

NNPCF response to the Shaping Future Support: The Health and Disability Green Paper

1. About the National Network of Parent Carer Forums

The National Network of Parent Carer Forums (NNPCF) is the independent, national voice of parent carer forums. We are run by parent carers with lived experience.

Our mission is to deliver better outcomes for families living with special educational needs and disabilities (SEND). We aim to:

- create a culture of participation and co-production across the education, health, social care and the voluntary sectors. This means that we are involved in all aspects of designing, commissioning, delivering and reviewing services as an equal partner.
- empower our members to ensure that their voices are heard at a local, regional and national level
- inspire our partners by sharing good practice and knowledge.

Our vision is a for the best possible opportunities and futures for all children and young people with SEND and their families

Parent Carer Forums are pan disability. This means each Parent Carer Forum includes Parent Carers from a range of backgrounds with a wide range of experiences in Health, Education and Social Care as their children have a wide range of conditions. We currently have approaching 100,000 members.

2. Our Approach to this consultation

As a membership organisation, the NNPCF Steering Group has based this report on a range of sources including:

- Feedback from forums through their regional networks to their Steering Group member.
- Feedback on our social media platforms.
- Feedback at an engagement event with representatives from DWP
- Key issues identified through direct conversations with parent carers at a local, regional and national level.
- A national survey of parent carer forums on employment opportunities.

3. Parent Carers have high aspirations – The Wider Context

“Our vision for children with special educational needs and disabilities is the same as for all children and young people – that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives.”¹

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Parent and carers of children and young people with special educational needs and disabilities share the same hopes for their futures as other families but the challenges are far greater. The NNPCF would ask that when considering the responses to this consultation, the government seeks to understand and address not only the challenges faced by young people with special educational needs and disabilities as they become adults but also the significant impact this has on families as they seek to care for, support and guide their young person.

4. Our Key Issues

The NNPCF welcome the aims of the Green Paper:

- to explore how the benefits system can better meet the needs of disabled people and people with health conditions now and in the future.
- to build a system that enables people to live independently
- to move disabled people into work (where possible).

However, our members have raised the following key issues that we want to make sure the DWP considers through the consultation process:

1. Providing the Right Support

Supporting a disabled child to prepare for adulthood is a very complex and difficult time for families. This is compounded when parent carers find it hard to access the health and disability benefits and related support for their son or daughter.

The current assessment process for benefits is not fully accessible especially for young people with neuro diverse conditions such as autism, learning disabilities and those with complex needs. We have heard from our members that there is a lack of understanding of specific conditions and this has an impact of the support available. The reasonable adjustments that young people need are not person centred.

In order to improve reasonable adjustments to make sure that services are accessible, the NNPCF would like to see training for all staff on specific conditions and an approach that is centred on each individual claimant.

Families have told us that information, advice or signposting is needed. **This should be provided through the Local Offer website which every Local Authority is required to have.** However, it is important to note that currently, many LOs are not always up to date, can be hard to access and the offer not robust.

The NNPCF agree with the principles that the Government have set out for advocacy support in the green paper, however, the reality on the ground is that there are very few advocacy services to access. Parent carers are the best advocate for their son or daughter. We know our children the best. Please listen to our voices and value the evidence we provide.

As part of the assessment process the NNPCF strongly believe that the views and wishes of both the young person being assessed and their parent or carer should be considered. The NNPCF would like the evidence that families provide to be taken into consideration as part of the assessment and to be given the same weight as the evidence submitted by medical professionals by the Decision Maker.

Families have raised significant concerns regarding the age at which a young disabled person transfer from DLA to Pip. Many parent carers described the lack of maturity of a 16-year-old with additional needs compared to their peers. Other parents are concerned that some young people say NO and refuse to apply for PIP because they think they do not need support (when they do) or do not want to be 'different'. There needs to be clearer guidance regarding a young person's mental capacity to make an informed decision as to whether they require financial support to help with the additional costs because of their disability. This could be discussed as part of the appointee process.

One parent described it as "My son maybe able to perform the functional skills set out in the descriptors, however, does he know that if he is hungry, he needs to eat everyday or if he is hurt that he needs to seek medical help?"

