



Spinal Injuries Association (SIA) response to Disability Living Allowance Reform – a consultation by the Department for Work and Pensions

Introduction

The Spinal Injuries Association (SIA) welcomes the opportunity to comment on the Government's proposals to reform Disability Living Allowance (DLA) by introducing Personal Independence Payments (PIPs).

Disability Living Allowance is of primary concern to disabled people who rely on these payments to mitigate the costs they incur to manage their disability. For disabled people who have been enabled to have a basic standard of living through DLA, the idea of a reduction or loss of these payments is devastating and the potential impact could be immense on both their mobility and their ability to live independently.

About SIA

SIA was established in 1974 and not only works to support and promote the wellbeing of the 40,000 spinal cord injured (SCI) people in the UK but also to provide assistance to their families, friends and health care professionals.

We work to support, advise and campaign on all aspects of spinal cord injury. Our vision is the full integration and participation of spinal cord injured people in society. Through our services and publications, we aim to equip spinal cord injured people with the knowledge and skills they require to successfully rebuild their lives after injury. Core activities include our Freephone Advice Line, Peer Advice Service and employment service."

As a true user-led organisation, which was founded and continues to be managed by spinal cord injured people, we fully understand the needs of the people we exist to serve.

Our aims are to:

- Provide a spinal cord injured person, and their relatives and friends, with life-long assistance that spans right from the moment of injury and throughout the remainder of their lives.
- Provide services to increase an individual's quality of life.
- Increase the knowledge and awareness of the causes and consequences of spinal cord injury.
- Campaign for the best medical and social care for spinal cord injured people.

Key messages in SIA's response

- **SIA strongly disagrees with the proposal to consider wheelchair use when assessing for the mobility component of PIPs.** Wheelchair use simply does not equate to the ability to walk. It also incurs considerable costs both for the wheelchair and additional expenditure such as accessible motor vehicles which come at a higher premium than standard equivalents.
- **SIA opposes the removal of mobility component for those in Care Homes.** This will severely disenfranchise disabled people and lead to greater isolation and institutionalism. It is likely the numbers of Care Home residents will increase in the light of Local Authority spending cuts.
- **SIA is concerned by the introduction of a six months qualifying period for PIPs.** This will mean that newly disabled people – those most in need of support - are left without the appropriate funding to meet their needs.
- **SIA is concerned that assessments for PIPs will be undertaken by independent healthcare professionals.** With very little understanding of the condition in the general NHS, SCI people will be horrified to learn that non-specialist assessors are being proposed as the gatekeepers to PIP.
- **SIA does not believe that reassessments should be necessary for permanent, incurable conditions such as SCI.**
- **SIA does not believe that the cumulative effects of cuts across both benefits and Local Authority budgets have been considered by Government.** By not viewing support for disabled people holistically the Government will not only severely impede independent living, but may also greatly increase costs to the tax payer.

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

Disabled people continue to face numerous barriers in their pursuit of an independent life. This may come from the physical environment, the attitudes of their community or the considerable costs they incur trying to overcome these barriers.

These barriers are as individual to a disabled person as their disability. As such, Disability Living Allowance (DLA) enables people to support these specific needs and tailor their expenditure where they will gain the most benefit.

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

It should be possible for those with conditions such as spinal cord injury that are permanent and will definitely not improve, to be awarded payments for life. As well as providing assurances that they will be securely supported, it will also have the benefit of reducing administrative costs to the state.

As per the Government's proposals, DLA should continue as a non means-tested benefit which is linked with the RPI.

3. What are the main extra costs that disabled people face?

Disabled people face a great many additional costs as a result of their disability. Disability Living Allowance is crucial in mitigating these costs although many would argue that their current payment is still insufficient to meet their needs.

"I am spending £523.10 per month (excludes council tax increase) due to my disabilities. I am getting £390 DLA towards my expenditure, made up off mobility on higher rate and middle rate for care."

The list below details some of the extra costs that disabled people face in their day to day lives, but should not be considered as exhaustive.

