Response to the Work and Health Green Paper consultation from the National Deaf Children's Society



About us:

The National Deaf Children's Society is the UK's leading charity for deaf children and young people. Our vision is of a world without barriers for deaf children. We support deaf young people up to the age of 25 and are currently running an award-winning campaign, Deaf Works Everywhere which aims to improve the careers support deaf young people receive, increase opportunities to gain work experience and challenge expectations of what deaf young people can achieve.

We are a member of the Youth Employment Group and co-chair their disability subgroup.

Our data:

Focus groups and 1:1 interviews were run with 11 deaf young people in September 2021 on careers and employment support. The views and experiences of young people are reflected in this consultation response. The insights from our focus groups have been combined with data from a 2020 report about deaf young people's experiences of careers advice and support. The report was put together with data collected from over 100 deaf young people across the UK¹.

We also have considerable insight from our membership surveys and our casework in supporting deaf young people and their families to claim PIP or to challenge discrimination in employment.

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¹ https://www.ndcs.org.uk/media/5665/dwe-yab-report.pdf

About our consultation response:

We have focused on the questions within the consultation that we believe are particularly relevant to deaf young people. We have grouped our insights and recommendations in the order that they are found within the Green Paper.

Chapter 1 - Providing the Right Support

Reasonable adjustments in accessing DWP services

Deaf young people communicate in a range of different ways, for example, speech and/or sign language. It is important that, whatever their communication needs, they are able to contact and access DWP services.

Some young people reported difficulties trying to get in touch with Access to Work (AtW) with some having to rely on their parents to phone AtW advisors on their behalf. One young person stated there was no obvious way to email AtW.

We are aware that DWP has made changes to make its services more accessible to deaf people such as rolling out British Sign Language (BSL) relay services. However, there is a perception that it is necessary to phone to progress an application (this may be linked to a relatively slow response to email correspondence by DWP staff). This means deaf young people without strong parental support or advocates could be particularly disadvantaged.

DWP state that you can use Relay UK (where an operator will type what is being said on a phone call) to get in touch. However, not all the young people in our focus groups knew what the Relay UK service was. It cannot be assumed that all deaf young people are told about how text or BSL relay services work.

There appeared to be a lack of confidence in being able to contact DWP by email. We are aware of significant delays in processing new AtW agreements or claims in recent months² which could further erode confidence.

British Sign Language (BSL) users can face difficulties claiming PIP, as they are asked to complete the form in written English, which is generally not their strength. We often see young BSL users who have filled in PIP forms without advice; they may not have not written very much at all and have no real understanding as to how much information they are expected to provide.

- New employment and training programmes from the Department for Education and
 Department for Work and Pensions should have an Equality Impact Assessment
 published prior to launch, outlining how they will be inclusive and accessible to disabled
 young people.
- 2. DWP do more to promote the different ways it is possible to get in touch with its staff. This may require providing explanations on how BSL relay or UK Relay services work. Also, assurance should be given that online forms or email will be responded to within a specified amount of time.
- 3. The response times to emails and submission of online forms are improved. It should not be assumed that an email is not urgent. For many deaf people email is a much preferred method of communication over using the phone, even with the availability of relay services. The DWP should also consider introducing a live text service, similar to those offered by many retail companies through their websites.
- 4. DWP make it possible for BSL users to complete the PIP and AtW application forms using BSL, using interpreters to translate from BSL into English.

² https://limpingchicken.com/2021/09/22/access-to-work-department-for-work-and-pensions-delays-deaf-bsl-interpreters-communication-professionals-dwp/

Signposting to DWP services

The Access to Work scheme is very important for deaf people in enabling them to find and sustain employment. However, 90% of deaf young people are unaware of the scheme. This means they are making decisions about their futures uninformed about what support and technology can be made available to them in the workplace through Access to Work funding.

Additionally, our focus groups revealed little awareness of the Disability Confident scheme which means young people may not specifically be looking out for Disability Confident employers when seeking work.

There were very few young people who had used Jobcentre services which could suggest a lack of signposting to the programmes that are available. One young person had accessed the Kickstart scheme but was only made aware of it through his mother. This was the first time he had accessed employment support despite being out of work for two years.

