



Putting disabled people at the heart of the benefits system – a charter for fairer access, design and provision

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Foreword

Benefits are not a lifestyle choice for the workshy – they are a lifeline for disabled people in and out of work.

Our benefits system should enable disabled people to stay financially secure, enabling them to afford the extra costs they face and giving disabled jobseekers the specialist support they need to look for work.

Sense's new report shows, however, that our benefits system is broken, with too many disabled people struggling to access the support they need and left feeling humiliated while accessing benefits they are entitled to.

We work with thousands of people with complex disabilities, including those who are deafblind, across England, Wales and Northern Ireland. Benefits are a lifeline for many of the disabled people we support, from the jobseekers using our employment service to people who live in our residential homes.

A working benefits system is vital to the lives of many of the UK's 1.6 million people with complex disabilities. ⁱ But our benefits system is letting disabled people down every day.

Over 2 million people in Great Britain claim Universal Credit because they cannot work, while around 1.5 million claim the predecessor benefit Employment and Support Allowance. Over 4.5 million disabled people claim either Personal Independence Payment or the Disability Living Allowance, which is intended to cover the extra costs they face as disabled people. ⁱⁱ

When compared to other developed countries, our benefits system is not generous. We spend only 1.3% of our GDP on benefits for disabled people who cannot work - lower than the average for Organisation for Economic Cooperation and Development (OECD) countries, which 1.6%. For some OECD countries like Switzerland, New Zealand and Spain, meanwhile, the figure is over 2%. ⁱⁱⁱ



Yet disability benefits are often treated as a problem in the public debate, with disabled people sometimes being demonised for claiming support to which they are entitled.

We need to reframe the debate on welfare. Benefits should be seen as positive because they enable disabled people to lead independent lives with dignity. And with the new Government placing a greater emphasis on 'Getting Britain Working', it is vital that our benefits system both gives disabled jobseekers the support they need to enter employment and recognises that not every disabled person can work.

That's why I'm delighted to share with you Sense's new benefits charter. Based on new research, it sets out how the Government could help to make the benefits system fairer for all disabled people.

Richard Kramer

CEO

Sense and Sense International



Executive Summary

Millions of disabled people receive financial support through the benefits system, but too many do not get the support they need to lead an independent and meaningful life. While trying to access benefits they are entitled to, disabled people too often end up feeling like frauds.

Our new polling has found that over half (51%) of people with complex disabilities who've been to an assessment for their benefits found it humiliating.^{iv}

Even those who are awarded support find it is not enough. 43% of people with complex disabilities on benefits told us they are in debt because their benefits payments are not enough to cover the cost of essentials like food and utility bills, according to our polling.^v

There are a range of recommendations in the charter, but we are particularly calling on the government to:

- **Commission an independent body to make an annual recommendation on benefit rate rises.** This will give the Government guidance on how it can make sure that all benefits cover the cost of essentials, including disabled people's extra costs.
- **Amend the Social Security Act 1992** to introduce a requirement to uprate all benefits at least twice a year by no less than the rate of inflation, so that disabled people can afford the basics.
- **Make as many decisions as possible using only application forms and supporting evidence,** so fewer disabled people are forced to go through the ordeal of benefits assessments.
- **Work with disabled people to introduce standards on accessible communication.** This should be incorporated into training for frontline staff, while assessment providers should face financial penalties if they fail to provide the right communication support in assessments.



It will take time to fix our broken welfare system, but together we can rebuild it to be fairer. This report sets out details against the following five principles that would enable government to do this.

1. A fully accessible, co-produced system.
2. An application process that makes it as simple as possible for disabled people to claim the support they need.
3. Benefits rates that allow disabled people to afford the essentials and have a decent standard of living.
4. Support for disabled jobseekers to enter work.
5. Recognition of the role of the benefits system in enabling people to live independently.



Our findings

Like the NHS, the welfare system should be there for all of us when we need it. It should be as easy as possible for disabled people to access the support they're entitled to. It should be provided in a way that helps them work when they're able to and achieve the highest quality of life. But that's not what we found while interviewing disabled people and polling people with complex disabilities who receive benefits.