The NNPCF would like the DWP to produce written guidance for families around Mental Capacity in terms of who should complete the PIP application form, their young person or the parent carer?

2. Improving Employment Support

"Those who have learning difficulties find it much harder to have the aspiration or see relevant opportunities for work but this starts at college level as very limited courses are on offer 7 years after the SEND Reforms."

Parent Carer Forum member

Families describe their young people approaching school leaving age as "the cliff edge". Whilst at school, they understand the provision and support their young person is receiving and can align this with the outcomes for their young person. However, upon leaving school the offer from many, if not most local areas are less clear and very often families are unable to see how the services and provision available will serve to deliver the best possible outcomes for their young people. This is because information about services

is often poor and too frequently, the services and support parents believe their young person needs are just not available.

Key Statistics from our November 2020 survey of Parent Carer Forums

The NNPCF surveyed our members regarding Employment pathways and opportunities in their Local Authority area.

- **96%** of forums who responded to the survey said that they were either unaware of whether their Local Authority had an Employment strategy for disabled people or their Local Authority did not have an Employment strategy for disabled people.
- **59%** of forums who responded said that their Local Area offer supported employment opportunities for young people with SEND.
- **26%** of forums said that this has led to an increase in the number of young people with SEND who is in employment.
- **41%** of forums reported an increase in young people with SEND who are not in Education, Employment or Training (NEET).

Forums advise that the main reasons for the rise in the number of young people with SEND who are NEET are:

1. Lack of appropriate locally available employment opportunities
2. Low aspirations relating to work
3. Poor information about employment and training opportunities
4. Off rolling, reduced timetables, exclusions

The most recent government statistics reveal that children with SEND are 8 times more likely to be permanently excluded.²

5. Lack of travel training opportunities
6. Narrowing of curriculum with fewer vocational courses on offer
7. Quality of FE courses for young people with SEND.

Forums have told the NNPCF that the impact of low employment on young people with SEND is social isolation, low self-esteem, poor mental health and wellbeing and limited life choices.

The NNPCF are concerned that the opportunities for a young person with an EHC Plan and a young person at SEND Support in a mainstream school differ. Those who do not have an EHC Plan are often forgotten; these young people get support from school but once they leave education, they lose all support and do not qualify for any employment support as the thresholds are too high.

² Permanent and fixed period exclusions in England <https://explore-education-statistics.service.gov.uk/find-statistics/permanent-and-fixed-period-exclusions-in-england>

The NNPCF would like to see parity in offer regarding employment support for young people with an EHC Plan and those at SEN Support. For example, help with career advice, vocational profiles, access to Job Coaches and information, advice and support.

The NNPCF would also like to see Local Authorities working with further education providers and voluntary sector partners who have the knowledge and expertise to support disabled people and people with health conditions into employment.

“Employers do not know how to employ these people and are unwilling to put the money in and training of all staff around disability”

Parent Carer Forum member

Many of the work programmes available focus on supporting the young person and the employer into a successful employment and there is strong evidence of the employability of people with disabilities. However, the disability employment gap remains high. Schemes to create more disability confident employers and so increase demand for disabled people in the workplace are key to addressing this.

The NNPCF would like to see details of the disability confident scheme posted on every SEND Local Offer across the country.

Currently the list of disability confident employers is weighted towards public sector organisations and charities.³ **We would like DWP to focus on adding more private sector employers to the list. The NNPCF would like to see a disability confident “kite mark” or sticker to encourage more small and local businesses to participate.**

Research shows that coproduction can bring out positive solutions to the many difficulties faced by families caring for a young person with SEND. We understand that coproduction can be difficult at the best of times; it is even more challenging during a pandemic.

We would like the Government to reinforce the message to Local Authorities and other partners on the need to co-produced solutions to create employment opportunities for young people with SEND.

The issues and challenges that this Green Paper seeks to address are beyond young people and families needing more information, they shine a light on the need for a different approach to ensure that employment opportunities improve for everyone, regardless of need or background.

³ List of employers signed up to the disability confident scheme
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/678962/disability-confident-list-of-employers.csv/preview

These changes will only happen if continued and sustained effort, attention, funding, and accountability continues to be placed on Education, Health and Social Care partners, but also that the wider community values the skills, gifts and strengths of this group of young people and their families. When agencies work well together, believe that young people can achieve and young people, their parents/carers feel empowered, the outcomes can be extraordinary.