Careers advice provided at school is too general and does not properly equip disabled young people to make informed decisions about their futures and to move into the job market. Currently there is good guidance to schools and colleges in England on provision of tailored careers guidance for students with SEND. However, our findings show this is not being followed. It is not explicitly required by law or through funding agreements for schools and colleges to adapt their careers programmes for disabled young people. Therefore, it is unclear education providers can be held to account on lack of tailored careers guidance.

DWP have advisors which visit schools to support young people at risk of becoming not in employment, education or training (NEET). However, we have consulted with many deaf young people and none of them referred to this support.

- 5. The Government should make it mandatory for schools and colleges to provide disabled young people with tailored careers guidance including the provision of information about Access to Work, Disability Confident, employer duties under the Equality Act and employment support schemes.
- 6. Youth Hubs should be used to pilot the joining up of Department for Education funded programmes such as apprenticeships, supported internships and college courses with DWP programmes such as the Work and Health programme. This could mean for example, that FE colleges would be able to link up with employment support providers and jobcentres to ensure disabled young people had ease of access to further support after finishing a 16-19 study programme.

Advocacy support

We, like other organisations that run national helplines, make referrals into the DWP Home Visiting Service for DWP to fill in DLA and PIP forms (as others will for AA) where we judge that a service user will be unable to complete a form without help. Often there is no other local service that can support. We make referrals usually for young people who also have other disabilities or where English is not their first language. For people who cannot access local advice services for whatever reason, or where none exist, it's an imperfect but incredibly useful service. It is conceded in the Green Paper that some people find forms long, stressful, difficult to fill in and that reasonable adjustments are not always available. Expanding the Home Visiting Service would be a straight-forward way for DWP to operationalise its commitment to advocacy.

- 7. The DWP Home Visiting service should be expanded both in scope and scale.
- 8. Deaf young people transitioning from DLA to PIP who do not have an advice agency supporting them should be given an advocate to assist them through the process. The advocates would need an understanding of how to communicate with deaf people and of the challenges that young deaf people face. We would be happy to work with DWP on ensuring advocates receive deaf awareness training.

Chapter 2 - Improving Employment Support

Improving the Access to Work scheme

As stated in earlier sections of this response, one of the main issues is a lack of awareness of the scheme, with most deaf young people in our focus groups not having heard of the scheme.

There were some complaints raised by young people that about AtW not being available for short-term placements (e.g. banking internships). This is despite AtW staff guidance referring to discretionary support being available for self-arranged work experience of 1 to 8 weeks in length where it is likely to lead to paid work. We have yet to come across any deaf young people who have accessed this support.

Even when roles are paid, AtW grants are not always available. One young person said they could not get interpreters for a short-term salaried role (4 weeks).

For those who had used the scheme, it was felt that AtW advisors are not always understanding of young people's circumstances. One young person taking an apprenticeship talked about the frustration of being asked by AtW advisors several times how many hours they were at work and how many were at college. He found it difficult and stressful to provide the necessary information as he was just starting work for the first time.

Another young person reported that whilst AtW had been helpful in getting a radio aid and fire alerting system supplied for his Kickstart placement, there had been issues with the communication between his manager and his Access to Work advisor. Despite being several months into his placement, he has still not had any awareness training sorted out for his colleagues.

- 9. DWP works towards annual targets on employer awareness of Access to Work. This would encourage greater promotion of the scheme.
- 10. Online information is provided setting out the availability of Access to Work for unpaid work experience, with clear criteria for eligibility and information about how this support can be accessed.
- 11. Access to Work is reformed to ensure that the support, training and equipment the scheme funds is in place from day one of a young person's employment. Where this is not possible, we believe that temporary interim support must be put in place for those who require support workers to carry out their role. (Currently this support is discretionary and is not referred to in writing within any AtW guidance for customers or staff).

