Disability Charity Consortium's manifesto for an inclusive National Disability Strategy

Contents

About the Disability Charities Consortium

The Disability Charities Consortium (DCC) brings CEOs and policy leads from the UK's largest national not-for-profit disability organisations together to work with Government to ensure disabled people's experiences are reflected in UK policy making. The DCC members are: Scope, Leonard Cheshire, Disability Rights UK, National Autistic Society, Mind, Mencap, Sense, Royal National Institute of Blind people (RNIB), Royal National Institute for Deaf People (RNID), and Business Disability Forum (BDF).

Key principles of our manifesto

This manifesto sets out the DCC's ambitions for the National Disability Strategy and beyond. While wide-ranging in scope, it provides a series of solutions to tackle the persistent barriers that disabled people face in their daily lives.

The DCC is keen to see the following from the strategy and its development:

- A strategy with clear and tangible actions that will be taken, deadlines, and measures for success.
- Monitoring and accountability of progress, including leadership and participation by disabled people.
- Engagement with disabled people that is accessible and meaningful. Online data collection must be one part of a wider consultation with multiple formats of participation enabled.
- Clear and tangible routes for engagement that are timely and accessible and include updates on progress.
- A clear way forward to bring transformation to disabled people's life opportunities and participation.

Necessarily, the asks set out in this manifesto are not exhaustive. They reflect the key themes that the DCC believes are the highest priority to address at this point in time and in line with the focuses set out in the Strategy.

The name of the strategy is important

Government policy towards disabled people has often been fragmented and piecemeal. This has contributed towards the continuation of inequalities and barriers. Therefore, we welcome the Government's commitment to creating a National Disability Strategy. A National Strategy should have at its heart a commitment to removing the barriers disabled people face across different areas of life. The strategy must have disabled people at its heart and first and foremost; therefore, the **name of the strategy** is vital in setting the tone of how society and Government should relate to disabled people.

This is not a strategy "for" disabled people. Such language implies disabled people are a passive recipient of strategic interventions rather than co-creators, collaborators, and active participants that add to the development of a national strategy. This strategy is instead 'for' an **inclusive society**. For the strategy to be successful, it must be 'for' everyone and is the responsibility of everyone and every part of society to work together to achieve it. We are therefore keen to see the title "National Strategy for Disabled People" left behind, and to instead use "National Disability Strategy" as was originally planned.

Themes embedded throughout the strategy

Based on the work and experiences of the DCC organisations, the strategy should include six main themes that should be embedded into each of the above area of focus. These main themes are as follows.

- **Changing perceptions.** This includes shifting public awareness on areas that affect disabled people and that increase levels of understanding about disabled people's lives. It also includes enhancing the understanding and helpful behaviours of public servants and providers who have a role in delivering the above focus areas.

- **Enforcement.** Enforcement bodies, such as the Equalities and Human Rights Commission, need increased appropriate resourcing so they can effectively and constructively challenge the services and providers who do not provide adjustments, accessible products, or inclusive delivery where they are required to do so.
- **Procurement**. Tendering, selecting, and procuring suppliers for all public sector contracts and for all public functions must be subject to the potential supplier evidencing they can fulfil defined accessibility and disability inclusion requirements specific to each contract. This should apply to suppliers across all sectors. Ideally we would also want to see this applying to all delivery but we recognise that it is in working with the public sector that Government has greatest leverage.
- **Consultation and engagement** with disabled people from the stage of designing a policy, product, or service and continuing throughout the testing, implementation, and review stages. This should be part of a robust and ongoing fit for purpose equality analysis process which is required by all organisations who deliver public services.
- **Transitions into adulthood.** Barriers for disabled people when transitioning to adulthood must be identified and removed in each of the above focus areas, particularly where it means changing policy settings (for example, from education to employment).
- **Data** about disabled people's lives must improve. This includes repeating the Life Opportunities Survey, disability and employment and social care statistics to be published more regularly, and better recording at Government level of people's disability or condition. This will allow better data-evidenced decisions about disabled people's lives to be made.

