



Shaping Future Support: Green Paper Consultation

Learning Disability England Member's Response

Learning Disability England is bringing people and organisations together to create a movement for change where people with learning disabilities, families, friends and paid supporters come together on an equal basis. As a membership organisation, members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others.

Members came together to share their views on the ideas proposed on the green paper across three online sessions. Around 40 members met to share their views and several organisations shared their organisational responses with us. This paper brings together their responses.

Making the current system simpler

The current benefits system is complicated, inefficient and anxiety inducing for people with learning disabilities, their families, and paid supporter organisations.

Members consistently told us how the system needed to be simpler.

For many of our members the lifelong and unchanging nature of their disabilities means repeated and ongoing assessments are unnecessary, onerous and costly.

One family member said,

“I'm tired of endless summonses to be reassessed by DWP, when you have to travel miles, produce piles of forms and papers and when you get there your assessor says to you, I really don't know why they sent you here. It's ridiculous. That was my son's last assessment. And I thought, what is this costing in human terms,

for my son, for me, but also for the government, all the people that are processing things”

Reducing the number of assessments and forms people need to fill in would significantly reduce the barrier to applying for benefits. Members shared that it takes them weeks to fill in the forms, that they are frequently asked to fill in forms that repeat the same information, and that they must seek help as the process is so complicated.

Reasonable adjustments

There is a level of frustration when discussing reasonable adjustments. People know they are entitled to them and talk at length about the difference they make when in place. However, a majority still do not receive the reasonable adjustments they need and are made to feel like they shouldn't be asking for them by professionals. Ensuring people with learning disabilities can access reasonable adjustments should therefore be a priority, as well as a way for people to report when professionals are a barrier.

Members want to see accessibility being made a priority, both physically in job centres and assessment centres and in terms of the forms and assessments.

Alternative accessible versions of forms and information should be available and be easy to find. Current forms are too long and complicated. The questions include jargon and people feel like they are designed to trip them up. Having easy read forms with photosymbols would help people understand what is being asked.

Families told us when they are filling out application forms it takes weeks to complete them and often need to seek help from a professional. For people without support this makes it much harder to access benefits.

For some people moving the forms online would improve accessibility. A service that allows you to save your responses so you to come back to it at another time and where information could be stored and duplicated for other forms is welcome. For others paper is still preferred so an option should remain. Removing this option when we know people with learning disabilities are disproportionately digitally excluded is unjust.

Building trusting relationships is an essential part of making the system less complex. Having local staff who act as case workers, who introduce themselves properly and are friendly makes a big difference to people's experience. People don't want to meet a new member of staff each time, they want to know who to ask for help. Having professional who implement reasonable adjustments without questions would make the process more accessible and reduce anxiety.

Assessments

Reducing the number of assessments individuals need to complete would significantly improve their experience of services. For most people with learning disabilities their disability will not 'improve' over time, therefore repeat assessments are unnecessarily costly and stressful. This should be noted on their file and the number of assessments reduced. If people's situation worsens or significantly changes, they must be able to request a fresh assessment to gain additional support. This new assessment must be delivered in a timely manner, so people aren't left unsupported.

Throughout the application and assessment process a personal deficit and medical models of disability is used. People must talk about their worst days to be given their entitlement. This often makes people feel dehumanised and demoralised, as one member said,

"But if you don't say anything negative about yourself, you won't get your benefits. I think it's very demoralising for people to do that. Because we don't naturally want to think about things that we can't do or bad days".

Members would like to see a shift in language following the example of Education, Health and Care Plans for children and young people which focus on skills, gifts, and talents. This would reduce the emotional toll of completing assessments.

In relation to benefits assessors a person with a learning disability said,

"they're trying to catch you out, that's what it feels like."

People with learning disabilities and their families do not trust benefits assessors. They don't think they have the relevant knowledge to be making decisions and often lack the skills to work with disabled people. Members would like to see more disabled

people employed within this process as assessors and for disability awareness training to be had by all staff. People and families want to be listened to. They want professionals to understand that just because one person with a learning disability can work in a full-time role that doesn't mean everyone with a learning disability can.

This lack of trust in assessors and inaccurate decision making often leads to people challenging decisions at tribunal. Members talked about the stress and significant periods of time spent waiting for this process to be completed. Most also had the decisions overturned and were awarded higher levels of benefits. It is important that assessment decisions are made correctly in the first place.

