheelchairs are only available to a very small section of disabled population. Aids to living at home, in the kitchen and the bathroom. Modified chairs in the living room

- Heating in the cold weather. Getting into Devizes for shopping. Taxis which is very expensive if one lives 6 miles outside Devizes. Taxis to hospitals Bath or Salisbury take nearly all the money that is given

- Household bills and leisure

- Transport because its not possible for public transport to all be accessible so we are told, in my area some is and others not, but as yet I am not confident I could go out and get back, and if I was to chose to keep my bus-pass I wouldn't be able to have the taxi vouchers for more difficult travelling. But biggest of all is peoples attitudes, being a wheelchair user I regularly get looked at with suspicion if I get out of my chair, it seems no-one realises we have fluctuation conditions, I would love to be able to either walk or sit but both are difficult and both are painful so I have to do a bit of each, there are so many people who think they know how to live my life better than me, or they are critical because I have to take huge doses of medication to make the pain just about bearable, sometimes I get it wrong and am not able to do anything, (thankfully not so often these days) food is more expensive, I have to have ready meals quite often because I am in too much pain to cook or to fatigued to get shopping, medication if someone is on Incapacity Benefit they would have to pay prescription charges, I am fortune to be on Income Support which means I get them free. Socialising is much more expensive as you/I need to take someone else with me to help me negotiate the environment, and things like days out become too difficult, I've not had a holiday for over 5 years because it's such hard work and so expensive, you have to investigate everything and plan before you go anywhere. Heating bills are enormous!!! I have to keep my home hot because cold is so painful, my spine goes into spasm and I am useless, having to take to my bed, but because I am not an older person I don't get the winter fuel allowance, and I have to do Christmas on the £10 extra, who can do Xmas for that? It wouldn't even buy the meal for most people. Let alone all the family and limited friends we are allowed to have, (disability isolates people because they feel less than other people and have much less in common with people who are self-sufficient in a financial way, I know I used to hate being beholden to my friends when they wanted to take me out for lunch because the relationship couldn't be even, as they felt they had to pay for my meals, I have since addressed that and don't allow that

- Personal hygiene and modern electronic equipment

Question Four

The new benefit will have two rates for each component:
Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?

Answers:

- Hopefully

- No

- Without seeing the breakdown I cannot comment. Why change unless it is for more money

- No leave it as it was. Two rates will only make extra paperwork. More money wasted

- No, I feel there should be four levels
  1. Can manage most things
  2. Needs a bit of help with some things
  3. Needs a lot of help
  4. Needs total care

- No

- Yes I think it will be beneficial, perhaps the over 85 would be the higher point
- Yes, though rates per component would last a month

- Whilst I agree the benefits need updating I think having two rates causes confusion and will engender the ability to give the lesser amount to everyone, and making people struggle. Administration of all the benefits is the bane of any disabled persons existence as the people running it are so pedantic and so unsupportive, some have been very condescending and some rude, though recently things have been better (significantly) they are all very easily confused and so many departments don't know what the other dept is doing, it is a mine-field of misery, so the simpler the better.

- We are forced to rely on the ethics of the administrator

What, if any, disadvantages or problems could having two rates per component cause?

- May be difficult to differentiate between them

- Those just below higher rate will miss out

- Confusion with different people with different types of disabilities
- The more rates the fairer the benefit, as it can be fitted more fairer as to disability
- More paperwork to look through and try to understand

- Lots of people will not get the higher rate as they will not meet the criteria but need more assistance that's at the lower rate – this could encourage people to exaggerate

- Many disabled people can do a number of tasks on a one off basis. Those with a fatigable condition like Myasthenia Gravis vary on a daily, even hourly basis in their ability to complete physical tasks. The tests proposed, assessed by tick list, do not take this into account

- As one gets older the body gets weaker, so as above answer

- The rates would not be enough to cover household bills and leisure

- It doubles potential errors

Question Five

Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

Answers:

- Should not be automatic as different conditions vary considerably

- Based on needs and circumstances, especially as some don't need it

- Yes, in some cases
- Some health conditions should be automatically entitled

- The needs of the individual should be taken into account

- Some should, but you must have a definite diagnosis by consultant signature. But also each persons needs are individual and should be assessed with some fluctuating conditions. You could be assessed on a good day= disaster

- There are a number of neurological conditions where an automatic entitlement should be in place. In these cases a consultant is the best judge of the patients needs

- No automatic entitlement as some people are much better, should be claims of the individual person.