Improving Disability Confident

We believe that an understanding amongst employers of the reasonable adjustments that can be made for deaf people in the workplace is critical for a positive experience. Deaf young people in our focus groups talked about the importance of 'deaf awareness' (i.e. when someone understands how to communicate effectively with a deaf person). Deaf awareness in the workplace is what they believed would make the biggest difference in when moving into work.

Through our helpline we've provided advice to deaf young people and their families who have been discriminated against by employers. Too often health and safety rules are used as a reason for dismissal. However, in most cases we find that the employers have not properly considered what reasonable adjustments could be put in place to mitigate and reduce workplace hazards.

We think the Disability Confident scheme can play a role in improving deaf awareness amongst employers by providing or signposting to information about making reasonable adjustments for deaf employees. However, the scheme's reach is limited with only a small percentage of the UK's employers signed up.

The scheme gives insufficient assurance to disabled people that a Disability Confident employer has strong inclusive practices. In order to sign up to Level 1 employers are only expected to 'consider' 5 commitments and commit to one activity out of a list of 9. There is no quality assurance until you reach Level 3. This means an employer can sign up but potentially do very little to change their practices.

Most young people in our focus groups were unaware of Disability Confident. A lack of awareness of the scheme amongst disabled young people will mean it has limited benefit for them. They will not know to look out for employers that are Disability Confident or understand what steps Disability Confident employers are expected to take.

One young person came across Disability Confident when applying for a civil service scheme and appreciated being able to apply through their 'disability confident process'. Through this she was able to get reasonable adjustments for the tests involved within the application process. She also felt that Disability Confident showed the ethos of the company was positive and meant she was more likely to apply.

- 12. DWP be required to work towards annual targets on the number of employers signed up to Disability Confident.
- 13. Disability Confident is strengthened by putting in place quality assurance of employers signed up to the scheme.
- 14. Disability Confident actively promotes disability-specific resources to employers and the guidance of the Health and Safety Executive on disabled employees.

Supporting disabled young people into employment

We believe the education system fails to properly prepare deaf young people for the transition from education to employment. Most young people in our focus groups complained about the lack of tailored support at school or college. Careers guidance was often seen to be too generic and too focused on grades and academic education.

Often young people talked about a reliance on parents to help ensure they were informed and to give support with interviews. We believe this heavily disadvantages young people without strong parental support. Our surveys of parents reveal that most of our members believe they lack information on post-16 pathways and support to find and sustain employment. This means most parents are not well placed to provide good quality support.

Accessing interviews can be challenging for deaf young people who rely on communication support such as British Sign Language (BSL) interpreters. One young person talked about the challenges of sourcing BSL interpreters in time for interviews. Deaf young people have lower levels of literacy compared with the general population. This means completing application forms can present difficulties. One BSL user stated she would benefit from having access to BSL interpreters to translate application form questions.

Deaf young people face significant challenges in gaining work experience and our 2021 survey of families revealed that only 50% of deaf 15–25-year-olds have any work experience of any kind. This can leave them disadvantaged when moving into the job market. A scheme like Kickstart could help bridge the gap between education and employment. However, only young people on universal credit are currently eligible for Kickstart which is also only a temporary scheme.

- 15. The new Access to Work Adjustments Passport is used as a key tool with young people with SEND in schools and colleges. It should be embedded in an updated Code of Practice following the completion of the Department for Education's SEND review.
- 16. The benefits of the Kickstart scheme for disabled young people should be evaluated.

 Assuming positive outcomes are shown for the majority, we recommend the scheme is extended beyond March 2022 and the eligibility is adjusted so that more disabled young people can participate.
- 17. See recommendation 6 on page 5 of this response. Youth Hubs should encourage greater join up between education providers and employment support programmes.

Chapter 3 - Improving Current services

Telephone and Video assessments

Some of our families and young people have found these useful. However, others have found them completely inadequate because they can be less accessible than a face to face meeting (lipreading off a screen is more difficult). For example, one young adult reported to us that they were not allowed to participate in the assessment; the assessor insisted on talking to their parent, even though they were not the appointee. The young person felt this was simply because the assessor found it easier to communicate with the hearing parent than the deaf claimant.