Areas of focus

1. Economic recovery

Disabled People face significant barriers when accessing employment (where employment is possible) and these have been exacerbated by the economic impact of COVID-19. While the strategy should look at mitigating these immediate impacts, it should focus on developing much needed long-term, sustainable economic solutions to the specific barriers disabled people experience. Practical problems have had an impact: some 11 per cent of employers furloughed a disabled employee at the beginning of the pandemic because reasonable adjustments could not be made to the way the job needed to be carried out due to the pandemic[1], and 26 per cent of disabled people who have been furloughed have not returned to work.[2]

Job retention and return to work schemes must be inclusive by design. Government and policy makers need to remove the barriers that plague current policies and programmes: inaccessible systems, lack of awareness from Job Centre advisers about Access to Work or inclusive assessment and interview methods, and effective adjustments-based conversations are examples of where this is not currently happening. Job schemes must also be flexible and tailored to the recent experiences of disabled individuals. Access to Work should engage with disabled job seekers and Job Centres to help prepare candidates for their interview – not wait until they are in employment to start the Access to Work application process. Access to Work is too often an 'afterthought' by central government in

[1] Business Disability Forum, 2020, "Business as (un)usual: How employers have supported their workforces during the Covid-19 outbreak and lockdown".
[2] Leonard Cheshire, 2020, "Locked out of the labour market: The impact of Covid-19 on disabled adults in accessing good work – now and into the future".

employment initiatives. As an example, the first lockdown, when those whose jobs could be carried out at home were asked to work from home, began in March, but changes to Access to Work which reflected this new way of working for many were not announced until May.

2. Employment

Access to Work needs better funding and resourcing to work more effectively for individuals and employers. The current process remains unwieldy, inaccessible to many disabled people (particularly people who cannot use the phone or do not have easy access to the internet or a computer), and reports continue from disabled people and business having to employ staff specifically to deal with Access to Work related admin. Increased flexibility within the Access to Work eligibility criteria would enable disabled people to start their own business, become self-employed, be a contractor, or become permanently employed. A fit for purpose Access to Work service would give disabled people more economic choices. There is also an opportunity to further explore how the Mental Health Support Service could be expanded and engage with job seekers and people who are at imminent risk of becoming economically inactive. The Access to Work support cap must be removed to enable more people with 'human' support (particularly people using sign language interpreters and other human communication support) to thrive and work in permanent, full time roles if they choose to do so. The cap currently means individuals who use this type of support have had to reduce their hours or resign from their chosen profession. It disproportionately and often catastrophically affects a small number of people, where - by contrast - the vast majority of individuals who receive Access to Work support come nowhere near the cap. The overall cost envelope needs to be changed to reflect this and to allow for actual support costs needed, rather than what was spent in a previous year. The same principle applies to Disabled Students Allowance (DSA) which again disproportionately impacts students who need human support such as a job coach or BSL interpreter whilst the vast majority of students do not incur DSA support costs anywhere near the maximum allowance.

In line with this, there needs to be a much better joining up between DSA and Access to Work to support education leavers at the critical point of transition. Under the current system, adjustments which have been agreed by DSA for students are removed once they leave education and cannot be reapplied for (even if they are granted) until the individual has secured employment. There is a critical gap here in equipping education leavers to be able to apply for jobs and demonstrate their full potential. Addressing this is crucial in terms of early intervention and to prevent disabled education leavers from falling out of or being unable to find employment in the first place. We have expanded on this further in the section on technology below.

Statutory Sick Pay (SSP) must become more flexible and realistic alongside ever-increasing waiting times for referrals and treatment in the NHS. Whilst many good employers offer sick pay beyond the statutory entitlement, many people's statutory sick pay entitlement expires before they get access to the services they need to recover, forcing many people back to work before they are well and then often resulting in them going on sick leave again.[3] Some conditions' treatment and rehabilitation can be undertaken alongside reduced hours, phased returns, or disability leave. However, for other conditions, particularly mental health conditions, 'recovery' often takes place in specialist settings after a long waiting period.

[3] Recent research identified sick pay is forcing people back to work when they should be recovering or self-isolating due to COVID (Resolution Foundation, 2020, "Time out: Reforming Statutory Sick Pay to support the Covid-19 recovery phase").

The current rate of SSP – £95.85 a week – should be increased as research has shown that too often, it leaves people struggling to pay bills or buy food while off sick. Currently, a person is not entitled to sick pay on their first three days of absence. These waiting days are having an unnecessary negative effect on employees. Mind surveyed 124 people about their experience of waiting days, in which 69 per cent of people reported that getting paid would have made a positive difference to them. Many detailed that it would have reduced stress, meant less difficulties with finances, and some mentioned experience of situations in which they were not able to take time off when they needed to, as they would not be paid. The UK Government must also expand the eligibility to claim SSP to cover those who earn under £120 a week. Without this, disabled people will be left feeling that they must work, even when unwell.[4]

Ultimately, an effective National Disability Strategy will require a review of other key strategies affecting economic activity. For example, a revision of the **Industrial Strategy** and the **Good Work Plan** should ensure disability inclusion is at their centre. A National Disability Strategy is an opportunity to revise the impact both strategies have had on enhancing the economic activity of disabled people since their implementation.

