Manifesto for a 'Better Normal'

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About This Report

Our manifesto focuses on 4 key concerns for disabled people in the North East of England – access and inclusion, health and social care, employment and welfare benefits. It is not an exhaustive list. A more comprehensive, national picture is provided by the recent EHRC evidence provided to the Women and Equalities Committee[1]

We focus on learning from the COVID-19 crisis, but also include some issues which led up to and set the context in which the crisis has unfolded. We propose changes directed primarily at local authorities, service providers and employers, but also for UK Government policy.

Much of this work is based on our rights to equality – under human rights law and the Equality Act 2010[2]. The UK Government has signed several international documents that protect our rights to health, social security, work and an adequate standard of living. These include the Declaration of Human Rights (1948)[3], The Convention on the Rights of Persons with Disabilities (2006)[4], and the International Covenant on Economic, Social and Cultural Rights (1976)[5]. In many cases, we are simply asking for these protections to be applied and our rights to be upheld, without discrimination.

Our aim is to be proactive and constructive. We are willing to work with organisations to help them develop action plans in order to address the issues we raise in this report. We are eager to champion real progress and share good practice.

Accessing This Report

We have made an Easy Read version available on Difference North East's website.

If you require any further help to access this report, please email richard@differencenortheast.org.uk.

About The Authors

The charities that have contributed to this report represent some of the key disability and human rights organisations in the North East.

Our expertise covers a wide range of disabilities, including mental and physical health, learning disabilities and autism, and social rights. This report draws on our collective experience to identify those issues affecting disabled people the most. We have not tried to capture all the issues specific to particular disabilities.

We are: Difference North East, Disability North, Inclusion North, United Response, Just Fair, Re-co-co, Skills for People, Newcastle Vision Support and Project Choice.

Summary

"If our voices are heard, conversations will be opened about disability. This in turn will normalise disability and inequalities will continue to fade."

- *Dr Lucy Reynolds, Vice Chair of Disability North*

Disabled people in the North East, like the rest of the UK, have been badly affected by the COVID-19 pandemic. Those in care homes have suffered in terms of exposure to infection. Those shielding have suffered isolation and feel forgotten about. Many others have not had appropriate support because they are not categorised as 'clinically vulnerable'. The negative impact the crisis has had on disabled people is stark. As demonstrated by the Office for National Statistics (ONS) reports on social impact[6], disabled people's levels of anxiety and loneliness have been disproportionately affected. The ONS data on COVID-19 related deaths[7] shows mortality rates of 1.9 and 2.4 times more for men and women with disabilities respectively.

In other ways, the crisis has brought benefits to some disabled people. Greater use of technology has helped to connect and support some people who would normally have found it difficult to engage in particular activities. Increased homeworking and flexible working arrangements have been a positive benefit to some disabled workers.

With this mixed picture, we have captured learning from the crisis so that policy makers, service providers and employers understand the impact that COVID-19 has had on disabled people in the North East, good and bad, and can take action. We have looked at four key areas:

- Access and inclusion
- Health and social care
- Employment
- Welfare benefits

In the following sections we look at these in detail and make specific recommendations for each. Recommendations are collated into 4 broader areas of action – we need an EPIC response:

Extra investment and support to ensure disabled people's rights are protected both during and after the current crisis.

Personalised support that is flexible enough to meet individual needs. Disabled people have a vast range of different needs – an individual, person-centred approach is key.

Involvement of disabled people in planning and decision-making, at an individual and community level. Nothing about us without us.

Compliance with existing disability and human rights legislation to make reasonable adjustments, reduce discrimination and protect human rights.

Access & Inclusion

During a public health crisis, it is more important than ever that public authorities and service providers adopt inclusive approaches. In this crisis there have been many examples of disabled peoples' needs not being met, putting people at risk of serious harm. As a result, people are feeling abandoned, ignored and devalued. Many service providers are now having to use more online delivery methods which, whilst offering some great opportunities for connecting isolated people, also bring new accessibility challenges.