Here are some examples of good practice:

Our Voice, Parent Carer Forum in the LB Enfield sits on the Employment Board and has been trying to influence local employment opportunities. LB Enfield have been working hard to support post 16 employment opportunities and are offering roles in the council.

Bexley Voice have coproduced a Parent Transition Planner to provide information for parents/carers who are supporting their child who has an Education, Health and Care Plan (EHC Plan) and complex needs, as they move from Year 9 into adulthood. The forum also offer parents and carers of young people in Year 9, with complex needs and an EHC Plan, the opportunity to attend a Parent Transition Workshop. This will help them prepare for their Year 9 annual transition review.

Oxfordshire PCF were involved with the Post 16 Network which consisted of post 16 providers, colleges, alternative providers, health, education, children and adult social care, providers of supported internships and employers keen to support employment opportunities for disabled young people. The forum supported work on supported internships, plus special events created in local Job Centre with DWP. The event enabled young people with SEND to meet face to face local employers.

How can we better support young disabled people who are moving out of education to find appropriate work?

Families report several consistent issues across the country:

- Whilst there are often good, co-produced preparing for adulthood strategies and intentions, provision of services is lacking across the board.
- There is frequently poor planning that is not started soon enough
- Information about employment support is limited and confusing both nationally and locally.
- Areas that have successfully implemented the government's reforms are jointly commissioning the services that families need and this leads to better outcomes for young people.

The NNPCF strongly requests that it is a requirement for each Local Authority to have an Employment pathway as part of their Preparing for Adulthood strategy. The strategy and information about Employment support for young people with SEND should be on published on the Local Offer.

There needs to be a clearer understanding of how local authorities and providers within the post-16 high needs system can work together to manage an increased demand for support for High Needs students to prepare them for employment, and what more can be done to make best use of resources. Funding also needs to be made available to FE colleges to support students with lower-level SEN.

“If a young person is off the radar or out of education then there seems to be lack of opportunities or even no progression/further advancement for the young person.”

Parent Carer Forum member

Supported Internships are only available for a small number of students with EHCPs whilst apprenticeships become unavailable to some SEN students who are unable to secure the necessary grades to access their chosen course.

“My daughter completed a supported internship in June 2019, it was meant to lead to a job. It didn't. She wasn't given enough training to make her employable. She doesn't meet criteria for any support & is now claiming benefits when she would prefer to work.”

Parent Carer Forum member

3. Improving our Current Services

Our members describe the current assessment process as inconsistent and stressful. The administration is crippling on top of our caring roles and the assessments have a huge impact on our lives.

For some the impact of a disability or health condition can change over time, however, for many of our families their children's lifelong disabilities. It is important for our families that their son or daughter does not need to have repeat assessments where their condition is unlikely to change.

It is important to note that skills can be lost where a person is NEET for a period. This may also be the case where the deficits caused by Covid i.e., individuals missed work experience during the pandemic, others became withdrawn, reclusive, increased OCD issues etc. and may need extra support to restore/reintegrate them.

Where an assessment is required there should be a flexible approach to undertaking the assessment, face to face, by telephone or by video. This should depend on the needs of the individual and preference.

Other changes that could be made to improve decision making include:

- Less rigid assessments. Conditions can vary daily, depending on the environment or individual needs/circumstances.

- Descriptors need to allow for the support that a young person may need to carry out everyday tasks and whether this skill is transferable. For example, Travel training ~ A person may be able to undergo 'successful' travel training i.e plan route, know which bus/train, purchase tickets etc. But when faced with peak commuter footfall, bus on divert, train cancellations, ticket office closed etc., the ability to cope will disappear.

Personal care: Whilst they may have ability to be independent there may also be an element of support required that is overlooked when making assessment. e.g., reminders of time, prompts to wash outside of routine times where needed, time for rituals (these cannot be rushed) etc. The environment can also impede things here e.g., at home a person may be comfortable and able to use the toilet totally independently but need significant support to tolerate public toilets. As anxiety ramps up the ability to cope reduces.

- Training is required for assessors and decision makers in order understand our lived experiences and impact of the disability on each young person.