- Depending on the assessment process. All health conditions are individual. Everyone is different.

- There must be some conditions that have priority like terminal care, however there should be judgements on how the person is affected, as some people would be very needy and dis-abled by their condition where as someone else may not be as affected, it also depends very much on how long someone has had a condition, say someone who has been dis-abled since birth may have developed better coping mechanisms than someone who is newly physically challenged by a condition. Also some people if they have been in highly paid jobs may not need to apply for some benefits, so the universality would bring in unfairness there. Though I do believe that people who have looked after themselves should have support and care when they need it, the system we have now is not about rights and entitlement its about crisis and charity, the system is so focused on fraud that those of us who are entitled feel guilt for asking for the help, we are said to have been with the malingering brush by the media and many people who don't see the misery they cause, nor do they care

- Faulty medical administration of steroids has left me with a financial burden. DWP and NHS can't decide which is responsible after about nine years of trying

Question Six

How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

Answers:

- Inability to get to meetings and social events, need support if unable to drive
- Activities essential are: cooking, shopping, bed making, bathing (sometimes), cleaning

- Organised occupation if person is unable to do it themselves and want it

- Help should be given when needed

- I worked all my life, because I now need help in my retirement does it mean i am not entitled to lead a normal life.

- Someone to talk to and help to get you out of the house

- ADL – Activities of daily living, washing, and dressing etc but as important are Psychological support, getting out and about and meeting others. Also being as independent as possible

- Support should not need prioritising it should be available at need. Prioritising to me means rationing

- Going out meeting people, more money for day centres, more money for taxis to get to places for a full active life, going to places for exercises

- Good food, warmth and exercise

- Being able to interact with family and with friends, having relationships with the people you care about, just because you have a disability doesn't mean you become less of a parent to your children or less of a daughter or son to your parents, but relations can get strained by the guilt from being different or needy that is the element that causes the most pain for everyone, if people felt worthy or valued no matter what their impairment or disability they would try to contribute to the level that they felt comfortable with. Disabled parents of children should have rights to support for themselves so that their children don't miss out, and don't get labelled carers, that is not a responsibility that children should shoulder alone, they should be supported to help where their age allows them to help. Currently we allow children to be abused by being the main carer for parents who rely on them, when the parents should be parenting and getting support from others. Direct Payments can facilitate empowering disabled parents to support their children in a healthy way

- Ensure that all contact jobs are fully staffed even in times of snow and flu

Question Seven

How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

Answers:

- An assessor should be fully trained in all varying medical conditions eg multiple sclerosis or any other deteriorating diseases such as Parkinsons

- Regular assessment

- One on one assessment

- You should be assessed at your most needy, when you are more vulnerable – not when you have a good day.
- Keep in contact with services users needs and wishes

- How about giving someone access to a video camera and record their condition over three months or more prior to assessment (Please try not to laugh at my suggestion!)

- By having an independent medically compiled list of such conditions

- Going to houses unannounced, getting carers to make sure houses are heated, making sure that people have a television working because of the change over, and radio. Fridge containing food, are they full for the bad weather.

- Not sure

- The right questions need to be asked & training of the assessment staff needs to include some sessions with service users themselves, to understand what it is like to be a service user to be in a wheelchair or be sight or hearing impaired. I would like to see some empathy training so that they are able to see that none of us have static conditions, that like anyone we have better days and worse days and the odd good day and to not expect because someone has had a good day that that means they are cured and able again. If the support from the benefits truly was encouraging and supportive then there should be no reason to be frightened of having a good day and enjoying it, and then hopefully increasing the good days to the point of being able to work if that is possible, but if someone feels huge pressure to be well and to get back to work the likelihood is that they will be to stressed which will increase their bad days and lessen the good days.