Medical costs

People with SCI and other disabilities face increased medical costs as a result of their disability. Whilst a small proportion of people with long term conditions can receive exemptions from prescription charging, the relevant criteria dates back nearly fifty years and is wholly unsuitable for use in 2011. For instance, when the current criteria were produced in 1968 life expectancy for a person after their SCI was only a few years. Now they would be expected to live for almost as long as their non-disabled peers, yet would not necessarily be eligible for support for their on-going prescription charges.

The expenses disabled people faced in their medical costs were recognised by the last Government who commissioned Professor Ian Gilmour to conduct an investigation into prescription charging for those with long term conditions in 2009. Unfortunately, the present Government has decided not to extend the criteria to everyone with a long term condition as Professor Gilmour's report recommended, meaning many disabled people will continue to face on-going costs throughout their lives for the drugs they require to manage their condition.

Beyond prescription charges disabled people will incur other healthcare associated costs such as vitamin supplements, dressings, incontinence sheets, gloves and aprons, pain killers and non-NHS funded treatments such as chiropody and physiotherapy.

Care costs

Many disabled people will make considerable contributions to the Local Authority Care packages which enable them to live independently. However, Local Authorities are having to reduce their budgets considerably and SIA is already aware of several areas where the charging for care is increasing. This is a situation which is likely to increase in the near future as more Local Authorities seek to reduce their social care budgets, exacerbated by additional cost cutting measures such as the closure of the Independent Living Fund.

“To take away choice and independence is a backward step. If the ILF ends as well, then life won't be worth living.”

Beyond directly contributing to care packages, further costs may be incurred for respite care, personal assistant/carer costs for social and fitness activities such as going shopping, going to concerts/the cinema etc.

Domestic costs

Disabled people incur costs for the day to day tasks which they are unable to carry out themselves. These may include:

- Cleaning
- Shopping
- additional laundry as a result of incontinence
- gardening
- decorating
- repairs, maintenance and basic D.I.Y.
- delivery costs for food, clothing and equipment.

There is also the additional cost of adaptations to disabled people's accommodation which can be considerable. Such changes would be likely to

affect areas such as the kitchen, bathroom and doors and may necessitate additions such as lifts and ramps. Whilst Local Authorities may provide a Disabled Facilities Grant (DFG) to mitigate these costs, they are means tested and therefore carry a significant cost to the individual.

Fuel costs

SCI people will face increases in numerous household fuel bills. These may include:

- Electricity to charge wheelchairs and electric hoists
- Gas or electricity heating costs. Many people with a SCI have no or limited body temperature control and are therefore very susceptible to temperature fluctuations (it is generally recommended that SCI people maintain their home environment to around 22 degrees Centigrade).
- Higher vehicle fuel costs due to usage of a vehicle for an increased number of short journeys
- Increased water and electricity bills to cover the additional laundry costs brought about by double incontinence.

Disability related equipment

- electric scooters or powered wheelchairs
- communication aids such as computers and software
- mugs, trays and eating utensils
- hoists
- shower and bath equipment
- sliding boards
- pressure cushions and mattresses plus spare covers
- pushing gloves
- cost of hire purchase, repairs, spare parts, service agreements and maintenance

Mobility costs

These are discussed in greater detail under question 8, but include:

Mobility aid costs

- Mobility equipment
- Wheelchairs
- Maintenance

Vehicle costs:

- Adaptations such as hand controls for self drivers
- Lifts / removal of seats etc for those who remain in their chairs during travel, lock-down devices, additional wheelchair modifications for lock-down mechanisms
- Larger vehicles such as people carriers for people who must remain in their wheelchair during transit, which incur additional fuel consumption
- Automatic transmission
- Maintenance and breakdown charges

Many of these items have significant costs which cannot be funded easily. For example, persons who need to use a wheelchair in transit have considerable capital costs when they exchange vehicles – for instance they may have to fund a vehicle-compatible electric wheelchair at the same time. .

