



Disability Living Allowance  
Reform

A Consultation by the  
Dept of Work and Pensions

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## Introduction

1. Autism NI is a parent led organisation working with professionals and relevant agencies to provide better services for the Autism community and to raise awareness of Autism throughout our community.
2. Autism NI supports the 20,000 people in Northern Ireland who have Autism through:
  - Helpline; Local Support Teams; Parent Support Groups.
  - Autism based training for people with Autism, their families and for professionals. Our training helps families to understand Autism and learn coping strategies.
  - Lobbying and media training for parents to act as advocates for better services in their local communities.
  - Research e.g. "Is Anyone Listening?": A Report on Family Stress, Trauma and Resilience in Northern Ireland.
3. The DHSSPS has recommended our training services to all Boards and Trusts in N Ireland. We received a Glaxo Smith Kline Impact award in 2008 for our work in community health. Most significantly of all we led the campaign for the Autism Act(NI) 2011 which now provides recognition for Autism within the Disability Discrimination Act definition of disability and will lead to a cross departmental government strategy on Autism. This was a process whereby a marginalized group, the Autism community in Northern Ireland, was strengthened and supported at a 'grass roots' level to engage with government to secure important social justice and human rights legislation.
4. Autism is a profound but invisible disability. All individuals with Autism have problems with social skills, social interaction and social communication. Some may not have skills for communication or independent living. Services for diagnosis and intervention are underdeveloped and delayed in Northern Ireland as a direct result of the 'Troubles', which saw social and health provision pushed into the background during a key period in the growth of global Autism awareness. Autism affects more people in Northern Ireland than the total number of those affected by Down's Syndrome, Parkinson's Disease and MS. Over 75% of adults with ASD rely on their family for financial and life-long support. Only 13% of adults with ASD live independently.
5. Autism NI welcomes the opportunity to respond to this draft and to aid our response has put the relevant page/paragraph of the draft in brackets at the end of our comments.

## General Commentary

1. Northern Ireland specific Autism legislation, Autism Act (NI) 2011 needs to be considered when introducing change to any disability benefit, policy or service to ensure legislative compliance, in particular the impact on amendment to the definition of disability, to include social and communication conditions, within DDA(NI), 1996. Whilst parity is currently being affirmed by the NI Executive, local legislation will inevitably be invoked within appeals and tribunals for decisions related to Personal Independence Payments. The Act requires public bodies to Autism proof policies and procedures and to ensure staff have sufficient Autism awareness training – generic disability training is not sufficient. This will have an impact on the Independent Assessors, Decision Makers and frontline staff.
2. Individuals with an Autism Spectrum Disorder have traditionally encountered significant difficulty in accessing Disability Living Allowance, as the invisibility of this disability was under recognized and not understood by many professionals and benefit decision makers. Making changes to Disability Living Allowance to simplify the process is welcomed but not if it continues to exclude and (because of gross misunderstanding and use of a medical model) discriminate against those people who have an Autism Spectrum Disorder and are significantly disabled within a neurotypical world.
3. Cumulative effect of multiple disabilities for an individual is not being given due consideration, it's not being measured with these tools or the daily living cost being recognized.
4. The introduction of Independent Assessors is a costly inadequate tier in the assessment process. Self assessment, carer assessment and professionals who know a person and how their disability affects them will produce more qualitative assessment information than a face to face brief meeting with someone who doesn't know the person, their situation and has a general understanding of their condition. What is the point of this tier of assessment? It potentially directly and indirectly discriminates against all and key disability groupings to different degrees. From Autism NI's perspective someone with a social and communication disability will be highly disadvantaged through this process. This tier of assessment remains a reflection of a medical model of disability and this is extremely outdated and not reflective of the standards signed up to in the UNCRPD. The impact on disabled people and their carers is that it creates another 'begging' hurdle for them to get through before their additional needs are potentially recognized.
5. Rates of diagnosis of ASD in Northern Ireland have increased by 400% in the last couple of years. The impact on claimant rates and potentially awarded rates are significant, if PIP is fit for purpose when finalized. This may well eschew projections if these rates continue. Also tied into these rate increases research has shown that carers of an individual with ASD are adversely affected by their caring responsibilities. With over 50% developing mental health issues themselves. As well, mental health rates generally post 'the Troubles' in NI have seen ongoing increases. Has any of this been taken into account.