- This requires continuous efficiency checks. Try to improve each year as the car industry does. Approx each year the “Care of the Year” is better than the year before. The car in the “Nine Elms” trade... would be a good starting point

Question Eight
Should the assessment of a disabled person’s ability take into account any aids and adaptations they use?
• What aids and adaptations should be included?

Answers:

- Yes, if they cannot do a particular thing without them, wheelchairs, walking aids, trolleys for carrying things

- Yes, those that cannot function without

- Guide dogs

- Aids and adaptations are expensive. Put “disabled” on a piece of equipment and manufacturers immediately put 100% on the cost price

- Yes

- Without these aids the person couldn’t do the job!
- If aids and adaptations are required it does not take away the persons disability. Some aids and adaptations, whilst enabling the patient to live round the disability, often carry with them their own problems and limitations. None should be included.

- Seats for toilets – high seats for sitting on. Tray for a frame. Sticks for walking

- Wheel chairs, crutches and support workers

- Of course aides and adoptions should be used and included, for e.g. someone who has a guide dog or a disabled helper dog they may not be as disabled as someone who doesn’t have one, also the same goes for wheelchairs and sticks, it is very sad that when people see me in my wheelchair they see my disability far better than when I am walking, but I am much more disabled by pain when I am trying to walk. An understanding of these issues and that medication is not the panacea for everything; it has to be balanced with life and the other elements of ones life. Also for people who have mental health issues medication can be a disabling issue as there are often side effects that are almost as bad as the condition, they are also often in a very fluctuating state because they will stop taking their medication as soon as they feel a bit better, then the symptoms return and they have to build up the medication in their systems again, all of which takes time and understanding from people around them.

- Every individual and their needs are unique

Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?

- Both
- The latter
- Should consider the person might need
- How can you assess need when someone has been unable to buy equipment because of cost. Of course you should assess what can be purchased if the need is there.
- Aids and adaptations should be constantly monitored and updated to the person needs
- No, as above
- No
- Yes for the assessment for the aids
- Yes
- If your assessors know of an aide that would improve someone's life surely they have an ethical duty to impart that information to the person, however what they can't do is expect that always the person will be pleased and will take their advise and be able to use it straight away, my mum needed a wheelchair but because of her very strong belief that she'd be seen as a failure and she thought of herself as a failure by having one that she wouldn't use it, yet to me mine is a life and energy conservation aide and I have to deal with my shame which I have, and am now proud to be able to use such an amazingly life enhancing piece of equipment, my mother died having struggled for years and never allowing herself to be assisted until she there was nothing she could do but lie in bed for the last 3 years of her life. I want to be out and about for as long as I am able and using the experiences I have had for the good of others where I can.
- My answer will always be out of date

Question Nine
How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:
• How could we make the claim form easier to fill in?

Answers:

- Make it easier in plain English or provide expert for first time
- Plain English
- Less questions. Straightforward questions
- The form is horrendous. The same question is asked over and over again as if you're trying to trip us up. It takes hours to complete even with help
- Ask less questions and make the questions easier to understand (most people are being seen by a doctor and that should be enough)
- Make the questions easier
- By providing advocates to assist claimants
- Have a copy of the claim form and take it to the elderly and ask them that question. Do not use words which people do not understand
- Provide support. The benefit office should help clients.
- Shorten it and make it less invasive, and don't ask the same questions over and over, one simple form should be all that is needed for all departments and they could be held on computer rather than have enormous paper forms, it maybe that doing them in two sessions if the information needed is tiring or allow the person a break between parts of the form.
- See answer No 8

How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?

- As written on the Executive summary should be ok

- As above

- Worded simpler and different format ie for blind people

- You talk as if you're already decided on the change and no matter what is said on this form you will go ahead

- More leaflets in doctors, surgeries and libraries instead of having to go to the local job centre

- De jargonise it. KISS – Keep it simple
- By presenting it in simple plain English (or other language).