Employment costs

In the reforms the Government is conducting outside of those for DLA, they are hoping to encourage more disabled people into employment. SIA broadly agrees with this approach providing that such work is suitable to their condition, within their capability and, most importantly, that they are sufficiently supported to achieve this aspiration. As such, the Government must recognise the importance of DLA in funding the support that they need to return to the workplace. A disabled person is of less cost to the state in employment and receipt of DLA than they would be unemployed, on out of work benefits and not contributing to the exchequer.

“DLA is an important component of the support I need as someone with a SCI. Particularly, it helps me to work full time making me an economically active tax payer and with concomitant benefits for physical and mental health.”

4. 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?**
- **What, if any, disadvantages or problems could having two rates per component cause?**

Reducing the rates per component to two will not make the benefit any easier to understand, but perhaps easier to administer because an individual is presumably less likely to move from one band to another once the initial award has been made.

SIA questions whether adequate support can be given to the most severely disabled people, in relation to others, if there are only two levels of support for Daily Living available to those with complex needs.

Those currently in receipt of the care component will have to be reorganised from three to two levels of support. It is likely that many will see their level of funding reduced to a lower level although their needs will remain the same.

5. 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?

There should not be an automatic entitlement to benefit unless it is for a condition so severe and permanent that there can be no doubt whatsoever that the process of assessment is unnecessary. For instance, someone who has permanent paralysis of the lower limbs will be permanently reliant on a wheelchair for mobility and should therefore receive an automatic entitlement to the higher rate mobility component of a PIP.

Please note that in the answer to question 8 SIA will argue why competent wheelchair use should not be considered when assessing for the mobility component of a PIP.

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

When introducing PIPs, the Government must recognise that current DLA payments are often the reason why disabled people are able to live full and active lives. Any assessment must take into account not only how active (or inactive) a claimant is but the effect that removing or reducing benefit will have on their ability to live independently.

“DLA is an important component of the support I need as someone with a SCI. Particularly, it helps me to work full time making me an economically active tax payer and with concomitant benefits for physical and mental health.”

As is noted in SIA’s answer to question 3, a disabled person may have numerous needs which they will use their DLA payments to meet. As such, every individual will likely have a different priority when asked which activities they considered most essential for daily life. The answer to this question is consequently the ability to live independently – both socially and in mobility - and make one’s own decisions about what is important to them and where they need support to help them achieve this.

“To lead a reasonable “everyday life” one must be empowered to both make choices relating to all aspects of that life, and have the ability (with whatever help is needed) to fully achieve them.”

These needs and priorities may change through the year. For instance in the winter months the priority may be heating and staying warm, whilst in the summer it may be mobility and getting about.

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

SCI is not in itself variable or fluctuating, but rather a stable and incurable condition. Whilst an SCI person will become further debilitated over time due to age and the unnatural stresses on the body caused by prolonged disability, SCI is neither variable nor fluctuating in the sense of other conditions.

However, some SCI people may, either regularly or periodically, have to stay in hospital as a result of pressure sores or other complications related to their condition. This could have considerable effects on an individual if they pay for a Motability vehicle and their benefit is stopped after 28 days. Prolonged periods of hospital stay can also affect care package funding, resulting in a loss of Personal Assistants (PAs). This would make it difficult to recruit or re-employ them when a patient is ready for discharge. Whilst not directly related to PIPs, this will add additional cost pressures. This situation may be exacerbated by care provision in some DGHs where refusal to carry out basic bowel and bladder management lead to further complications, In these cases an individual may wish to retain their PA so that they can come into hospital to carry out these procedures.

8. 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?**
- **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?**

SIA is extremely concerned that the assessment process will 'take greater account of the successful use of aids and adaptations'. It suggests that somehow the use of an aid or adaptation obviates the need for support.

SIA would like to make clear that however able one may be in their use of a wheelchair, this in no way equates to the ability to walk unimpeded. For example:

- A wheelchair user is unable to cover the same distances as someone who is able to walk. Even slight gradients or uneven surfaces will impede this ability even more.

“How does using a wheelchair make you independently mobile? That is only applicable if the surface is smooth and obstacle free. Are they going to use the fact that we use a wheelchair against us?”