## Draft Regulations & Explanatory Note

1. **Definition of Repeatedly** – Should include 'when completed as effectively in a different setting, such as in the home and as effectively in the day centre. Individuals with ASD often cannot apply learning and understanding of a task/skill to different settings eg

blowing nose at home to blowing nose in shopping centre are two completely different tasks/skills (Pg 44, 7.4)

2. DHSS&PS has 'temporarily' placed Autism within learning disability but with over 70% of individuals with an ASD (Autism Spectrum Disorder) having an average or above average IQ (yet still significantly disabled by their condition) the term physical or mental within this document does not adequately reflect those with an ASD, example 4.17 (2<sup>nd</sup> Draft Assessment Regulations). Rather the term developmental disability should be included in any reference to the category of disability a person may have. (Pg 4.17)
3. Individuals with ASD may have cumulative impacts of stressors and a serious adverse affect is likely to occur when the 'tipping' point is reached. The adverse event is likely to occur if support needs are not met on a continual, and sometimes discreet, basis. Therefore risk and safety is constantly planned for by carers. (Pg 45, 7.5)
4. Aids and appliances in relation to ASD can be physical devices such as time timers, Schedules, PECS, Comic Strip Conversations, Social Stories, Ear Defenders. These should be taken into account as aids and appliances. Also adaptations within the home for those with weak muscle tone/Dyspraxia such as push button toilet flushes, lever door handles, swing hinges on doors are all physical adaptations relevant to individuals with ASD yet aren't reflected in this document. Also, physical adaptations within the home are one thing but accessing things like adapted toilet flushes in the wider environment, if you have ASD, is another thing entirely. So people with ASD who have these additional needs either have to have additional help in the outside environment or remain restricted at home. (Pg 45, 7.6)
5. **Support Dogs** – are also aids used by people with ASD to prevent wandering/bolting and as such are a safety device with higher attached costs (7.10)
6. **Variable and Fluctuating Conditions** – Please note that re '(T)aking a view of ability over a longer period...' that for individuals with ASD there may be ability but the application of that ability, being able to judge when best to use that ability, being able to manage risk and anticipate consequences of actions can be inconsistent and seriously compromised. This is a continuous impairment. (Pg 46, 7.13)
7. One of the keys to assessing individuals with ASD (not just epilepsy) is consideration of risk. Meltdowns, managing and coping, being able to apply skills and understanding of consequences, being able to accurately process and identify risk, being able to formulate an appropriate response and apply a sequence to a task are all significant difficulties and are evidence that a serious adverse incident is likely to occur if the person carried out that descriptor. (7.17)
8. People with ASD will experience sequencing difficulties/organizational difficulties. There can be lack of understanding of consequences, for example if a chicken was undercooked (they will have compromised judgement of this and it's potential effect on their health). This should be reflected 'safely heat' and 'cook' and 'consume' food. Also in preparing a drink, is that a hot or cold drink, as this requires significant different risk management and sequences. Preparing a drink is very different to preparing a meal and should not be lumped together in (G) when there hasn't been a definition or reference to it earlier in the assessment criteria. (Pg 48,)
9. **Activity 2 – Taking Nutrition** – someone with an ASD will often need another person to take account of their sensory issues and difficulties with change and manage the right/appropriate food or drink to avoid a 'trigger' or reaction and therefore enable that

person to eat. They may also need someone to manage the speed and volume of what they are eating in order to avoid choking and to manage their appetite, which may be absent for the person with ASD. (pg 50,)