- I think I have answered, the over 85's, perhaps a letter from a doctor

- To get support from organisations

- The biggest is to have people administering it who know what they are saying and what they are doing, who know what benefits suit, no amount of info will stop there being confusion, what we need once we are brave enough to take the next step is someone on the end of a phone who will be kind and caring enough to walk you through the form and the eligibility criteria for it, being honest and not promising anything, not being condescending or patronising or offhand with customers, treat people with respect and dignity, the things everyone wants and deserves, but that when you feel like your life is ended because you have pain or a condition that you will have to ask for help to cope with is very hard to ask for, at that point it is so easy to dismiss someone and to ensure they feel too guilty to ever phone again

- The answer can be no better than an opinion!

Question Ten
What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

Answers:

- Should physiotherapist or own GP be approached if they have time. It should be done in own home so that any difficulties are identified

- A professional visit

- There is no person who will give a clear assessment. Many people concerned with you will give a different aspect to your care needed and ability

- The persons doctor

- Pain/mood diary
- Observation of daily life and activity. A carer or relative. The GP or Consultant. Community Nurse. The welfare officer of a support organisation

- The doctor, carer if one has one. People coming to the home.

- Support workers, family and GP.

- Could be doctors or consultants diagnoses, though I don't like labels often they are the only way that a professional will recognise you have something wrong that is not just a day to overcome, sadly though I would love the world to take to its heart the social model and break down barriers to disability that is unlikely when the world is governed by medical decisions and medical cures and promises and expectations. I could still be like my mother cure chasing till she died, but I had a consultant who was brave enough to tell me that I needed to find a way to live within my limitations and that any further surgery may in fact increase the pain, which I was only just coping with, I would have been screaming if it had increased to any degree. Have medical tests and social tests, questions like how often are they able to go out, etc, my life was housebound until I found I could use a wheelchair and have a Motability car that got me out, it was amazing, but without Appealing for DLA I wouldn't have had that, I could easily have taken my own life rather than be the reasonably healthy person I am now, I maybe limited but I make the most of the life I have and enjoy it for the things I can do.

- A death certificate

Question Eleven

An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- What benefits or difficulties might this bring?

Answers:

- Yes definitely but time factor comes in – what about an OT as an alternative?

- Not accurate – I can get out of a bath but cannot walk one step without a balancing stick, therefore no care allowance!

- Explaining and understanding

- Would be able to see how disabled the person applying is

- Healthcare professional or not, they are one person and know nothing about you. Are they disabled? Then they have no idea about disability

- A fair view of the person needs

- It may prevent bogus applicants. But pain cannot be seen.

- The less articulate claimant will be a disadvantage. If the healthcare professional is employed by a private contractor they will no doubt be under pressure to fail as many as possible.

- Yes, I do not think this will be a difficulty if the person is genuine
- Anxiety

- As long as venue is accessible and the professional is open to really listening to the person and spending time to understand what they need then I would see face to face as a good thing

Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?

- Can't think of one unless the person is very ill or terminal

- If the person does not want a visit or benefit
- Who will be the <u>advocate</u> for the claimant? That's most important. Being interviews by a stranger is stressful
- no
- An honest applicant would have no problems with this as long as an appropriate appointment could be made. I am disabled but still work some Health Care Professionals have a problem with this
- Where the patient is terminally ill
- No, I do not think it is inappropriate again if the person is genuine
- Hostility
- I would think the only time is really when someone doesn't want any further intervention and they just want to die or be left alone, which we all should have the right to chose. Apart from that occasion I would think that most people would welcome being seen by a healthcare rather than medical professional, health care should help people become healthy, which can mean being as fit as you can be yet being in a wheelchair, whereas medical professionals will often want to cure the person to make them normal and dispense with the wheelchair, where the person has reached their own inner calm and is okay with there condition and doesn't want any more intervention that person should be respected, and believed. I have a condition that means when experience the pain of say an injection or a canula being inserted, because my pain gate is always open due to the arachnoiditis it means that pain is excruciating and I would not be able to tolerate the things other people have as a matter of course. Respecting the persons own experience is a must to do this properly and well. Make use of Expert Patient programmes, people using peer support to cope, it's absolutely brilliant the confidence and support people get from that sort of intervention.

- Yes

Question Twelve
How should the reviews be carried out? For example:
• What evidence and/or criteria should be used to set the frequency of reviews?