"I spent multiple evenings trying to find available online [food shopping] slots, and even tried logging in to the app in the middle of the night to try and secure a slot… You can imagine my relief then when I heard that supermarkets were going to prioritise vulnerable people, giving them priority for delivery slots, and also imagine my horror and increasing frustration when I found out that a totally blind person wasn't classed as vulnerable according to the [UK] Government's guidelines issued to supermarkets. At that point, I felt completely let down and abandoned."

- *Newcastle Vision Support staff member*

Disabling Factors

- The approach of the UK Government's COVID-19 response has been one which has prioritised support for those with medical/health needs – the 'clinically vulnerable'. Many disabled people have not been 'vulnerable enough' to qualify for that support. As a result, they have been put at risk, e.g. not being able to get priority shopping slots and therefore struggling to access food.

- Some of the clinical guidance relating to the prioritisation of treatment was biased, devaluing the lives of disabled people.

- Communications from the UK Government about COVID-19 and the support available has failed to meet different communication needs, such as providing BSL signed briefings and Easy Read guidance. Many voluntary organisations and charities have had to fill the gap.

- The large scale move to online services and support has highlighted the problem of digital exclusion. Too many people in our region cannot access essential information, goods, services and support. This is due to affordability, poor infrastructure, poor digital literacy and inaccessible design.

Enabling Factors

- Some VCSE organisations have found great value in providing online support. They have been able to reach some service users who would not normally have been reached through traditional methods.

- VCSE organisations have shown great agility and innovation in responding to their service users' needs during a hugely difficult time.

- Some disabled people have benefitted from a new level of community support, with many examples of help provided by local people.

Looking Forward

Disabled people will suffer due to the backlog in support and treatment, particularly in healthcare, but also in other public services such as welfare. As the non-disabled world adjusts to the new socially distanced ways of living and working, the needs of disabled people may not be properly considered or may be considered too difficult to meet. Measures rushed in, such as changes to our high streets to meet social distancing requirements, are taking effect without proper consideration of disabled peoples' needs. Putting in place emergency measures does not negate the need for reasonable adjustments, it makes them all the more important.

Recommendations

E
- Local authorities and businesses should take action to reduce the digital divide across our region, recognising that digital access and inclusion is now essential, not a luxury. These plans should improve access to data services and equipment, but also skills-building so that service providers and service users are able to use digital services in an inclusive and accessible way.
- We recommend individuals and organisations support the regional [Better ConNEcted](#) campaign.

P
- Service providers should, wherever possible, use flexible delivery methods in order to meet the individual needs of their customers. For example, offering different communication formats, and the opportunity for support/assistance.

I
- Service providers from all sectors need to consult with their disabled customers to find out how they have been impacted by the COVID-19 crisis and to assess their ongoing needs.

C
- Emergency plans should be updated to learn from this experience so that gaps such as those identified by disabled customers can be filled before another pandemic or similar emergency.
- Local authorities and businesses need to listen to their disabled customers as they adjust to new ways of operating and make reasonable adjustments to ensure disabled people are not discriminated against.
- Government, local services and businesses need to provide information in accessible formats in line with legislation.

Health and Social Care

Easy access to thorough and non-judgemental healthcare is essential to many disabled people, even outside of a global pandemic. It is also a right enshrined in the International Covenant of Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities, both of which the UK Government is party to. Despite this, throughout COVID-19, many disabled people are reporting feeling like an afterthought in health guidance and planning. The Coronavirus Act 2020 has brought changes to the Care Act 2014, creating fear and uncertainty about the security of support packages available. Terms such as 'vulnerable' and 'shielding', commonly used in pandemic policy and procedure, are disempowering. They are affecting decades of hard-fought progress to change the narrative around disabilities from that of reliance to independence.

It has been apparent that disabled people who have been able to take control of their own support have been less affected by COVID-19[8].