Applying for benefits is emotionally distressing

While people sometimes talk about benefits being too easy to access, the reality experienced by disabled people themselves is very different. Nearly half (45%) of people with complex disabilities on benefits said that the application process made their conditions or impairments worse.^{vi} In the words of Charlotte, the application process is 'frustrating' and 'tiring', with the Department for Work and Pensions sending her paper application forms that her mother had to read out for her, despite them knowing she was deafblind.

Our research has found that this is not an isolated example, with nearly one in two (49%) people with complex disabilities on benefits we polled saying they could not apply for benefits independently.^{vii} The whole application process is long, complicated and distressing. The assessment process often causes anxiety and unnecessary shame for disabled people. Nearly three in five (58%) people with complex disabilities who went through an assessment felt scared beforehand, while half (51%) felt humiliated by the process.^{viii}

As one disabled person told us: "They asked the same question, but in a few different ways, as if they wanted to catch me out or something."



Benefits barely meet the cost of essentials

Even when someone manages to get the support they're entitled to, they often find it is not enough. 43% of benefit claimants with complex disabilities say they are in debt because their benefit payments do not cover essentials like food and bills.^{ix}

On top of expenses like food and housing costs, many disabled people face other essential costs because of their condition or impairment. Research from Scope has found that, on average, disabled households would need an extra £1,010 a month to have the same standard of living as non-disabled households.^x These extra costs might include relying on taxis to get about or paying higher energy bills because they need to use medical equipment at home.

But half (51%) of people with complex disabilities on benefits said the financial support they receive did not cover the extra costs they face because they are disabled.^{xi}

Many disabled people are left struggling to afford the things they need, let alone the cost of doing the things they enjoy. During the cost-of-living crisis, one mother of a disabled daughter told us that the financial support she received fell so far short of her energy costs that she was worried she might have to put her daughter into care.^{xii}

Disabled jobseekers are being let down

In recent years and months, disabled people who claim benefits have been dismissed as being 'workshy'.^{xiii} This narrative has negatively affected disabled people, with 54% of benefit claimants with complex disabilities saying that the public debate around benefits has left them feeling pressured into getting a job, even if it would harm their health.^{xiv}

While it's vital that the welfare system recognises that not every disabled person can work, it's also crucial that the Department for Work and Pensions supports disabled jobseekers to overcome the barriers to employment they face. Yet two in five people with complex disabilities on benefits we polled did not feel that the welfare system enabled them to move towards paid employment.^{xv}



Our charter for a fairer benefits system

Based on our research and our experience of working with thousands of disabled people through our services over the last 70 years, we've developed the following five key principles to re-design our welfare system and help make it fairer.

1. A fully accessible, co-produced system

The benefits system should enable disabled people to be as independent as possible. Yet, 12 years after the Welfare Reform Act that first introduced Universal Credit and Personal Independence Payment, and despite countless Green and White Papers proposing further changes, the system is still not set up for independence. ^{xvi}

Our research found that almost half of people (49%) with complex disabilities on benefits say they could not apply for benefits without the support of friends, family or a support service. ^{xvii} Over a third of people with complex disabilities on benefits (37%) found it difficult to apply for benefits.

Often, disabled people cannot access the benefits system because it is not designed around their accessibility needs. When applying for benefits, disabled people should receive documents in the formats that they say are right for them. Blind or partially sighted people, for example, should be able to choose to receive letters and forms in a format like Braille or large print, depending on what they say is best for them.

At the assessment stage, applicants should receive the support they have told the Department for Work and Pensions they need to communicate, giving them the best chance of expressing the impact of their condition or impairment on their life. Yet 43% of people with complex disabilities on benefits said that the Department for Work and Pensions had not communicated with them in a way that did not meet their needs as disabled people, even though they had shared their preferences with them. ^{xviii}



In the words of one deafblind person we spoke to, “Why should I answer the Department for Work and Pensions’ questions when they don’t even send me the documents in the right format?”.

Assessments are not always accessible either, with 45% of people with complex disabilities who’ve been assessed saying they did not get the right communication support.^{xix} As well as robbing disabled people of their independence, this also leaves disabled people at risk of missing deadlines or making mistakes in their application – potentially costing them the financial support they urgently need.

To make sure that as many disabled people can access the benefits system independently, the Department for Work and Pensions needs to work with disabled people to introduce clear standards on how to communicate accessibly with disabled people, using NHS England’s Accessible Information Standard as a starting point.^{xx} The Department for Work and Pensions’ standards should set out how the benefits system should record and act on applicants’ communication needs.