- Poor weather such as the recent snow storms of 2010 will severely impede wheelchair use and would likely render a wheelchair user housebound until it clears. Mobility will be further impeded as a result of wearing additional, bulky clothing.

“I find it hard to wheel in wet, windy weather and impossible when the pavements are icy.”

- A wheelchair user cannot carry heavy or bulky shopping and would not be able to either travel with it or negotiate it onto public transport. No matter how accessible transport is the designated space only takes into account access for a wheelchair, not any additional luggage. Without these options being open to them a wheelchair user will be required to drive otherwise walkable distances, incurring further cost.
- Whilst access to public transport is improving, the date that full access to these vehicles becomes compulsory is still a decade away. The timescales are likely to be even further away for infrastructure such as the National Rail and London Underground networks. Even with accessible transport there is no guarantee that their routes will be sufficiently located to replicate the journeys that non-disabled people would be able to walk.

“Despite there being many stations near my home, none has wheelchair access. Some buses do in theory but not in practice, since the ramps to board and disembark are usually too steep for me to use.”

“I have known bus drivers to refuse to deploy ramps, or claim they are faulty. Wheelchair spaces on busy routes can be used up with prams and luggage”

This is particularly true in rural settings. A recent report from the Campaign for Better Transport has revealed that 70% of Local Authorities intend to reduce spending on public transport following significant cuts to their budgets from Whitehall. This will doubtlessly make it harder for disabled people to access suitable public transport and consequently further increase the costs of travel for disabled people.

Vehicle cost also increases for wheelchair users and is something that they are disproportionately reliant on. In addition to the points made above, other examples include:

- The costs of adapting a car with hand controls or to carry a wheelchair user whilst seated in their wheelchair are considerable.
- The vehicle itself must be suitable. Three door vehicles are preferable for many wheelchair users as the wider doors enable them to transfer into the seats more easily. These options are more commonly associated with the 'sports' version of vehicles which carries an additional cost.
- Hand controlled cars will require automatic transmission which incurs a higher premium and higher fuel consumption.
- As a wheelchair must be carried in the vehicle, larger vehicles are required to afford space for passengers, shopping and luggage etc rendering smaller, cheaper vehicles unsuitable for their needs. Those who cannot transfer into a seat and instead travel whilst in their wheelchairs will have to buy larger people carriers or vans at a considerable additional cost purely to accommodate their needs.
- Larger vehicles consume more fuel.

The question is also raised as to how an individual's ability to use equipment such as wheelchairs will be assessed. There is a huge difference in the specification between different pieces of equipment in matters such as weight, durability and functionality all of which will impact upon how independently an individual is able to live. For instance, a self propelled steel wheelchair may weigh in the region of 20kg whilst a titanium model could weigh as little as 6.5kg. With such disparity between different models of equipment, any assessment is in danger of assessing a claimant on the quality of their equipment as opposed to their ability. This is of course unacceptable as an individual may become penalised because they have chosen to invest a considerable amount of money in their own independence.

"Are they going to dock points if we have better "Stuff" than the NHS can provide?"

"If someone chooses to purchase a piece of equipment to improve their mobility or quality of life, surely they should not be penalised. This makes me question why should I bother to try and overcome the effects of my disability."

Wheelchair use itself brings additional costs to the disabled people who use them. There is a considerable cost disparity between the top and bottom ends of the mobility aids market from less than a hundred pounds to several thousands for a wheelchair. This disparity is such that the Office of Fair Trading is now conducting investigations into the market following a Consumer Focus report in 2010.

Despite these costs, it is likely that in the quest for an independent life an individual will seek to invest in a chair of as higher specification as possible. The specification of a wheelchair is directly mirrored with its cost. Whilst the Government may help to meet these costs through NHS wheelchair services, the amount of money varies significantly between local PCTs and is never likely to match the costs of the lightest and most versatile wheelchairs. In order to purchase the best wheelchair that they can, and therefore maximize their independence, an individual would have to contribute a significant amount of their own money into its purchase.

“In Scotland we have a rubbish wheelchair services and anyone who can buys their own chair.”