"The lack of clear directive information available from the [UK] Government on the run up to the pandemic and during it for those with disabilities was and still is an afterthought. The stress to find clear, understandable information was anxiety provoking, disheartening and extremely taxing, as well as frustrating."

- *Direct Payments employer*

Disabling Factors

● There has been a reduction in regular support due to staff shortages and closure of services leading to increased isolation, reductions in independence and a greater reliance on unpaid carers. All of these have had an impact on family relationships.

● Delayed and lacking Government guidance for those using direct payments has led to added confusion and additional stress.

● Many carers and Personal Assistants (P.A.s) have had trouble accessing correct and adequate Personal Protective Equipment (PPE).

● Mixed messaging around the guidance for those on the 'extremely clinically vulnerable' list has increased isolation and put many at risk.

Enabling Factors

● In some instances, the direct payment has been given more flexibility. For example, some people have been able to use their budget on technology to help with contacting family and friends. Others have been able to employ family members for support if they have been shielding.

● Remote/virtual services have increased, giving many better access to healthcare appointments. This has helped reduce costs, time and stress associated with travelling to appointments for some people.

● User led organisations and VCS networks have worked together to ensure advice and support has been reaching larger numbers through their deepened knowledge of their local communities.

"…we still do not have a comprehensive Care and Support plan which causes a great deal of anxiety over the use of the budget and unnecessary phone calls and emails to the Clinical Commissioning Group for guidance. We would like this to change going forward, we would like it to be recognised that a care and support plan is an integral part of a Personal Health Budget, and more work is needed in this area."

- *Personal Health Budget Holder*

Looking forward

With the financial strain of the pandemic, there are naturally concerns about how many of the measures put in place by the Government will be funded. For example, will health and social care budgets be reduced even further? But there are many other concerns and questions that are arising as lockdown measures ease. What are the long-term impacts of the Coronavirus Bill 2020 changes to the Care Act 2014? How will health and social care services deal with the backlog of appointments? Will organisations and charities offering support to disabled people survive? If not, how will that affect the support available?

If these questions are not fully considered then there is a risk of increased isolation, reliance on family members, pressure on relationships and increased risk of mental health needs coming out of this pandemic. There are also opportunities to look at how Direct Payments and Personal Health Budgets (PHB) are delivered in the North East. Many Direct Payment support services in local authorities are in-house and that often means total control is not passed to the disabled person. In order to ensure services can recover and build back better, disabled people must be given back control of their support.

Recommendations

E
- Improve recognition for the work P.A.s and carers carry out.
- Ensure P.A.s and carers wages meet the real living wage and rise in line with inflation.
- Ensure work and pay conditions meet human right standards.

P
- Ensure that remote/virtual services remain an option for those who have benefited.
- Reduce reliance on public sector contracts by better utilising local community support networks. This will increase the control disabled people have in recruiting P.A.s and choosing how they spend their Direct Payments.
- Local authorities should promote personalised support and encourage a greater uptake in the use of Direct Payments.
- User led organisations should be put back at the forefront of PHB support, creating opportunities to work with local authorities to deliver user led training around PHBs and personalised support.

I
- Ensure that disabled people and unpaid carers are leading social care discussions and at the centre of policy making going forward.
- Ensure person-centred and user-led support plans for those whom Direct Payments are not suitable.

C

- Ensuring the rights and protections within the Care Act 2014 are not eroded. It is encouraging that many local authorities did not have to use the easements within the Coronavirus Bill 2020. This should be continued throughout the period the bill covers.
- Work towards putting personalisation back into self-directed support. Moving away from the use of set hourly rates within Direct Payments. Ensuring flexibility within support plans and ensuring they are outcome focused rather than time and task focused.

Employment

The effects of the COVID-19 crisis have been mixed in terms of employment practices and their impact on disabled people. For some, work has proved impossible because of the need to shield or not being able to access support. For others, the adoption of homeworking has been liberating, enabling them to have greater control of their working environment and reducing travel problems.