Workforce reporting

The DCC is also supportive of the introduction of mandatory workplace reporting and, broadly, of the Workforce Information Bill which is currently progressing through Parliament. To be truly effective, however, such reporting needs to be accompanied by a significantly revised and strengthened reporting framework. The current Government Voluntary Reporting Framework is not fit for purpose, so we want to see that overhauled and developed. Importantly, any quantitative measure needs to be accompanied by a process that is coproduced with disabled people and which, for example, requires organisations to demonstrate and report on how they have engaged with their disabled employees to understand their experience. It should also include broader measures to triangulate results, such as the number of people working with adjustments. This is important as we see that many businesses who open up their language and adjustments processes widely typically have lower 'declaration' rates because their practices effectively remove the onus on employees to share that they have a disability as a prerequisite for getting support at work. We would welcome the opportunity to engage with Government to shape this vital issue.

3. Products and services

There are immense barriers to many different products and services for disabled people. Most can be prevented if all products and services are subjected to an **equality analysis at stage of design** and regular disability inclusion reviews. Following Brexit and our departure from the single market, the Government has the opportunity to be a world-leader in accessibility by removing the manufactured goods exemption to the Equality Act, ensuring all new products and services are made with inclusivity in mind. At the very least we should enact the requirements of the European Accessibility Act, meaning all online content must be accessible.

Such an equality analysis would help avoid unintended consequences; for example, the banning of plastic drinking straws (without the provision of an alternative) as a positive environmental measure has had a significant negative impact on disabled people who rely on them to drink. The creation of silent electronic vehicles has a positive effect on noise pollution but was very dangerous for people who are blind or have a visual impairment (and

[4] Mind (2019). Research has been shared with the Disability Unit. Currently unpublished.

thanks to lobbying from RNIB, this has since been overturned). Where an impact analysis is carried out but on balance a policy needs to be implemented even where it has a negative impact on some people, it needs to be accompanied by proper messaging around any exemptions. The introduction of social distancing and the mandatory wearing of face masks are good examples here and the lack of a properly funded public awareness campaign that makes it clear that some people are legitimately exempt from wearing a mask and that some people struggle to socially distance has very unfortunately contributed to an increase in hate crime against disabled people.[5]

Disabled people experience significant extra costs when purchasing **energy and insurance.** Households with a disabled person can pay up to £300 per year more than non-disabled households.[6] This can be due to barriers also experienced when accessing other products and services – inaccessible websites, lack of information in useable places (such as comparison sites), and not knowing where to get trusted and accessible information about alternatives.

Autistic people, people with mental ill-health, learning disabilities, deafness, blindness and complex disabilities commonly experience significant barriers when accessing healthcare, public services, education, shopping[7] and other essential services (such as banking). Access to many of these services has become even more difficult for many with these disabilities during the pandemic.[8] **Training for those delivering public services** and carrying out public functions is essential to implement a minimum standard of knowledge, understanding, and appropriate communication when working with people who have these types of disabilities.

4. Benefits and Welfare

There are seven key actions that disabled people need from an inclusive benefits system:

- Disability benefits must ensure they cover the costs of being disabled. During the pandemic, there was a £20 per week uplift to Universal Credit, but the same uplift was not applied to legacy benefits (Employment Support Allowance, Job Seekers Allowance and Income Support).
- Disabled people must have more choice over the method of assessment. This will help make sure that all disabled people have the opportunity to put their case across and get a fair hearing.
- The five-week wait for Universal Credit must cease. Universal Credit is there to prevent people from falling into poverty, and a five-week wait for an outcome is sending people into despairing situations. Equally, when managed migration from legacy benefits is reintroduced, those moved on to Universal Credit should not see a drop in their incomes; we must ensure that disabled people are not worse off.
- The accuracy and frequency of assessments must be reviewed. Both cause unnecessary stress and burden to the very people the system is there to support.[9]

[5] A survey by Disability Rights UK in June 2020 found that almost 40 per cent of disabled people cannot wear a face mask or covering, and 60 per cent of those fear being challenged on this.
[6] Scope, 2018, “Out in the cold”.
[7] 46 per cent of disabled people have faced difficulties when trying to get essential items (Scope, 2020, “The disability report: Disabled people and the coronavirus crisis”).
[8] For example, the healthcare challenges experienced by people with learning disabilities in Mencap’s research (Mencap, 2020, “My health, my life: Barriers to healthcare for people with a learning disability during the pandemic”).
[9] Litchfield, 2014, “An independent review of the Work Capability Assessment - year five”; Disability Benefits Consortium, 2019, “Has welfare become unfair?”.