Benefits in the long term

The green paper talks about the idea of reducing the types of benefits available by pulling them together into one overarching benefit, with hopes that this would make the system simpler. Members like the idea of only having to apply once and for the system to guide them through, ensuring they get what they are entitled to. This appears much simpler than trying to understand all the benefits you might be entitled to and applying for each separately.

For members it is essential any change to benefits needs to be well communicated and enacted. While it was hoped universal credit would make the system simpler, for many it has just added to the confusion and distress. Any new approaches need to be well explained and easy to understand in order to prevent anxiety.

There are concerns that if there was only one benefit the potential impact of the system going wrong would be much more detrimental, in that you would be left without any benefits.

When discussing this idea some members felt restricted by the scope of this consultation and green paper, that while it offered the opportunity to make some changes in the short and medium term, these were mostly tweaking the system.

“When we take part in consultations, we feel like we have to answer their questions, like ‘what do you think of ESA?’ but we just want to say it's all rubbish, it all doesn't work. We are restricted by their questions and ideas.”

The current system is failing people with learning disabilities and their families. Many feel that a radical change is needed to ensure disabled people have what they need to live good full lives. Discussing a singular means tested benefit only works towards solving part of the problem.

Members are supportive of replacing current benefits with a universal basic income with an additional disability component recognising disability related costs. They have seen such policies being implemented and discussed in other European countries. Universal basic income offers a much easier process for gaining access to benefits and is more generous allowing people to be lifted out of poverty. Universal basic income approaches employment differently to our benefits system, removing requirements to work and recognising other ways people contribute to society. Members recognise that removing means testing will enable more people to access the benefits they are entitled to.

Goods and services instead of cash benefits

The green paper proposes providing people with goods and services instead of cash benefits. Members think the current Motability service works well. People who currently use the service report being mostly satisfied.

However, members are also confused and concerned about the potential withdrawal of cash benefits in favour of goods and services. Many didn't understand, outside of Motability, what other goods or services would be useful for them. They were concerned that they wouldn't have as much choice without cash benefits and would end up being offered particular products or nothing. This would see them receiving inferior and non-personalised goods and services.

Additionally, they are concerned about companies profiteering and that this represented '*benefits cuts by stealth*'.

Advocacy Services

For many of our members local advocacy services and self-advocacy groups are trusted sources of information and support. They are highly valued by the local

community and seen as independent, safe places. Most members tell us these are not qualities held by the Job Centre.

Self-advocacy groups offer both specialist knowledge and support as well as peer support. Self-advocacy groups have faced severe funding cuts over the last decade. Many of our members feel they should be given more funding to support their work in helping people access benefits and employment.

Additionally self-advocacy groups provide many of our members with meaningful work. These groups successfully demonstrate the wide range of opportunities people with learning disabilities can access and achieve in, they can offer good case studies to other employers.

Employment

The way we think about people's contributions

Many of our members who have a learning disability told us about their traumatic experiences of employment. They spoke about short term jobs that had large impacts on their mental and physical health and left them unable to work.

People told us they wanted to be valued for the work they can do. Many told us about their volunteering or part time jobs that are meaningful and which they enjoy, often completed as part of the 16 hours a week they can work while remaining on benefits. They felt it was important to recognise that not everyone can work, not everyone can work full time, but that everyone is contributing, and we should value that contribution. This was often about work as an expert by experience for self-advocacy groups, support providers, researchers, and NHS England. Being part of improving the lives of people with learning disabilities and being recognised for their skill and contribution was important to many of our members.

System change

There were concerns throughout our consultation about systemic issues that prevent disabled people from working. We know that many businesses do not employ people with learning disabilities, for reason including prejudice and ignorance. The ongoing

pandemic means the job market is difficult to navigate and it feels unjust to push people into employment at this time. For many, it feels like they are being set up to fail.

Members shared how other people's low expectations of people with learning disabilities has affected their aspirations and opportunities. A lack of work experience, careers advice and support in schools meant many didn't have plans to enter the labour market or an expectation that they would. People report the opportunities on offer to them as being limited, unmeaningful and not centred on their goals and aspirations. Often people felt their only options were in gardening, catering, and retail. Pursuing a career or job outside of these sectors often isn't seen as attainable. People with learning disabilities aren't given the chance to fail but told they shouldn't pursue their dreams because they might.

Professionals also lack imagination when helping people search for jobs. This was something we heard consistently; disabled people were told that dreams were unattainable rather than helping people explore their aspirations in different ways. For example, it may not be possible for everyone to be a pilot however there may be opportunities in airports or in travel agents that might meet people's aspirations. These avenues are often left unexplored.