The costs of a wheelchair are coupled with other costs associated with their upkeep and maintenance, including replacement parts such as tyres, wheels and upholstery.

It is imperative that the mobility component of PIPs continues to support those with the greatest need of assistance with mobility and incur the most costs to live independently.

“I consider the mobility component of DLA/PIP is essential to any SCI wheelchair user, no matter how able they are in their wheelchair.”

“If I had to stop using my car on the grounds that my higher rate of DLA for mobility was reduced or not allowed at all then life would become unbearable. I would in effect become a prisoner in my own home.”

If they were to lose the mobility component of DLA, wheelchair users who work could find that they can no longer afford to run a car to get to their place of work. This would be counter productive to the Government’s aim to encourage disabled people back into work.

9. 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?**
- **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?**

SIA would welcome any changes that would simplify and make the claim form easier to understand, although beyond this we do not have any particular concerns about the current claim form.

The process could be simplified by introducing a check-list page, with tick boxes for different areas of need, followed by supplementary pages which can be

completed if necessary. This should make the process of applying quicker, although such a process must be thorough enough to genuinely reflect an individual's need. Establishing the accuracy and credibility of the information given by the claimant would then be part of the face-to-face assessment.

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

It is important that if assessments are undertaken by a Government appointed healthcare professional, evidence can be supplied from other healthcare specialists such as a SCI person's Spinal Cord Injury consultant. For reasons discussed in greater length under question 11 knowledge of SCI, and other disabilities, is not prevalent amongst healthcare teams outside a specialist SCI Centre, to the extent that many SCI people will feel that a treatment at their local hospital may actually have a negative effect on their health. With this in mind, it is vital that the testimony of specialists in the condition be allowed as supporting evidence to a PIP claim.

"I am paraplegic T12 and believe I should be only assessed by a qualified person from a spinal injuries unit who is well versed in the true understanding of a person's needs and requirements."

11. 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?**
- **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?**

SIA is concerned about the prospect of face to face meetings with healthcare professionals when assessing disabled people for PIPs. SCI is a complex neurological condition which can manifest itself quite differently in two seemingly identical injuries. Outside of the 11 specialist Spinal Cord Injury Centres situated across the UK, knowledge and understanding of the condition is not prevalent and often leads to shocking cases of mistreatment at the hands of community healthcare teams and district general hospitals. With very little trust that the general NHS understands the condition, SCI people will be horrified to learn that non-specialist assessors are being proposed as the gatekeepers to PIP.

This fear will be further compounded in the light of the assessment for Employment Support Allowance. These experiences have shown that where a doctor fully assess a complete stranger in 30 to 40 minutes serious errors can occur, especially in cases of neurological diseases where there is considerable variation in individual cases.

“In my experience if I go to my GP or local hospital they are clueless when it comes to someone with a SCI. We all know that no two injuries have the same outcome, so how can they pigeon hole us?”

“I have never, in the 20 years since I left the Army as a wheelchair user ... been assessed in any of my attempts for assistance, whether financial or actual by a disabled peer who was actually aware of my difficulties/limitations.”

12. How should the reviews be carried out? For example:

- **What evidence and/or criteria should be used to set the frequency of reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

The frequency of reviews should be tailored both to the individual and to their condition. For instance, SCI is a permanent disabling condition for which there is no cure. It is both stable and permanent, so an individual's needs will only change through age and the unnatural stresses on the body of living with a permanent disability. Consequently, most SCI people currently receive their DLA awards for life in recognition of the permanence of the condition and its consequences. Similar sense must be used when establishing the frequency of PIP reviews for people with this or similarly permanent conditions.

A process of continuous review for people whose needs will not change would be a considerable bureaucratic burden for both the state and the individual. It would also breed resentment and offence amongst claimants who found themselves regularly informing the state that a cure had not been found and that there had still not been a medically impossible recovery from their condition.

A frequent review for a stable condition, although worsening changes through age will occur, is a nonsense. Apart from creating additional unnecessary cost, different reviewers will inevitably come to different determinations of the same service user. We are already seeing this with Continuing Health Care assessments, although these are being driven by backdoor budgetary pressures. A system of repeated review will inevitably lead to more instances of challenges, thus creating further bureaucratic costs.