Recommendation:

- 18. Deaf young people are given the choice of whether to have a face to face, telephone or video assessment.
- 19. Deaf young people who want to participate in their assessments (including when they have an appointee) are given sufficient opportunity to do so.

Holistic decision making

The commitment to reducing the number of cases that have to progress to appeal is welcome, and ideas such as obtaining better medial evidence will help. At the National Deaf Children's Society we find that young people who we can assist with claiming PIP have a very high success rate, over 90%. For those who approach us later in the process, we find our success rate at appeal is over 95%. We can explain the eligibility criteria to them and

focus the information they have about their daily life, so it addresses the eligibility criteria. Costs associated with appeals could be much reduced by ensuring young people have appropriate support and information when applying for PIP.

However, a great many young people claim PIP without any advice and are not awarded the benefit. Too often with the cases we support with where the initial claim has been refused, the problem is that the young person has simply not been believed, either by the assessor or the DWP decision maker or both. The young person finds that unless they can provide professional evidence that 'proves' that their hearing loss causes them a problem they are refused.

We believe deaf young people claiming PIP should not have to provide proof of facts that are well established within the evidence base on deafness. For example, that their hearing technology does not restore normal hearing or that background noise impairs their ability to hear. These are all facts that any audiologist will verify.

We think assessors and DWP decision makers need to focus their attention on whether the stated level of problems are consistent, plausible and relevant to the PIP descriptors. More than anything else, this would improve decision making on PIP cases for deaf young people.

Recommendation:

19. DWP decision making on PIP claims for deaf young people should be informed by a real world understanding of deafness. This means PIP assessors assessing deaf young people having sufficient specialist knowledge.

Transitioning from DLA to PIP

We welcome the commitment to improve the experience of children and families transitioning from DLA to PIP. The transfer at age 16 is a legacy of when DLA was a benefit for those aged 0 - 65, and the transfer involved taking on responsibility for the claim, not making a claim for a new benefit with different rules of entitlement and assessment process. Eligibility to claim many benefits at age 16 is restricted. PIP is an outlier and so amongst the very few 16-year-olds who must make benefit claims themselves are those with a disability. The claim itself must be made when a child is only 15 and they can face barriers in applying for reasons linked to their disability. We believe the age of transition is a factor in the dropout rate between DLA and PIP we observe. Many deaf children in receipt of DLA either are not awarded or do not even claim PIP but would undoubtedly be entitled if they did claim.

Numerous decisions of the Upper Tribunal considering appeals in such cases have stated that medical evidence used to support a DLA award should be used when determining a PIP award. It assists in decision making and can help ensure that those who clearly have qualifying needs for PIP do not miss out on the benefit simply because they are unaware of the new criteria or have not provided supporting evidence. DWP have accepted this and has given evidence in some of the cases before the Upper Tribunal to say it has changed its procedure to ensure that this happens. However, we continue to see cases where it does not.

Currently, when transferring from DLA to PIP at age 16, DWP are legally obliged to establish if an appointee is still required, i.e. whether the child has mental capacity to manage their own claim. This is because the legislation governing appointees for children and adult is different.³

Our experience is that this process is not routinely adhered to, and appointees are "carried over" into PIP, with minimal or no real assessment of the young person's capacity. However,

³ . A child on DLA has an appointee under Regulation 43 of the Social Security (Claims and Payments) Regulations 1987 whereas an adult can have an appointee because they are unable to act in relation to their PIP claim because they lack capacity is made under Regulation 57 of the Universal Credit, Personal Independence Payment etc (Claims and Payments) Regulations 2013.

to correctly apply the law and avoid financial abuse of young adults, DWP must send out visiting officers to assess capacity in every case.

- 20. Young people in receipt of DLA should have the option of deferring the transition to PIP until they are 18.
- 21. Once the transfer process is underway, payment of DLA should continue to allow mandatory reconsiderations and appeals to be completed, up to a maximum of one year.
- 22. DWP should ensure that in all transitions from DLA to PIP, the young person is asked if the medical evidence used to support the DLA award should be used when determining the PIP award.
- 23. DWP must send out visiting officers to assess capacity in every case of transition from DLA to PIP and there should be no automatic transfer of appointees.