The Department for Work and Pensions should have a duty to consider these standards while developing or reviewing any process related to the benefits system.

These standards should also form a key part of training for any Department for Work and Pensions employee involved in either communicating directly with applicants and claimants, or developing communications aimed at claimants and applicants.

Recommendations

The Department for Work and Pensions should:

- Work with disabled people to introduce standards on communicating accessibly. This should be incorporated into training for staff, while assessment providers should face financial penalties if they fail to provide the right communication support in assessments.



- Embed co-production with disabled people into development of new processes and services, giving disabled people the opportunity to identify and address inaccessible features before they are made available to the public.

2. An application process that makes it as simple as possible for disabled people to claim the support they need

While it should be as simple as possible for disabled people to get the support to which they are entitled, our research has found that the application process for PIP and Universal Credit is long, complicated and stressful. 45% of the people with complex disabilities on benefits we polled told us that the application process made the impacts of their condition or impairment worse.^{xxi}

Rather than getting the right support after making their application, too many disabled people are ending up having to appeal their benefits decisions.

In 2023/24, almost 47,000 people took the Department for Work and Pensions to a tribunal to challenge their initial PIP decision, with 69% of these being successful.^{xxii} As well as highlighting that the process for getting the right support can be unnecessarily long, this high success rate suggests that the application process is too often failing to reach fair decisions the first time around.

A lack of expertise from assessors may be a contributing factor to this. A quarter (25%) of people with complex disabilities who had been through a benefits assessment told us that their assessor did not understand their condition or impairment.^{xxiii}

As a result, assessors cannot always make a judgement about how someone's condition or impairment affects their life. This could lead to unfair and inaccurate results that might leave disabled people without the support they need.

As well as lacking expertise in the condition or impairment of the person they are assessing, assessors sometimes behave in a way that leaves applicants feeling distressed.



It is understandable that there are checks in place to make sure that someone really is entitled to support. But the assessor can do this in a supportive way, making sure that the applicant can make their case as clearly as possible.

Instead, the process is antagonistic, with the starting point seeming to be that applicants are often frauds. This leaves too many disabled people feeling like they are on trial. As one deafblind person we support told us: "They asked the same question, but in a few different ways, as if they wanted to catch me out."

Whether it's free prescriptions or council tax exemptions, many public services need to conduct eligibility checks, usually managing to do this without causing emotional distress.

Yet humiliation is the norm in our benefits system, with over half (51%) of people with complex disabilities who have been assessed felt humiliated during their assessment.^{xxiv} It is unacceptable that disabled people are so often left traumatised while trying to access support to which they are entitled.

For this reason, Sense is calling for a dramatic reduction in the number of people going through assessments. Our research shows that many disabled people agree with this call, with 57% per cent of people with complex disabilities on benefits preferring to receive a decision without an assessment. ^{xxv}

We believe that the Department for Work and Pensions should, wherever possible, make an award based on someone's application forms and supporting evidence. Applicants should then have the right to request an assessment if they are unhappy with their initial decision, without this leading to a lower award.

Alongside reducing the number of assessments, the Department for Work and Pensions needs to take steps to make sure that assessment providers treat applicants more fairly during the application process.



Recommendations

The Department for Work and Pensions should:

- Make as many decisions as possible using only application forms and supporting evidence.
- Require assessors to go through comprehensive disability equality training designed and delivered by disabled people.
- Make sure that assessors can consult experts in different conditions or impairments before they conduct an assessment.
- Introduce financial penalties for assessment providers who fail to provide the right communication support in assessments.
- Make sure no one is penalised for making a mistake or missing a deadline as a result of the Department for Work and Pensions' failure to communicate accessibly with them.

3. Benefits rates that allow disabled people to afford the essentials and have should a decent standard of living.

While the benefits system should make sure that no one faces financial insecurity because they are disabled, whether they are in work or not, a lack of financial support is leaving many disabled people struggling to get by. 43% of people with complex disabilities on benefits we polled said that they are in debt because their payments are not enough to cover the cost of essentials like food and utility bills. ^{xxvi}

The benefits system is also failing to support disabled people with the extra costs they face as a disabled person. Our research has found that 53% of people with complex disabilities on benefits face significant ongoing extra costs as a result of their disability. These costs could include, for example, the cost of needing to use taxis to get about, or the higher energy bills some people face because they need to charge powered wheelchairs at home.