13. 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?

Spinal Cord Injury is a stable and permanent neurological condition for which there is no cure. Consequently, any changes in an SCI individual's needs will be as a result of further debilitation caused by age and the punishing lifestyle of living independently with a disability. As such it is important that the Government suitably conveys the message that PIPs are an evolving benefit that will offer additional support as a recipient's condition deteriorates.

For the reasons given under question 12, it is possible that a claimant might be put off reporting changes in their needs for fear that, despite their needs increasing, a reassessment would actually result in them losing their benefit. As such the Government must make its assessment process for PIPs clear, transparent and above all consistent so that claimants have an expectation of what benefit they should expect in relation to a particular set of needs and feel confident that the system will correctly identify this level of support.

14. 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?

There should be clear and simple guidance about the criteria for each level of award and this should be included in the claim pack.

Claimants would also benefit from receiving information on local services for disabled people. This might be useful whether or not benefit is ultimately awarded.

Specialist Impairment Disabled Peoples Organisations like SIA could be provided with central government funds to provide advice and information for those they represent who are applying for PIP.

In addition to providing information to disabled people themselves, training and support materials should be provided to all those supporting disabled people in making an application for a PIP, including hospital discharge co-ordinators and voluntary sector advice workers.

15. 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?

A requirement to access advice and support would assist those people who are unaware of the general help that is available to someone in their position, for instance the extra support and services which DLA might make them eligible for.

However, accessing advice and support should be a matter of personal choice, rather than a requirement. Instead, the government should regularly mount awareness raising campaigns and encourage potential claimants to seek advice and support if they are unsure about whether to apply.

In the event that it becomes a requirement for claimants to access support, additional resources must be made available to those organisations that would be providing it.

16. 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?

For disabled people independence is key, and where this is afforded by equipment such as wheelchairs or adaptations to homes, they will seek to obtain the best that is available, thereby giving themselves the highest level of control over their lives. In general there is a direct correlation between the effectiveness of a piece of equipment and its cost.

Where this equipment is not provided by the state, either at a high enough specification to meet an individual's needs or even at all, this equipment will be bought wholly or partially from their own finances.

“In Scotland we have a rubbish wheelchair services and anyone who can buys their own chair.”

“While the NHS [wheelchair] option includes maintenance, it lacks the wider advantages of the voucher option, such as choice of wheelchair and control over the timing of repairs.”

As alterations to a kitchen, buying a manual or electric wheelchair or installing a lift or overhead hoist may cost thousands of pounds and as no aid or adaptation lasts forever, it will have to be replaced and maintained on a regular basis. As such it is absolutely essential that a disabled person can retain capital for a future major expense. It is vital that those with the highest reliance on equipment and adaptations receive both higher awards and extra supplements to enable them to

buy the expensive equipment they need to live a properly independent life. Similarly, it is essential that the capital level of the means test for obtaining free personal care is raised substantially from its current level of £23,500, or that disabled people are able to ring fence a proportion of their savings which will not be considered in such assessments, so that they can make the necessary savings without being penalised through their care provision.

“Improvements in aids and adaptations are only helpful if you can afford to buy them.”

It is therefore also of vital importance that the government continues to fund and support the Disability Facilities Grant.

17. What are the key differences that we should take into account when assessing children?

A disabled child's needs will change as they grow into adulthood. These changes will not only be physical as they learn to manage a rapidly changing body and their disability, but they are also likely to experience changes in their aspirations, for instance seeking to pursue an independent life away from their parents.

These changes should be recognised in any assessment, as well as the fact that a child has not had the same opportunities to amass wealth as an adult. Consequently they are likely to require more support to achieve independence, for instance to assist them into their own accommodation or employment for the first time.

The consultation document states that a child's needs could change “gradually”. However, they may also change rapidly, for example as they grow and become too large for their wheelchair. As a piece of bespoke, orthopaedic equipment it is not possible to merely supply a disabled child with a larger wheelchair which they will grow into, it must be replaced and the Government must recognise the additional costs that this will incur. This will similarly apply for many items of equipment, those that aid mobility or otherwise.