Answers:

- Annually or more frequently if requested by either patient or health professional

- Maybe proof of need from doctor, or personal visit

- Depending on disability

- If you have a medical condition that is not going to improve why the reviews? You have no idea how stressful reviews are. They make me ill!

- Health care professional recommendation

- If there is an increase in rate. Then every 2-5 years or sooner if required in your home

- Reviews should only be carried out where a claimant's condition could improve. It is pointless reviewing claimants with a permanent physical disability

- Maybe another person present

- Not sure

- Yes! Knowledge from the internet and medical research should inform what time frames are required, and when a judgement is made that a condition is long term and likely to deteriorate, ensure that support can be had between reviews, having a named benefits officer would be the best way or a social worker to be able to adjust things as and when the (n/y) are needed, if things improve to back off a bit or if more is needed to offer more assistance. A big issue for us all is Trust or rather the lack of it, we feel marginalised by society but also penalised by a system that doesn't want to support us, no-one goes asking for benefits with a happy contented face on, it is hard to ask for help. Unless the person is a fraud in which case they should be monitored but I am sure that assessors get a feeling for who is not genuine. I can't even think of having to be reassessed without feeling tiny and apologetic for even living.

- Face to face with frequency set by calendar
- Should there be different types of review depending on the needs of the individual and their impairment/condition?
- probably
- yes nothing is identical
- yes
- The person interviewing should have an intimate knowledge of your condition and should have access to your history. Instead of finding a way to stop the DLA!
- No
- Of course it should be personalised
- Yes
- No, I think the visit at home is enough
- Not sure
- Yes

Question Thirteen
The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

Answers:

- By making sure they know they could get more money by keeping the dept informed. Bribery?!!!
- Regular checks
- We are always frightened the DLA will be stopped for any excuse. We all know that the object of reviews is to save the Government money

- Rely on health care professionals recommendations

- DWP to send a freepost questionnaire to each recipient to complete and return with a signed declaration. No better/no worse. Every 6 months. Failure to complete form means you lose your allowance

- I doubt that it will be easier. Remove the fear of being hauled in for a review leading to total loss of support

- Only to visit them and watch the reaction

- People are sometimes not literate or self aware

- Have a named person for the person to phone, have a phone-line that doesn't take half an hour to get through to, and is manned/womaned by people who what to be there and who care about the person on the other end of the phone line. It should also be possible for the agency to phone the person every six months or so and to ask, have you had any changes, and if there are to not jump on them if they have forgotten. I have written to the DWP more times than I have had hot dinners this winter and I never but never get a straight answer from them they will send me another formal letter, or they don't respond, the first time I got anything satisfactory was last year when their debits department got involved, because they hadn't received a letter I had written and accused me of not informing them soon enough, I was terrified and they were threatening to take £85.25 of me that I didn't have, because until the dept office got involved no one had ever said that my week for permitted or allowed earnings goes from Weds to Weds, my week and therefore calculations went from Monday – Sunday, it was a mistake that cost me a huge amount of stress and is still unresolved because despite having written another twice they have not notified me what I am allowed to do and what information they require, the three offices I dealt with didn't know what each other did, debits office wouldn't comment on Benefits, benefits had two departments Income Support and Incapacity and neither spoke to each other nor had computer systems that spoke to each other, so they would ask me over and over for the same information and give me very different advise

- ?

Question Fourteen
What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

Answers:

- Intelligence to read the Executive Summary. So they know what they are entitled to.
- Same as DLA
- Other formats
- Don't know
- Clear concise information in plain English
- I suspect that an explanation of what the wording on the forms and supporting literature means. Any support of this kind would need to be independent.
- No, I don't think so
- The benefit stuff should provide help and support
- Honest!!! Respectful, up-to-date, clear and concise, the letters that are sent currently are full of legal jargon that is just frightening, and something's are irrelevant, it is not necessary to send me a letter every time I get a cold weather payment, and put an appeal against the decision I bet not one person has ever appealed having been given the payment in the history of cold weather payments, its wastage like that and inconsistencies that make people wary and tired of the system. It's not a happy place for people to

work either, they sound so low themselves some of them and moral is pretty pants, how can they be expected to give their full attention and be supportive when they are feeling under supported themselves, I have had advisors tell me allsorts of things they shouldn't but feel that they have no-one to turn too, so where is there backup and supervision?