10. **Activity 3 - Managing therapy or monitoring a health condition.** Examples of therapies should include sensory 'diet' for sensory integration issues, exercise regimes as part of occupational therapy or counseling as part of anxiety management for mental health issues. These examples need included so as to indicate to claimant with ASD that some aspects of their therapies are recognized. What should also be included is the management of appointments, getting to appointments on time, advocating at appointments, managing supplies of medication to ensure prescriptions are appropriately maintained (pg 51)
11. **Activity 4 – Bathing and Grooming.** Cleaning ears should be included as this requires a level of dexterity, co-ordination and risk management that many individuals with ASD struggle with. Aid or appliance should include Schedules, PECS, etc. Should also include not just help with beginning/initiating grooming but ending also. Many individuals with ASD will be sensory seeking ie they will seek out and crave certain sensory inputs. This can be for example from a shower and can cause health problems by not being able to judge appropriate length of time spent on a hygiene activity or how to end a sensory seeking or obsessive behavior (Pg 53)
12. **Activity 5 – Managing Toilet needs or Incontinence.** Should include reference to continence management as a need. As well as having a more positive aspect it is often a need to ensure someone with ASD adequately manages their continence. Often obsessions will interfere with toileting and can lead to incontinence or kidney infections, impaction of bowels etc. This activity also needs to reflect issues with managing toilet equipment for example being able to flush a toilet or cleaning a toilet regularly or after soiling. Managing toilet needs should include managing the need for privacy, managing toilet needs at home and/or managing in public toilets. Managing continence – may include regular use of enemas/suppositories/diet management linked to bowel issues. (Pg 54)
13. **Activity 6 – Dressing and Undressing.** Should include purchasing clothing, judging appropriate sizing, managing to dress and undress not only in the home but in changing rooms in shops. Need to include reference to any support that might be needed to help purchase easy use clothing inc Velcro shoes for adults, non-tying laces, purchasing certain clothing to reduce or avoid unacceptable behaviours such as self-stimulation, removal of clothing labels, purchase on non-seamed socks, washing and hiding of new clothes to appear like old clothes, removal of old clothing no longer usable but part of a negatively impacting obsession. (Pg 55)
14. **Activity 7 – Communicating.** Needs to include delays in processing, ability to process multi layered information or instruction, understanding of aural communication, the need for visual communication, inability to 'mind read', struggle to understand that what is thought by a person with ASD is not necessarily heard by another person (theory of mind), literal interpretation of communication, unable to understand local colloquialisms, sayings, expressions example 'its raining cats and dogs' or 'watch that cup of hot tea'. The inability to apply understanding or to transfer understanding to different situations example 'don't cross the road without looking for traffic' may be applied readily at the same spot on the road it's communicated about but not applied at

other roads or indeed another spot on the same road. Include needing assistance to access verbal communication and to apply understanding of both verbal, written, or visual communication. Could also include someone to understand and teach Makaton. Also include being able to follow complex verbal or written information or instruction. (Pg 56)

15. **Activity 8 - Engaging Socially.** As well as mention of 'an individual's ability to engage socially, .... and establish relationships' – need to include the maintenance of relationships, this indicates a deeper quality of social relationship that is meaningful and that enable healthier social interaction, with less isolation and more meaning and a consistency that is building social integration. This is one measurement about how a person with a disability can live in a socially integrated way and is a basic daily living requirement reflecting a quality of life. It should also include a measure of assistance needed to judge relationships to avoid exploitation, manage risk, reduce vulnerability, avoid or realize about being bullied. (b) This needs to include whether a person needs prompting to disengage socially, as some engagement may be intense and therefore inappropriate. Also a person with ASD will need additional help to understand roles and responsibilities and therefore the social appropriateness of types of interaction. This includes being able to recognize and engage appropriately to the police compared to engagement with a friend, help may be needed to understand different types of relationships, ie acquaintance, friend, best friend, girl/boy friend, boss, etc and how to be socially appropriate with each. (Pg 58)
16. **Activity 9 – Making Financial Decisions.** This activity considers the ability of an individual to make financial decisions but doesn't adequately reflect a person being able to weigh up the pros and cons of a financial decision or financial commitments for example mobile phone contracts and their duration/ongoing financial commitment. (b) should include needing assistance to process and understand implications of complex financial decisions. (c) Needs to include assistance to process and understand implications of simple financial decisions. May include element of supervision and managing risk in relation to simple and/or complex financial decisions, reducing risk to health and welfare and/or reducing risk of exploitation.
17. **Part 2. Mobility Activities**
18. **Activity 10 – Planning and Following a Journey.** Should include being able to cope with hazards safely and/or to make adjustment to plans when something goes wrong in the journey example unplanned strike by bus drivers or road closures. (b) the measurement should be instead of all journeys be the majority of journeys – as this would potentially discourage trying to manage some journeys. (d) Should say cannot follow any journey because it would cause overwhelming risk to self or others (c) and (e) should say a journey to and from an unfamiliar and a familiar place.
19. **Activity 11 – Moving Around.** Should include ability to judge and negotiate hazards safely. For example someone with Sensory Integration difficulty may be at risk of physical harm negotiating stairs/steps in the home, corners of tables and door frames, they may have bruised, bumped, strained, sprained or broken limbs many times before. Also this physical ability to move around should include a reference to managing this movement safely and being able to manage any risks that arise during this movement. Co-ordination difficulties will be indicated by increased risk of falling, with a previous history of falling or receiving medical treatment for falling. An aid may include a sensory

integration aid such as a weighted jacket. Dyspraxia is a common co-existing diagnosis with ASD and weak muscle tone and poor co-ordination can then be impacted upon – when then combined with Sensory Integration – proprioception and vestibular issues – transferring from one chair to another may be affected. But how limited is test of moving from one chair to another, how real life is this, who would need to do this on a frequent basis. Moving from an aid such as a wheelchair to a chair would be common for those with this type of physical disability but moving from one chair to another is less common surely.