4. Re-thinking Future Assessments to Support Better Outcomes

The assessment process is often a source of anxiety for young disabled people and their parents or carers. Our members report a lack of trust and confidence in assessment outcomes and decisions. 'Walk alongside families' and assess our children and young people over time. Only ask families to provide missing evidence rather than repeat our stories.

The NNPCF would welcome an approach whereby future assessments for financial support are made as simple as possible so that people understand how they have been assessed, and how and why a decision has been reached. Any changes to the assessment criteria and process must result in a more transparent and consistent decision-making process. The right evidence needs to be gathered to enable robust benefit and assessment decisions first time round so that families are not subjected to an appeal process on top of their caring responsibilities.

DWP should make use of other information and evidence that is available. This information needs to reflect the current needs of the young person and the impact on their ability to carry out day to day tasks. However, seeking additional health evidence at the current time is not realistic. **Families should NOT have to pay for these reports.**

Evidence from other people who are known to the young person, such as other health professionals, social workers and support organisations should be taken into consideration. This could take the form of a written report, EHC Plan, Care Act assessment or Care Plan.

The current PIP activities and descriptors that should be reviewed and extended to understand so that the assessor consider the 'So What?' question i.e., what is the benefit or impact of awarding the benefit for that individual? Evidence collected before a WCA or PIP assessment must not only directly relate to a person's ability to do certain things but also to the amount of support needed to do it. It must also consider the things that a person cannot do, why, when, and where.

Each assessment should be person centred, identify need and the impact of that need. The assessment should focus on supporting the young disabled person/adult to achieve better employment, health and social outcomes. i.e., to live as independently as possible.

The NNPCF would like to see an assessment framework which sets out the outcomes that young disabled person/adult is seeking achieved. The outcomes will be expressed from the young person's/adult's point of view. For example:

**I am supported
I am active in my local community
I am healthy
I can work**

The framework will have a set of questions for each outcome and a list of factors for the assessors to consider when undertaking the assessment based upon specific conditions. This would improve consistency in decision making. And improve the outcomes achieved.

The NNPCF can see how separating the assessment for financial support from the process for determining an individual's employment support in the future maybe a sensible way forward and welcomes in principle the proposal to hold Employment and Health discussions to better understand how the DWP can determine employment support in the future. However, this will be dependent on the knowledge and skills of the person facilitating the discussion.

5. Exploring Ways to Improve the Design of the Benefit System

The current health and disability benefits system provides different levels of financial support depending on the impact of a person's health condition or disability. This can mean that people are worried about the level of their benefit payment changing after an assessment. We want to explore whether there are better ways to target financial support so that people do not feel discouraged from trying out work.

Forums have told us that poor support offered to families about what impact even a very modest salary will have on their family's benefits can act as a

barrier to employment. Families often express fears that paid employment for their young person will result in a fall in overall family income – often something that they cannot afford. As young people are supported into work and benefits are reduced, there needs to be process in place should the employment break down.

The NNPCF would like to see clear benefits guidance offered and signposting to specific benefits guidance as a part of pathways into employment.

Families report that often very simple, everyday activities and considerations are a major barrier to employment. For example, the accessibility of local transport services or the timing of social care visits (for example to get ready in the morning). Small adjustments in the wider support package for young people with SEND can remove otherwise intractable barriers.

The NNPCF would like to see a more holistic approach to employment taken that considers more of the barriers that disabled people face in to get employment We would like to explore a holistic “Employment Support Plan” that outlines the support that will address these barriers in the same way that an EHCP addresses the support a young person requires to access education.

6. Our final messages

Some individuals in receipt of either DLA or PIP may have found that Covid measures have severely impacted upon their health, especially mental health. Their benefit award would have been made based upon their pre Covid condition. It is doubtful any of these individuals would have revisited their benefit claim. Is this something where DWP could be proactive and survey the impact of covid?

The NNPCF would request that Local Areas work in partnership with their local Parent Carer forum to discuss and agree local their PFA strategy and employment pathway for children and young people with SEND.

In addition, the NNPCF would like to see a unified strategy across Government departments which join up the Disability strategy, Autism Strategy, NHS LTP for Learning Disability and/or Autism and the SEND Review

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