- Learn all you can of the tricky unethical methods of our local national markets, inflation is 'autochthonous'

Question Fifteen
Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?

Answers:
- Organisations like WSUN would be a key function
- Avoided – the minority of moaners
- A number to ring
- Don't make the claimant feel he has to beg for the payment. If he is eligible for it he should get it

- There are a lot of charities who do so at present. People could be encouraged to continue to this

- It must be independent of the DWP or any other government body

- Only for them to apply if the claim sent is appropriate to them

- Expect people to accept services they don't want.

- The whole system needs to earn peoples confidence before some people will ever come forward, it take years and some significant desperation to ask for help, we live in a world that sees impairment as failure or heroic, we have a charity ethos that expects and wants people to be hidden if they have problems, minority groups and individuals wont access services because they are not in a format that they understand, or because the shame of it is too unbearable.

- Inflation, Buy into investment trusts

Question Sixteen
How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

Answers:

- Privately or via specialist charity. No way should this be an option. A Personal Independence Payment should fund it <u>without</u> a long waiting period
- I get the big ones, eg bed, wheelchairs and rails from NHS, or social services. Other things I buy
- I fund my own aids and adaptations I get no help paying for them as I am a blind person
- Any help in purchasing much needed equipment and aids would help
- Out of savings sometimes. One off payments could be helpful
- Funded by self out of savings. Yes on definite diagnosis
- I have to buy everything for myself and pay for maintenance. Yes
- This is surely what the money should be used for to help people to stay in their own home
- Yes
- Even the Social Fund doesn't fund one off costs like the need for a new electric wheelchair, it would pay for a cooker or something else practical for normal usage but when it comes to specialist equipment you have to find the means yourself or apply to charities who will consider applications from individuals. If one off payments for such things could be included that would be such a step forward, however some people may abuse that kind of offer, and not use it themselves, I have heard of people naming other family members as drivers of their Motability vehicles and not getting the benefit from it at all, some however are absolute life lines too. It is a tough call as some disabled people like myself (this is in the past now) used to be at the mercy of other peoples whims, because I felt so useless and at the other peoples mercy, if I needed something I would be able to ask, however now I

have learnt to ask very well and communication is much better for me and I am respected now, because I have worked on respecting and liking myself. Disability faces you with adjusting to a different person and a different future than you had imagined. Anything that can help make life more comfortable and manageable has to be worthwhile trying to provide it.

- Variety is essential. A rich uncle sometimes helps

Question Seventeen
What are the key differences that we should take into account when assessing children?

Answers:

- They grow older, taller and larger and need school etc. Need more supervision and assistance.
- Present and future needs and development
- Don’t know
- Sorry not a specialist in this field
- The needs of the parents in caring for the Child. Provision of respite for the parents
- To speak to mothers or carers, or friends
- Choice
- Children are innately honest and will not put on any airs and graces they will generally not be martyrs except where they have learnt to get attention that way, Children are just as worthy of our support and in fact the earlier good support, encouragement and interventions of aides and adaptions are available the better they well adjust and have a life that is confident and enjoyable, children adapt well to disability when they are encouraged and not seen as poor little things, feeling sorry for anyone is discouraging and disempowering
- Variety

Question Eighteen

How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these access to other benefit arrangements?

Answers:

- Not good except for servicing wheelchairs. The DLA does nothing more – reassess. It has to be done via WSUN or asked for personally
- A list of contacts

- I have had no support for them

- Social Services should without doubt give benefit advice and forms. At present they do not help with such information at all

- DLA is very useful to gain other services

- Yes, more information. I have had to find out mostly by myself

- In terms of accessing a Blue Badge it has been a big help. Some social services should be automatic

- The DLA is very good, it does enable people to afford all the things in their life, perhaps a little more would help

- DLA means access services like free bus pass or disabled sticker for the car.