These costs can be significant, with research from Scope finding that, on average, disabled households would need an extra £1,010 a month to have the same standard of living as non-disabled households.^{xxvii}

The people we spoke to said that Personal Independence Payment (PIP), which is meant to cover these costs, often does not go far enough, with one person saying that ‘it’s a struggle to pay all the extra costs I face as a disabled person.’ As well as causing financial distress, this also leaves disabled people leading less independent lives. 44% of people with complex disabilities on benefits told us that they regularly go without the support and equipment they need as a disabled person because they cannot afford it.^{xxviii}

This stands in marked contrast to the previous Government’s characterisation of the system as being too easy to access and widely open to abuse. When announcing proposals for welfare reform in April 2024, the then Prime Minister, Rishi Sunak, said that PIP was being ‘misused’.^{xxix}

The previous Government’s subsequent ‘Modernising support for independent living: the health and disability green paper’ proposed moving away from a system based on cash PIP payments, arguing based on limited evidence that the system offers some disabled people more financial support than they needed.^{xxx} Fortunately, it seems that the new Government has decided not to proceed with these reforms.^{xxxi}

It is vital that future decisions about the financial support available to disabled people is based on robust evidence of how much support they need. For this reason, Sense believes that the Government should be making regular assessments of how well benefits cover the cost of living.

Under the Social Security Act 1992, the Government has a duty to increase disability benefits such as PIP in line with inflation every year, a process known as ‘uprating’. There is, however, no obligation to increase benefits like Universal Credit in line with inflation.



While, in practice, most Governments tend to uprate unemployment benefits in line with inflation, the Government decided not to do this between 2016/17 and 2019/20. With benefits frozen while inflation rose, their value fell in real terms. Although the Government started increasing benefits in line with inflation again in 2020/21, this did not undo the fall in the real value of benefits. As a result, benefit rates are today lower than they would have been had the Government been required to uprate benefits in line with inflation every year.

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Even when the Government does decide to increase all benefits in line with inflation, the current system of annual uprating is too slow to react to rising prices. This was clear during the cost-of-living crisis, when a sudden rise in inflation left benefits lagging behind rising costs. While inflation rates have since fallen, the effects of benefits lagging behind inflation are still being felt by disabled people. The Institute for Fiscal Studies have estimated that many benefits will be worse off until April 2025 because of the failure of rates to keep up with inflation. ^{xxxiii}

To prevent the value of benefits from falling in real terms in the future, Sense is also recommending the introduction of a duty on the Government to increase all benefits at least twice a year by no less than the rate of inflation. The rate of inflation should be as up to date as possible.

While fixing the current system of uprating is vital, this measure alone will not be enough to make sure that benefits rates reflect the real costs faced by disabled people. This is because uprating benefits only makes sure that they do not lose their value in real terms. It does not address the underlying problem that benefits rates have long been too low.

To rectify this, we believe that the Government should commission an independent body to make annual recommendations how high benefits rates should be to cover the cost of essentials. This body would work in a similar way to public sector pay review bodies, which make annual recommendations on public sector pay increases. The body's recommended rise would be at least the rate of inflation.



Rather than establish a new body to produce these annual recommendations, the Government should expand the remit of the Social Security Advisory Committee, an independent statutory body that provides impartial advice on social security and related matters.

The Government should expand the remit of the Social Security Advisory Committee so that it is required to calculate what the rates for income-replacement benefits like Universal Credit would need to be to cover the essentials. This could draw on the work of the Trussell Trust and the Joseph Rowntree Foundation, who have sought to calculate the cost of an 'essentials guarantee' for Universal Credit.^{xxxiv}

The Government should also make sure that Personal Independence Payment rates reflect the real extra costs faced by disabled people. 61% of people with complex disabilities currently receiving Personal Independence Payment agree it should rise.^{xxxv}

In both the National Disability Strategy and Disability Action Plan, the last Government set out plans to establish an Extra Costs Taskforce, which would work to better understand the extra costs faced by disabled people.^{xxxvi xxxvii} Shortly before the election, the last Government confirmed that work had begun on this.^{xxxviii} However, under the new government the future of this taskforce and the wider strategy is unclear.