Members think a cultural change where we value the contributions of people with learning disabilities and have expectations for what they can achieve is necessary for them to have good quality, long term, meaningful employment.

Short term changes

The Job Centre

Members had strong reactions to discussions about the Job Centre. Many didn't relate it to finding a jobs at all, with one saying,

“And that's all they do, they just to do your benefits and sanction.”

Many didn't trust Job Centre staff, finding many coaches to be pushy, rude and aggressive. People felt they were being pushed into roles they didn't want or were unsuitable. There was a concern that staff are target driven so want to get people into

any job rather than the right job. This often means the job doesn't work out in the long run.

While some felt disability awareness training would improve people's experience at the job centre, others felt it was more of a tick box exercise that wasn't enough to solve communication and cultural issues presented by staff.

The quality of Job Centre services varies around the country, with some people telling us their local services are very helpful. Others tell us they are scared to go or attending makes them very stressed.

Programmes to get people into work

The Work and Health Programme discussed in the green paper had some support although people said they were more likely to seek support from independent employment services. There was a concern that the six months of support after getting a job wasn't long enough. Members told us how it took longer than six months to become confident in a role, especially as Access to Work and reasonable adjustments can take some time to set up.

Members told us that generally they prefer support finding employment or learning skills with organisations that work with people with learning disabilities, like self-advocacy groups.

Once in work, maintaining that job is also an issue. People who use Access to Work told us it was essential, giving them the opportunity to pursue a career. However, they largely felt it was a difficult system to navigate and underfunded.

Many of our members did not know that Access to Work can also be used by people who are self-employed or trainees/apprentices or for attending a job interview. Therefore, the scheme also should be promoted to disabled people. The support offered through the scheme needs to be flexible and responsive, especially for support in job interviews which might be short notice.

People felt Access to Work mostly catered to people with a physical disability and that support for someone with a learning disability wasn't as good or thought through. It's

important Access to Work thinks about how it can best support people with a learning disability.

Work needs to be made accessible

Members think the Disability Confident Employer scheme doesn't do enough to help people get into work. They don't think most employers know about or use the scheme; more should be done to promote it. As with Access to Work, people with learning disabilities feel forgotten and that this is mainly aimed at physically disabled people.

Members think there should be greater incentives for companies to employ people with learning disabilities and that companies should have to tell everyone the percentage of their staff who are disabled.

Helping people get back on benefits

Starting employment and being cut off benefits straight away is a big concern for people with learning disabilities. They are concerned about losing income, the gap between the last benefit payment and first paycheck and how long it will take to get back on benefits if they lose their job. Members think there should be a winding down period when benefits stop to ensure people aren't left without. They also think it should be much easier to move back to benefits if their job doesn't work out, including not having to complete the forms and assessments over again.

A slow reacting system can have significant impacts on people's lives. For example, under the Universal Credit 'zero earnings' rule people with disabilities who've bought a home of their own using the Government's HOLD (Home Ownership for people with Long-term Disabilities) model face a 39 week wait to receive their SMI (Support for Mortgage Interest) payments if they have to go back on benefits after trying to work in a paid role. This is a huge disincentive for people with disabilities who may want to try working. Given that SMI is now a loan rather than a benefit we suggest that the Universal Credit 'zero earnings' rule is abolished altogether as any money paid out will be returned to the state when the individual's property is eventually sold. This will encourage more people with disabilities to work. It's even possible that some may

eventually earn enough to enable their benefits to be replaced by a salary, but this can only happen if the 'zero earnings' rule is scrapped.

Having a system that can react to change quickly protects people's physical and mental health as well as preventing crisis situations that could lead to people being threatened with homelessness or poverty.

Investment

The last decade has seen both councils and communities impacted by austerity, our members think now is the time to reinvest in them.

In terms of investing in services members talk about brilliant support workers or rights-based services that have reduced or folded due to austerity. The impact of this is people's support networks disappearing or them not know where to go to get help. Many services have been cut so significantly that they will never meet current demand. Investing in local authorities and services is therefore essential to ensure people get the human support they need and are not queuing for hours.

In terms of investing in communities' members feel that the current benefits system, while trying to prevent fraud, treats everybody like they're criminals. In attempting to catch people out, people's lives are made miserable. Members feel that the balance here is not right. We know the majority of people are not trying to cheat the system, how good and supportive our communities are. Members want to see the government invest in people.

Members would also like to see the government pledge that people will never lose income as a result of working. Investing in communities, investing in people with learning disabilities, understanding and valuing in their contributions should be a central part of how we make the benefit system fairer, more humane and sustainable.