18. 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 passporting arrangements?

DLA is more than merely a monetary award. It is nationally recognised to be ‘proof’ of disability, and as such is a gateway to numerous other services and schemes which enable disabled people to live independently. DLA is an indicator of eligibility for other crucial monetary benefits, such as Carer's Allowance, Housing Benefit and Council Tax Benefit. It is also a gateway for vital mobility services such as Vehicle Excise Duty, Blue Badge Parking and the Motability Scheme. It also passports to various concessionary rates at sports and leisure

facilities, enabling disabled people to engage in the same pursuits as their non-disabled peers.

With the reduction of PIPs to two rates for both care and mobility components, SIA is concerned about how disabled people may become further disenfranchised when moving from one rate to another (or off PIPs entirely), subsequently finding that they are no longer eligible for services and benefits which they had previously relied on.

19. 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?

As the de facto ‘proof’ of disability for numerous services and benefits, DLA is vital in passporting disabled people to other services which can assist them in living with their disability. Any change in the status quo will leave service providers having to establish a new means of assessing disability, therefore increasing the bureaucratic burden which currently afflicts many avenues of support for disabled people. Such assessments may also disenfranchise disabled people seeing them lose their right to services which are vital for their wellbeing and independence.

“Any change to DLA that stopped or restricted me using Motability would have an extreme impact on my quality of life. I have been able to use Motability for the last three years and it has been the most dramatic improvement of my life I have ever experienced.”

“The car is my independence, and gives my husband a reprieve. He’s the one who takes the brunt of it. This has changed my life dramatically but, it has also changed his.”

20. 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?

Disabled people currently face separate assessments for many services and benefits – for instance Employment Support Allowance, Disabled Facilities Grants, Personal Budgets and other health or social care packages. SIA welcomes any opportunity to reduce the bureaucracy disabled people face when pursuing the support available to them from diverse agencies. However, the Government must ensure that such an assessment is suitable for all the purposes for which it is meant and does not inadvertently disenfranchise disabled people by inadequately conveying their need for any of the numerous different services to which it could be applied.

The reassessment for PIPs in 2013/14 will be a considerable bureaucratic process and there is as yet no indication of what the assessment will cover and how comprehensively it will represent the lives and needs of disabled people. As mentioned previously, SIA has considerable reservations about the ability of 'healthcare professionals' to successfully recognise the needs of SCI people. For these same reasons SIA must be tentative in welcoming the notion of an assessment with a more universal scope. In practice lessening bureaucracy is commendable, but the success or failure of such an initiative will rely solely on the suitability of the assessment and its ability to fully reflect the nuance of a disabled person's need in all circumstances.

21. 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?

SIA cannot immediately see why there should be any differences between different equality groups in implementing the proposals, provided that information is disseminated with due regard to minority groups. This question will be better answered by those organisations with a specific remit to represent people who are both disabled and affected by other equality strands.

22. Is there anything else you would like to tell us about the proposals in this public consultation?

1) Disability Equality in 2011

The consultation document seems to imply that, disabled people now live in an environment where all physical and attitudinal barriers have been negated by legislation such as the Disability Discrimination Act and that they are now on a level footing with their non-disabled peers. As one of 12 organisations involved in the Office for Disability Issue's Network of Networks project SIA has contributed to the UK's response to the UN Convention on the Rights of People with Disabilities. This national consultation conducted by these 12 pan-disability groups highlighted the primary areas of concern for disabled people in 2011. It is a sad indictment of the failure of the DDA that, some fifteen years after its inception, access to buildings and employment should still be identified as two of their five primary concerns.

"Are we going to be penalized for being more able to cook our own food, wash our own hair? Yet we cannot gain access to buildings, fit under tables at restaurants or find a parking space that isn't already occupied by [someone who doesn't need it]."