Chapter 4: Rethinking Future Assessments to Support Better Assessments

PIP descriptors

Most deaf young people receiving PIP rely on hearing technology and are awarded points for using "aids and adaptions". We believe any changes to the PIP descriptors that would undermine these awards would be a hugely retrograde step.

We are concerned by the assertion within the Green Paper that "since the assessment criteria were introduced, some of the activities referred to may have become less of a barrier to independent living and employment. For example, new assistive technology has become available."

Hearing technology does not replace normal hearing, and nor does its use turn a deaf young person into a hearing person. Barriers to social participation, employment and educational attainment remain prominent despite the use of aids and appliances, and the advances in assistive technology.

For many deaf young people, the financial support provided by PIP is essential in enabling them to participate in social activities, education, work, or to live independently.

Evidence for PIP decisions and quality of PIP assessments

We have found the quality of PIP assessments carried out on behalf of DWP extremely variable. Deaf young people face the problem that their condition is a low incidence disability and so assessments are carried out by assessors who have no expertise in deafness. Common problems that repeatedly appear in assessment reports include:

- assumption that hearing technology restores normal hearing
- complete lack of understanding of the impact of background noise on hearing technology
- difficulty of lip-reading strangers in real life situations
- lack of awareness of "concentration fatigue" experienced by BSL users and lip readers.

All assessments carried out for deaf young people should be reviewed by an expert in deafness and deaf issues. Whilst it may not be feasible for an expert in deafness to carry out all assessments for deaf young people, it is entirely possible for one to review them.

A problem for deaf young people is that when they finish education, professionals whose evidence may have previously helped with DLA claims, like Teachers of the Deaf or speech and language therapists are no longer available. We would recommend that in these cases, reports be obtained from audiologists that address the PIP criteria, and that DWP should pay for these reports.

- 24. All assessments carried out for deaf young people should be reviewed by an expert in deafness and deaf issues.
- 25. Medical or corroborative evidence should only be sought from professional specialists who are able to comment on the impact of deafness on the young person, i.e. a Teacher of the Deaf or audiologist rather than a GP.

Chapter 5. Exploring ways to improve the design of the benefits system

Single new benefit

The Green Paper asks if, in the future, a single new benefit could provide support for disabled people on a low income and help meet the extra costs of disability.

The clear evidence from the families and young people that we support with our advice service is that receipt of PIP can have a significant positive impact on their overall wellbeing. Any move away from a non-means tested benefit designed to meet the additional needs of disability and facilitate participation would undermine the value of this to them.

Research⁴ carried out prior to the introduction of PIP on how adults spend their DLA highlighted spending on:

- specialised equipment, particularly to ensure their health and safety at home;
- communication support including paying for interpreters and communication support workers for social events, activities outside of work, and appointments where communication provision is not supplied
- communication support specifically with written English
- additional costs incurred as a result of deafness
- taxis and other assistance with transport.

These additional costs are exactly what PIP is designed to meet, and to truly assist the life chances of deaf young people we believe they must remain available on a non-means tested basis.

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⁴ Disability Living Allowance for Deaf People. A BDA survey 2013.

Aids, appliances and services in lieu of cash benefits

Deaf young people, like many other disabled people, already use their PIP to purchase equipment or services to aid participation, get around outdoors or to help with daily living. It's unclear if the suggestion in the Green Paper would include equipment currently provided by the NHS like hearing aids or cochlear implants. It is hard to see the value of this idea for deaf young people who appreciate the flexibility the benefit currently gives to meet their individual needs.

In any event, changing the structure of PIP to incorporate the provision of services or equipment, whether voluntarily or not, would present a severe operational challenge. A national equipment service would appear to be an anachronistic return to a paternalistic approach towards disabled people and a backwards step in promoting independence. Delivered via local authorities, it would bring swathes of working age adults within the ambit of hard-pressed social services. If neither of these methods of delivery were chosen, the chosen model of delivery would have to work alongside the NHS and local authorities, adding complexity.