20. **Annex B: Reliability and Validity Analysis. Methodology** – if experts were asked to assess level of need based on nil, low, medium and high standards how does this equate to the two bands of payment and assessment ‘standard and enhanced rate’ that is being proposed.
21. **Second Draft – 8.29.** This finding affirms that there needs to be account taken of adverse impact on certain disability groups - this needs not only to be addressed at this stage but also in the post implementation stage, monitoring those who are turned down, going to appeal/tribunal data needs to be gathered on the disability group a person belongs to. Only in this way can a true picture of impact on certain disability groups be gathered. If this happens, as it is expected to by key disability groups, then Dept of Work and Pensions will be accused of actively working to discriminate against key disability groups, who will as a result be then doubly discriminated against and doubly disabled. But if the data highlights no potential discrimination against key disability groupings then the DWP can show the way in disability discrimination proofing and impact measurement.
22. **Personal Independence Payment: assessment thresholds and consultation – January 2012.** If the breakdown and assessment of Daily Living Activities is measured across 9 activities and the Mobility component is only measured across 2 activities, yet the payment of each is calculated separately then surely this means opportunities to highlight mobility impacts is much less than for Daily Living. This does not seem equal and has potential to be seen to target those whose mobility is affected. (Pg 3, 1.4)
23. Autism NI welcome the high relative priority and breadth of activity assessment for Daily Living component but is concerned at the lack of breadth for activity assessment for Mobility component. (3.5)
24. Autism NI doesn’t feel that the activity breakdown in 10 and 11 are wide enough to capture the impact of physical and non-physical mobility issues. It ‘dumbs down’ the impact of mobility because it is so narrow. Wheelchair usage for enhanced weighting does not take into account the impact of sensory integration and dyspraxia type issues. These are not adequately reflected in the Mobility component. If someone’s ability to anticipate, judge, assess, manage, plan and execute a journey or movement is doubly impaired by co-ordination, weak muscle tone and sensory issues then the accumulative affect must be taken into account to avoid consciously disadvantaging disability groups where this is a factor.
25. **Methodology for analysis.** Need to clarify what is meant by the over representation of the additional specific impairment groups in the sample. This is unclear re the significance of this. Either it replicated or didn’t replicate relative proportions; it can’t be significant in both? (Pg 8, 4.7)

## Consultation questions

### Q1 – What are your views on the latest draft Daily Living activities?

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Daily Living component (activities 1-9). These include three new activities: *Communicating*, *Engaging socially* and *Making financial decisions*. We would welcome your views on the activities.

Are the changes and the new activities an improvement? Do you think we need to make any further changes?

***Some of the changes and the new activities are an improvement but they need to go further in their detail to grasp the additional care and living needs that a person with an Autism Spectrum Disorder has that is invisible to the wider public. Autism NI has included information above that should contribute to the further development of all the activities and PIP in general.***

### Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Daily Living component (activities 1-9). In this document we have set out the entitlement thresholds for the benefit.

How well do you think they work to distinguish between differing levels of ability in each activity?

***Autism NI has detailed above it's response to individual activities and their weightings. But we would reiterate that in order to capture the invisible disability impacts and the affect of multiple diagnoses more work remains to be done in this area.***

How well do you think they work to prioritise individuals on the basis of their overall need?

***They don't reflect the individual in their situation. Age has an impact on levels of need, multiple disabilities have an impact on levels of need, diagnosis of disability alone does not.***

Do you think we need to make any changes to weightings or thresholds?

***Autism NI has highlighted above the areas of change it recommends. We would encourage DWP to take on board these recommendations as they are based on a level and equal 'playing field' for all those affected by disability.***

• **Q3 – What are your views on the latest draft Mobility activities?**

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Mobility component (activities 10-11).

Are the changes an improvement?

***Autism NI feel that the changes are the beginning of an improvement. That being said without further work we feel strongly that it would only be tokenistic if these activities and measurements were not further developed.***

Do you think we need to make any further changes?