The new government should recommit and expand the remit of the Extra Costs Taskforce so that it is required to recommend rates of PIP that would better reflect the extra costs faced by disabled people. The methodology for this could draw Scope's approach to calculating the extra costs faced by disabled people, which found that, on average, disabled households would need an extra £1,010 a month to have the same standard of living as non-disabled households.^{xxxix}

This approach would be more flexible than the current method of uprating, which relies solely on the headline rate of inflation. With their new expanded remits, however, the Social Security Advisory Committee and the Extra Costs Taskforce would be able to consider whether prices have risen at a higher rate for disabled people.



This is important as the headline rate of inflation does not take into account the fact that some groups of people are more affected by certain types of price rises than others.

During the cost-of-living crisis, for example, high energy costs have had a disproportionate impact on disabled people, who tend to have higher energy bills.

Recommendations

The Government should:

- Amend the Social Security Act 1992 to introduce a requirement to uprate all benefits at least twice a year by no less than the rate of inflation.
- Expand the remit of the Social Security Advisory Committee so that it is required to calculate what the rates for income-replacement benefits like Universal Credit would need to be to cover the essentials.
- Re-commit to the Extra Costs Taskforce and expand its remit, so that it is required to calculate what PIP rates would need to be to more accurately reflect the costs faced by disabled people.

4. Support for disabled jobseekers to enter work

Disabled people are often excluded from employment, with the employment rate for disabled people being 28.6 percentage points lower than it is for non-disabled people.^{xi}

People with complex disabilities tend to face the highest barriers to work. Previous Sense analysis of Government data has found that 82% of people with complex disabilities are unemployed, compared to 23% of non-disabled people.^{xii}

While not every unemployed disabled person would be able to work, many disabled people who want to work find that they are not getting the specialist support they need to overcome the barriers they face. Previous Sense research has found that over half (55%) of people with complex disabilities who did not have a paid job would like more support looking for paid employment.^{xiii}



This support should be coming from the benefits system, but this research has found that 41% of people with complex disabilities on benefits did not feel the welfare system enabled them to move towards paid employment. ^{xliii} One deafblind person told us that they had eventually given up on going to the jobcentre, deciding that “no one wants to listen to the fact I want a job and I’d just have to accept that.”

These are not isolated examples. Over half of jobseekers (54%) with complex disabilities did not feel supported by their Work Coach according to previous Sense research. ^{xliv} The new Government has emphasised the need to offer support to enable disabled jobseekers to overcome the barriers to work they face.^{xlv} We therefore call on the Department for Work and Pensions to make sure that its upcoming ‘Get Britain Working’ White Paper addresses the lack of support too often faced by disabled jobseekers.

Recommendations

The Department for Work and Pensions should:

- Work with disabled people and disability charities to improve the training for Work Coaches and Disability Employment Advisors. This training should cover specific training on the barriers to employment faced by disabled people, including those with complex disabilities.
- Fund more specialist employment programmes to work in partnership with Job Centre Plus.
- Make sure that all jobcentres are equipped to enable disabled people look for work by introduce a £5 million Jobcentre Assistive Technology Fund. This fund would cover:
 1. Additional software for every jobcentre including screen readers, specialist screen magnification software and speech-to-text software.
 2. Assistive hardware for every jobcentre including refreshable braille display and headphones.
 3. A £2.1 million support fund for jobcentres to access if they need any additional pieces of assistive technology they need.



More details about our recent recommendations on support for disabled jobseekers and employees can be found [here](#).^{xlvi}

5. Recognition of the role of the benefits system in enabling people to live independently

Disabled people do not just need reform of how the welfare system works. It's vital that there is a change in the way that benefits are discussed in the public debate. The UK's benefits system is not perfect. But it is the mark of a civilised society that there is support for people who cannot work, or who face additional financial pressures because they are disabled.