"One of the reasons I quite enjoy life during lockdown is because being at home means not being disabled. You're not subject to people's expectations – I can go upstairs on my knees and bum-shuffle down them without censure that it's the wrong way because it's only right to walk – that's liberating"

- *Sam, Difference North East member*

Disabling Factors

- Disabled people who rely on the services of a P.A. or support worker have not been able to access this support due to COVID-19 restrictions, making work more difficult or impossible.

- Applications for support through the UK Government's Access to Work scheme have been processed very slowly, denying disabled workers much needed support.

- Disabled people who must also manage chronic illnesses and health conditions are also being impacted by restricted availability of routine healthcare and rehabilitation services.

- Supported work placements, such as those provided through Project Choice[9] in the NHS, have been temporarily halted.

Enabling Factors

- In many cases, disabled workers are benefitting from the increased flexibility offered by working from home arrangements. This helps some disabled people to balance work, health and caring needs. Disabled people often live with conditions which cause fatigue, pain and discomfort. Being able to work flexibly, at times when the individual feels more able to work, is of great benefit to some disabled workers.

- Working from home has allowed some disabled workers to more easily manage self-care, in the privacy of their own homes.

- Some disabled people have found the large-scale move to home and online working arrangements to be a 'leveller' – the majority of people are having to cope with restricted movement and isolation.

Looking Forward

The expected downturn in the economy, and resulting high unemployment levels, will impact severely on disabled people. There is already a significant employment gap in our region and previous experience has shown that disabled people do not come out of an economic crisis well[10]. Built-up pressure on health services and support services will impact negatively on disabled workers. They will have to wait longer for operations, equipment, training and support.

Public finances will be under huge pressure due to the impact of the COVID-19 crisis. There is a risk that services that support disabled people to find and retain work will suffer.

On the plus side, there is a great opportunity for employers to harness the benefits of more flexible working, at the same time improving efficiency, boosting employee wellbeing and reducing environmental impact.

Recommendations

E
- UK Government, local authorities and charitable funders should commit to providing more support for disabled jobseekers.
- The Access to Work scheme plays a vital role in helping disabled people to find and retain work. It requires greater investment from UK Government.
- Support through Access to Work should offer more flexibility, recognising that a person's work situation may have changed due to COVID-19 and that new or different support may be needed.

P
- Employers should not assume that home working is the answer for all their disabled staff. Disabled workers need to be treated as individuals, with individual needs and preferences. These are best reviewed regularly with the employee so that further adjustments can be made over time.

I
- Employers must also recognise that online platforms for meetings present their own challenges and accessibility issues. Managers need to communicate with all staff to ensure they are coping with new ways of working, to explore any accessibility problems and find appropriate workarounds. Training should be provided to help all managers and staff to understand accessibility features of systems used.

C
- Employers need to develop their employment practices and policies to ensure that disabled people, and other staff, working from home have appropriate support, equipment and training.
- Human Resources policies should be applied sensitively to reflect the reality of conditions facing disabled workers, particularly in relation to the knock-on impact of a backlog in health and support services.

Welfare Benefits

A decade of austerity measures and regressive welfare 'reforms' have led to growing inequalities for people with long-term health conditions and disabilities. Policies such as the benefit freeze, the benefit cap and the 2-child limit, along with a 5 week wait for first Universal Credit (UC) payments, have pushed more disabled people into financial hardship and debt. The cessation of the Work Related Activity Group addition for Employment and Support Allowance (ESA) has also has negative impacts. The transfer from Disability Living Allowance to Personal Independence Payment for working age people has seen many claimants lose their entitlement or have their payments reduced.

On top of this, 'Legacy' benefit rates have not been increased as they have with UC. There are also situations where people may be worse off on UC compared to legacy benefits.

There has been a significant reduction in new claims for disability benefits since lockdown measures were introduced, meaning many people with long-term health conditions are going without money they are entitled to. Equal rights to adequate social security must be upheld in order to reduce inequalities and help bring people out of poverty.