***As above, further changes are essential in order to ensure a level 'playing field' for all those affected by disability and to give greater recognition to the modern interpretation of disability within a social model as opposed to a medical model.***

• **Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?**

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Mobility component (activities 10-11). In this document we have set out the entitlement thresholds for the benefit.

How well do you think they work to distinguish between differing levels of ability in each activity?

***Autism NI feel this is too narrow a way of distinguishing between differing levels of ability. We would draw your attention to our points raised above about how only two activities are assessed for mobility in comparison to daily living and how much more there are in relation to issues of mobility for disabled people.***

How well do you think they work to prioritise individuals on the basis of their overall need?

***Autism NI believes they don't work to prioritise individuals on the basis of their overall need as they don't take into account multiple diagnoses, type of disability and how it impacts on the detail of mobility (see points above), and how narrow the activities are in relation to assessing mobility.***

Do you think we need to make any changes to weightings or thresholds?

***Autism NI think that DWP need to broaden the weightings and thresholds and activities in order to adequately reflect the social model of mobility issues for people with disabilities. See our points raised above as well.***

• **Q5 – What are your views on how the regulations work regarding benefit entitlement?**

Draft Regulations 1 to 4 set out how the assessment will work to prioritise individuals and determine entitlement to the benefit.

How well do you think the draft regulations achieve the intent of the assessment set out in the explanatory note?

***Autism NI believe they don't, we draw your attention to the points raised above regarding definitions of aids, journeys, mobility needs, inclusion of invisible disability issues, and the issue of a social model of disability***

Do we need to make any changes?

***Yes, see above. Amendments are required when all the above issues highlighted are resolved and included.***

**• Q6 – What are your views on how we are dealing with fluctuating conditions?**

Regulation 4(4)(c) of the draft regulations and paragraphs 7.13 to 7.15 of the explanatory note set out how we are proposing to assign descriptors to people who have fluctuating conditions. These are that:

Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in a 12 month period.

If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.

Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of different days – the descriptor satisfied for the highest proportion of the time should be selected.

What are your views on this approach and how this is set out in the regulations?

***Autism NI feel this is a very narrow way of assessing the impact of a disability on a person's life. Fluctuation timeframes are irrelevant as the intensity of daily living support and mobility support needed are often unpredictable and therefore require a level of support, planning and preparation to take account and respond to the worst day scenarios. In European legislation if someone is on stand by to work then under the working time regulations they are regarded as working. If a disabled person or the carer of a disabled person needs to be on standby to respond to the worst day scenario then they are contributing to a daily living and mobility need. This proposed new benefit is called Personal Independence Payment. In order to be independent a disabled person needs to be able to manage changing and fluctuating need without reliance on the goodwill or unpaid work of a family member.***

• **Q7 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely manner’?**

In the assessment an individual must be able to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. Otherwise they should be considered unable to complete the activity described at that level. In paragraph 7.4 of the explanatory note we set out draft definitions for these as follows:

**Reliably** means to a reasonable standard.

**In a timely fashion** means in less than twice the time it would take for an individual without any impairment.

**Repeatedly** means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual’s ability to subsequently complete other activities.

**Safely** means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

What are your views on these? Some organisations have suggested that these terms should be included within the regulations. Do you agree? If so, do you have views on how we should do so – for example, as a general provision or referring to them in the detail of activity descriptors?

***Autism NI believe the meaning of these terms should be included within the regulations, and refer to them in the detail of activity descriptors. Some of the terms themselves have potentially negative connotations or are perceived as judgemental such as reliably and in a timely fashion. Could they not be replaced with consistently and within a comparative timeframe?***

• **Q8 – What are your views on the definitions in the regulations?**

The draft regulations contain a number of definitions in Regulation 1 (Interpretation) and Schedule 1. Do we need to make changes to any of these?

***Autism NI would draw your attention to the points raised above. The regulations and definitions need to reflect amendments that have been recommended.***

• **Q9 – Do you have any other comments on the draft regulations?**

Regulations 5 to 10 of the draft regulations relate to elements of the assessment process for Personal Independence Payment, around the requirement to provide information and attend face-to-face consultations, the consequences of failing to meet these requirements and when individuals might have good reason for not meeting these. Do you have any comments on these regulations?

***Autism NI has raised a number of points in relation to this above, including how discriminatory a face to face consultation will be for someone with a social and communication disability, given the impact of the persons disability, the effect of creating a one-off snap shot of a person’s life, and the consultation being facilitated by someone who doesn’t have the expertise or knowledge of a professional who has worked with that person all their life or for a considerable amount of time.***