There must be a clearer route to long-term awards to reduce the burden of repeated assessments on people who are already unwell.
- An independent regulator for the benefits system would redress the imbalance of power, which leaves so many of us struggling to challenge inaccurate decisions.
- An end to benefit sanctions for disabled people would give people who are unable to work the financial security and peace of mind needed to stay well and move forward with their live
- An independent commission led by disabled people would give people with experience of the system a role in designing the future of disability benefits assessments.

5. Social care

Social care is crucial for many disabled people to meet their full potential and therefore is key to other policy areas such as employment and health. However, social care needs a long-term plan to ensure that all can rely on a **financially sustainable social care system with a well-funded workforce**. A National Disability Strategy must push for proper funding of social care to enable a person-centred approach that focuses on promoting independent living as a positive solution and prevents working aged disabled people and older people from being pushed into generic and larger group settings which decreases independence and subsequent life chances. We instead need properly funded transition support to enable people to be supported to live independently in the community. There is an increase in older and working age disabled people facing long-term hospitalisation, often in seclusion and isolation, when they could have otherwise remained living in their communities if they had access to the appropriate social care. The upcoming Cross-Departmental strategy to address this issue must be brought forward and provided with the funding and political will break down the existing barriers and perverse financial incentives that currently exist. In tandem with this, disabled people should have choice when approaching the housing market whether as tenants, homeowners, or in shared ownership schemes and this is explored further in the housing section below.

In addition, local authority resourcing and provision of Care Act 2014 tertiary specialist rehabilitation services must be considered as an equal priority alongside adult social care needs-assessed services. These services should be monitored and reported against agreed national standards to ensure transparency and accountability. Despite the vision and ambitions set out in the Transforming Care programme, there are many people with a learning disability or complex needs who remain secluded and excluded from society in Assessment and Treatment Units (ATUs). The National Disability Strategy should ensure properly funded transitions from institutions with the funding of “in-reach” services and step-down provision to equip people to move onto more independent living. Whilst such services would incur a higher cost upfront, they are likely to result in lower cost support packages in the long term, as well as upholding the human rights and promoting the life chances of people with profound and multiple learning disabilities.

6. Technology

Affordability and availability of **assistive technologies** is preventing disabled people from getting the interventions they need at the right time. Many young people need technologies to make school curricula accessible to them, yet there is no defined way for children to get access to the technologies they would benefit from. Research by DCC organisations and calls to our helplines has shown disabled people often do not get access to assistive technology unless they reach university or become employed. This keeps people who do not

reach these settings locked out of opportunities that could otherwise be available to them if they had access to the technologies they need. A 'Tech for life' fund – modelled similarly to how Motability provide adapted vehicles – would ensure greater access to assistive technology with personalised assessments by specialists and solutions tailored to both an individual's disability or condition and life situation.[10] Disabled people need a solution that is going to address the current gap in the provision of suitable, tailored assistive technology solutions.

Since moving into an increased virtual and digital way of working, conducting assessments, and e-health, it is essential to implement a **programme to increase digital skills**, for disabled people[11] and public servants. This must include public servants knowing how to arrange and host inclusive digital meetings and appointments.

7. Built environments

Access to accessible homes must be improved. There is insufficient housing built to accessibility and or wheelchair standards, forcing disabled people to live in homes which are not fit for their needs. Many people continue to be housed in buildings without lifts, and solutions are often found only by local advocacy groups or support workers.[12] As above, disabled people should have choice when approaching the housing market whether as tenants, homeowners, or in shared ownership schemes. This must include enhanced mandatory accessibility standards (including Changing Places areas and "Visibly Better" standards of accessibility for blind and partially sighted people) to be met in all new residential and non-residential buildings. These should be regulated in the same way fire safety requirements are regulated in the housing market.

Streets and public spaces planning must be designed and planned with robust consideration and impact analysis of how disabled people would be impacted. People who use wheelchairs, have visual impairments, or who use other aids to help mobility or navigate public places experience many difficulties when items such as café furniture, A-boards, pavement parking, and bins block clear access.[13] A lack of kerbs and accessible crossings as found in shared space or mini-Holland developments can create "no go" areas for blind and partially sighted people. Recent planning regulations have further allowed businesses to place tables and chairs on pavements, and guidance on Inclusive Mobility is outdated.