Whilst there are on-going improvements in medical treatments and in aids and adaptations, this does not necessarily change personal circumstances or lessen the additional costs of living with a disability. The Government must recognise

how DLA payments currently support people to live independent lives and take heed of it's commitments both under Article 28 of the UN Convention for the Rights of Disabled People and to 'Living Standards' under the Office for Disability Issue's Equality 2025 Roadmap.

2) Mobility component for those in Care Homes

SIA would like to express their complete rejection of Government's intention to remove the Mobility component of DLA and PIPs from disabled people resident in care homes. As has been discussed previously in SIA's response, mobility is absolutely crucial to a disabled person's independence. Those who live in care homes will be even less able to exercise this basic human right.

Newly injured SCI people are increasingly being discharged straight from hospital into a Care or Nursing home as an interim arrangement while they wait for suitable care packages, housing or property adaptations to be arranged. These can be drawn out processes and may leave such people in care homes for extended periods.

It is of vital importance that newly injured SCI people start to reintegrate into main stream society as soon as possible to avoid becoming hospital dependent and institutionalised. Removal of the mobility component, or indeed any of DLA or PIP, could severely restrict their ability to leave their institution, adapt and become independent.

With the considerable cuts being faced by Local Authorities across the country SIA anticipates that many more disabled people will be housed in Nursing and Care homes in the foreseeable future as savings are plundered from social services budgets. Removing such an individual's means for mobility will dramatically reverse the independence agenda for those disabled people most in need, in many cases irreparably.

The Government states that it "is committed to supporting disabled people to exercise choice and control and lead independent lives. We believe that, with the right levels of support, everyone including disabled people can play a full part in society. We recognise that financial support plays an important role in enabling disabled people to lead full and active lives and we are committed to maintaining an extra-costs benefit for disabled people." This is a commendable statement, but one that the Government will be jeopardizing by limiting access for those who rely on this benefit for the independence they currently enjoy and is their right.

3) Qualifying periods for PIPs

The amount of time a newly spinal cord injured person spends in rehabilitation following their initial injury is reducing significantly - people being treated in certain Spinal Cord Injuries Centres can now be discharged within three months and in some cases just six weeks. SIA is concerned that introducing a 'qualifying period' of six months for PIPs will mean that newly disabled people – those most in need of support - are discharged without the appropriate funding to meet their needs.

4) The cumulative effects of reform

SIA is concerned about the cumulative impact these changes will have on disabled people when taken into account with the wider reforms to the benefits system and cuts to the Independent Living Fund and Local Authority budgets.

We do not believe that the Government has looked at these reforms holistically and by reducing the support costs to disabled people across the board they will severely disenfranchise disabled people and prevent them from living the independent lives which should be their right.

Indeed, such cost cutting reforms may actually burden the tax payer with additional costs elsewhere. For instance, inadequate care packages, which result from a drive to cut budgets across numerous different areas, are likely to result in increased hospitalisation episodes due to poorer standards of care management, with conditions such as pressure ulcers and urinary tract infections becoming more prevalent. As a result of seeking savings from a social service budget, the cost will inevitably transfer to an NHS budget, but at a higher rate as the treatment of such conditions is considerable. Not only will the cost to the tax payer increase by hundreds of millions of pounds, the cost to the individual will be even greater, resulting in poorer health, loss of independence and reduced capabilities, in many cases for life.

5) Consultation process for PIPs

Despite the significance of the consultation and its potential impact on disabled people, it is regrettable that the DWP decided to run a short 9 week consultation which included the Christmas holiday period. The recommended time frame in Government guidance for such consultation is 12 weeks and this reduced amount of time will have impacted on the opportunities for individuals to put forward their views.

The fact that the Government has published its Welfare Reform Bill – including proposals to introduce PIPs – a day before the PIPs consultation has even closed indicates that the Government has little regard for the views of disabled people when deciding those matters which are absolutely critical to the way they live their lives.

Contact:

Daniel Burden
Head of Public Affairs

Spinal Injuries Association
SIA House
2 Trueman Place
Oldbrook
Milton Keynes
MK6 2HH

d.burden@spinal.co.uk
0845 678 6633