- I have no idea as I haven't ever known what other services are available, but I would imagine that if a benefit opens the door to another, if someone feels that the person is in need of that service then to put the information in an envelope with their benefit info would be a kind thing to do. I have found all the support that I have got now by blundering about and finding other people who had been there and who were willing to pass on what they knew. None was gained from the public sector itself, in fact when I have asked questions they are much more likely to be evasive and unhelpful.

- None in my experience!

Question Nineteen
What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

Answers:

- Disastrous
- Financially serious in my case
- You get so little help in accessing benefits by the Social Service system mainly because they know so little about benefits. I go to CAB
- There would be a lot of people finding it difficult to cope with life
- Too much for anyone to possibly do. Many departments would crumple under the strain of applications if we suddenly became aware of our rights!
- It would increase the work and stress involved in accessing them. It would involve addition expense for the service providers in administering and verifying the applications
- Maybe to go into a home. Even trying to get to a surgery. Paying someone to take you for a meal out, or maybe the cinema
- Loss of services
- They will have to survive! Rather than be able to live! What Personal IP's should do is facilitate disabled people being able to have a life and being able to assess other support if necessary, however with the ILF fund being severely restricted some people who are having the worst of times will be struggling even more, because the ILF is no longer there to top up their support package, it is frightening, though I don't personally have any ILF payments, they have been in the background as a form of security in case things every get to the point where I need that support.
- It would confirm the umpire is cheating

Question Twenty

What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

Answers:

- Could the specific charity (ie MS Society) be combined with WSUN and just verified by health care professional and their advice
- Every case is different. To complicated to answer!
- Don't know
- The assessing person must know the condition prior to performing any assessment and the possibility of fluctuation in said condition
- I am not sure
- Not too many people are worried about their disability being assessed, if they really are disabled, once assessed that should be enough
- Not sure
- Health and Social Care need to work together to pool resources and to stop the duplication of services for people some people currently have lots of very similar yet different services going in to see them, some skills could be transferable.
- The information is there if you understand arithmetic

Question Twenty One

What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?

Answers:

- Don't know
- Can't answer as have not got pg 28

- Don't know

- We are all equal regardless of creed, colour and age

- I think you have considered the developing policy. I cannot think of anything else

- Not sure

- Being open and having no practises that could be exclusive, the service must be representative and good role models of equality and inclusion, if the system does reflect that then people will not trust it. The policy should also cover employing diversity and individuals from all walks of life, though not going out for tokenism or the mix by any means, people have to have a good chosen career path and be happy in an accessible! Inclusive environment. The do as I say not as I do will not work and never has.

- The gap between rich and poor will increase!

Question Twenty two
Is there anything else you would like to tell us about the proposals in this public consultation?

Answers:
- I feel it is very unfair that any benefit should be taxable. I am lucky to have a little capital but why should I have to pay for it? I am still disabled whether or not I can afford an up to the date monthly aid or not

- If I lose DLA the way it is I would lose money that I need to pay for every day costs. As a blind I can not drive a car/scooter and have to walk or pay for taxis to get to places I need to go

- It is obvious the decision has already been made and as usual our thoughts and worries will not be considered

- No

- No

- I do not believe it is being done for the benefit of the disabled, rather to cut the DLA's costs. Only DLA staff should be involved in assessments. The use of contractors doing it for profit and with an interest in keeping the number of successful claims to a minimum is not acceptable
- My worry is people not being able to get to their surgery, which could be 2-3 miles away, a district nurse will not come if you can use a frame. This is wrong because one has to beg a neighbour to take you, if one cannot get to a surgery or go out all, something must be done.
- This form is lengthy and difficult

- They sound good but please! don't let it all be hot-air and empty promises, we understand cuts in services we have lived on survival mode for so long, we know there is no honey at the end of the rainbow, what we all need is some encouragement some help and positivity. Above all else don't see us as charity cases that should be pitied because that makes us all depressed, we need to know that the world will be accessible at some point and we can **all** of us help towards that end.

- Even in England many people are alone. The system will not allow significant change

General Comments

Could not answer some questions as they have been worded in a way that is hard to understand.

I'm not normally a complainer.. I just get on with it.