8. Access to justice

Access to justice must be enhanced by increasing the **availability of Appropriate Adults**[14] and by establishing an effective way of identifying if someone is in the right system (for

[10] See Business Disability Forum's response to the All-Party Parliamentary Group's inquiry on assistive technology in employment (2020).
[11] For example, 18 per cent of disabled people have never used the internet (Office for National Statistics, 2019, "Internet users in the UK").
[12] Equality and Human Rights Commission, 2015, "The Housing experiences of disabled people in Britain". See also Anderson et al, 2019, "Match Me - What works for adapted social housing lettings?". Another study by the Equality and Human Rights Commission found that 38 per cent of councils were able to meet the demand for supporting disabled tenants (Equality and Human Rights Commission, 2018, "Housing and disabled people: Britain's hidden crises").
[13] RNIB, 2015, "Street Charter Toolkit".
[14] There were around 150,000 to 350,000 cases where no Appropriate Adult was recorded as being present (National Appropriate Adult Network, 2020, "There to help: The identification of vulnerable adult suspects and application of the appropriate adult safeguard in police investigations in 2018/19").

example, identifying if interactions with the justice system are instead a symptom of a missed care or support needs).

In addition, there must be greater understanding throughout the justice system and court procedures of disabled people's needs and the duty to make **reasonable adjustments** for all disabled participants, including defendants, accused people, and witnesses. This includes ensuring **inclusive communications** throughout the process, and the cessation of video conferencing use where this may prevent full participation in a justice procedure or court appearance. This may include a more consistent approach to ensuring public servants in the justice system receiving fit for purpose mandatory training on autism, mental health conditions, learning disabilities, and deafblindness.

People with learning disabilities and people with mental health conditions are both disproportionately represented in the criminal justice system and particularly in the prison population. [15]This is not only damaging to those individuals but costly to the taxpayer. Properly funded social care support that looks out for people who are vulnerable in this respect can pay dividends in preventing them from falling through the gaps in society. We urge government to look across ministerial department budgets when designing a National Disability Strategy and any subsequent legislation to ensure that a properly joined up approach is taken that provides both the best outcomes and the best value to the public purse.

9. Political participation

Increasing the political participation of disabled people will mean more disabled people at the heart of political life and decision-making. Increasing political participation of disabled people relies on:

- Enabling more people to take up public appointments and political office by promoting opportunities and ensuring Access to Work is available.
- Ensuring voting is accessible to everyone. Currently only just over 1 in 10 blind people, and around half of partially sighted people are able to vote independently and in secret.[16]
- Tackling attitudinal barriers, in particular around the misconception that there is a 'mental capacity' test for voting which can see people with learning disabilities challenged, and in the past, prevented from voting.
- Extending and promoting the EnAble fund to remove financial barriers preventing disabled people from being elected to office.
- Enacting the recommendations set out in the Lord Holmes Review of Public Appointments (2018) and the Commissioner for Public Appointments' subsequent progress report (December 2020)

Meaningful consultation

The DCC has identified the above areas of focus and cross cutting themes from the work we have focussed on with our various stakeholders. However, not all disabled people engage with disabled people's organisations. It is therefore imperative consultation with disabled people to **design and review** the progress of the strategy should include the following:

[15] House of Commons Committee of Public Accounts, 2017, "Mental health in prisons".
[16] RNIB, 2020, "Turned Out 2019".

- Co-production and active listening with direct contact between government and disabled people in each region of the country.
- Communications that are accessible by design. This includes providing alternative formats of information about the strategy and consultation documents and enabling people to participate by submitting responses in different formats such as British Sign Language (BSL).
- An accessible media campaign to communicate and raise awareness of both the Strategy and the consultation so that the maximum number of disabled people and their carers can engage in the process.

Fulfilling the strategy

The DCC welcomes the National Disability Strategy and we are therefore keen that the delivery of the Strategy will be as successful as possible. To do this, the Government must define:

- The purpose of the strategy, by establishing the questions it is aiming to answer.
- Meaningful targets for year-on-year progress so policy interventions can be evaluated effectively and changed if necessary.
- How success will be measured, including who will regulate the implementation of the strategy and monitor its progression.
- Funding should also be identified to deliver the strategy.

To support the above, we would like to see the role of the Minister for Disabled People bolstered in both scope and resources. We recommend that this role should sit across Government rather than be based specifically in DWP to reflect the much wider remit of the role in covering all aspects of disabled people's lives.