Results from the 2022 British Social Attitudes Survey suggest that there is considerable support for increased spending on welfare, with 37% saying that the Government should spend more on benefits, even if that leads to higher taxes.^{xlvii} It is true that the survey found that 19% of people believe that the most people who get social security don't really deserve any help, but this is a significant drop from the high of 40% in 2005.^{xlviii}

Too often, however, the public debate around welfare treats disabled people as 'workshy', claiming benefits they do not really need. In recent months, commentators have claimed that 'our disability benefits system invites abuse', and that the UK is 'hooked on sickness benefits'.^{xlix}

While announcing its proposals to reform welfare, the last Government suggested that PIP was being 'misused' and that disabled people have a 'duty' to look for work.^{li} ^{lii} Over half (56%) of people with complex disabilities on benefits say that senior politicians have made comments that make it seem like disabled people are faking it, according to this research.^{liii} A similar percentage (53%) said that these comments have made them less safe as a disabled person.^{liv} Words matter, and negative rhetoric about benefits is having real and harmful impacts on disabled people across the country.

Recommendations



The Government should make sure that its language on benefits:

- Recognises the barriers disabled people face.
- Celebrates the fact that many disabled people can lead more independent and meaningful lives because of the financial support they receive.

Conclusion

The benefits system should enable disabled people to lead independent and meaningful lives, whether they are employed, looking for a job, or not able to work at all. But this research shows that our broken benefits system is failing to offer the right support. To change this, the Department for Work and Pensions should:

- Work with disabled people to introduce standards on communicating accessibly. This should be incorporated into training for staff, while assessment providers should face financial penalties if they fail to provide the right communication support in assessments.
- Embed co-production with disabled people into development of new processes and services, giving disabled people the opportunity to identify and address inaccessible features before they are made available to the public.
- Make as many decisions as possible using only application forms and supporting evidence.
- Require assessors to go through comprehensive disability equality training designed and delivered by disabled people.
- Make sure that assessors can consult experts in different conditions or impairments before they conduct an assessment.
- Introduce financial penalties for assessment providers who fail to provide the right communication support in assessments.
- Make sure no one is penalised for making a mistake or missing a deadline as a result of the Department for Work and Pensions' failure to communicate accessibly with them.
- Introduce a £5 million Jobcentre Assistive Technology Fund.



- Fund more specialist employment programmes to work in partnership with Job Centre Plus.
- Work with disabled people and disability charities to improve the training for Work Coaches and Disability Employment Advisors.

The Government should:

- Expand the remit of the Social Security Advisory Committee so that it is required to calculate what the rates for income-replacement benefits like Universal Credit would need to be to cover the essentials.
- Expand the remit of the Extra Costs Taskforce so that is required to calculate what PIP rates would need to be to more accurately reflect the costs faced by disabled people.
- Amend the Social Security Act 1992 to introduce a requirement to uprate all benefits at least twice a year by no less than the rate of inflation.
- Make sure that its language on benefits recognises the barriers disabled people face.
- Make sure that its language on benefits celebrates the fact that many disabled people can lead more independent and meaningful lives because of the financial support they receive.

This charter for a fairer benefits system sets out how the Government can begin to put this right. It is a plan to put disabled people at the heart of the benefits system, involving them in its design and ensuring that it always meets their needs. We look forward to working with the Government to make this a reality.



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I would also like to thank the people we support at Sense who were involved in the research, including our Experts by Experience and the Usher team.

I am also grateful to Meagan Levin from Turn2Us, who carried out a review of this report. “

Methodology

This report draws on both new and previous research carried out by Sense. To inform our recommendations, we commissioned Censuswide to poll 1000 people with complex disabilities in receipt of benefits. This poll took place between 24 May and 30 May 2024.

As well as running a short survey for people with complex disabilities on benefits supported by Sense, we held a focus group with deafblind people and conducted interviews with people with complex disabilities who claim benefits. We also spoke to Sense staff about their experience of supporting people with complex disabilities to claim benefits.



About Sense

Sense is here to support people with complex disabilities, including deafblindness, to feel connected and included. From the first weeks of life and through the major milestones of adulthood, we want to ensure disabled people and their families are supported to live fully at every stage of life.

There are 1.6 million people in the UK with complex disabilities, most of whom need significant or high-level care in their daily lives. Sense also offers practical information, advice and support to the carers and families who provide that care, enabling them to build the resilience to thrive, not just survive.

People with complex disabilities tend to have two or more of the following:

- Deafness or hearing impairment;
- Blindness or vision impairment;
- Learning disability;
- Autism.

People who are deafblind aren't necessarily totally deaf and/or totally blind. Even with mild sight and hearing loss, you'll still experience unique daily challenges.



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