"Being told I was getting my PIP interview over the phone was a scary thought, but the DWP gave me a code so a third party could join in and support me which was fantastic."

- Newcastle Vision Support service user

Disabling Factors

- Regulations and guidance regarding changes in benefit processes are changing rapidly and are not always confirmed in writing – communication from the Department of Work and Pensions (DWP) to benefit claimants about these changes has been limited.
- Significant increases in waiting times for benefit enquiries and applications on phone lines and major technical issues with online benefit claims processes have created barriers in accessing support. Some people have had to wait up to 1.5 hours to get through to the Personal Independence Payment (PIP) enquiry line and UC helpline.
- Access to remote, online support with benefit applications/reviews is not accessible for all and can be limited by disability, literacy, digital literacy or access to technology.
- Increased difficulty in obtaining and sharing written consent or authorisation online has limited the type of assistance available to benefit claimants.
- People who lose their job due to the COVID-19 crisis who are in receipt of working tax credits will lose their 'transitional protection' and be forced to move to the UC system. They may see a significant reduction in their benefit income with no opportunity to return to the old system of benefits.

Enabling Factors

- Benefit claimants were being given 3 months to complete benefit application and review forms. This has recently reverted to only 1 month.
- Electronic versions of some benefit claims forms made available to support remote assistance (ESA, UC, Attendance Allowance, Disability Living Allowance) increased the support available to claimants remotely.
- Introduction of electronic PIP2 'How your disability affects you' forms – although these are currently only available upon request to claimants who have their own email address.
- All face to face assessments for disability benefits have been suspended from 17th March (to be kept under review).
- The increase in UC standard allowance and Working Tax Credit (WTC) rates increased by £20 per week for 1 year from 06/04/20.

- Welfare benefit appeals are currently being conducted remotely. The conference call system being used allows a representative to participate in the tribunal.

Looking Forward

In order to build a fair, equal and 'better normal' for disabled people, social security policies must meet human rights standards. It is essential that positive steps taken by the Government during the COVID-19 pandemic are not removed - for example the increase in UC payments by £20 per week. To do so would be a regression in the realisation of people's right to social security. No policy should worsen living standards.

Recommendations

E
- Urgent action is needed to expand the DWP's capacity to reduce benefit application and decision wait times and resolve technical issues with the online claims process.
- Rates for 'legacy' benefits should increase in line with increased rates for Universal Credit and WTC.
- UK Government must re-introduce the Work-Related Activity component for ESA and corresponding Limited Capability for Work element of UC.
- Make the increased UC and WTC rates permanent.
- Reverse damaging welfare reforms including the 2-child limit, benefit cap and bedroom tax.

P
- Increase technical capacity to allow benefit claimants, representatives and supporting professionals to submit applications and supporting evidence electronically across benefit systems.

I
- Continue to allow remote welfare benefit appeals and medical assessments in line with the feedback and experience of many disabled service users.

C
- Permanently extend the time allowed for benefit claimants to submit benefit applications and additional supporting evidence from 1 month to 3 months.
- Replace the advanced payment loan in UC with a non-recoverable grant for disabled people.

Further Information

Difference North East - www.differencenortheast.org.uk

Disability North – www.disabilitynorth.org.uk

Inclusion North – www.inclusionnorth.org

United Response – www.unitedresponse.org.uk

Just Fair – www.justfair.org.uk

ReCoCo – www.recoverycoco.com

Skills for People – www.skillsforpeople.org.uk

Newcastle Vision Support – www.newcastlevisionsupport.org.uk

Project Choice - www.hee.nhs.uk/our-work/talent-care-widening-participation/supported-internships-project-choice

References

[1] Evidence to the Women and Equalities Committee inquiry on coronavirus (COVID-19) and the impact on people with protected characteristics, May 2020

[2] https://www.legislation.gov.uk/ukpga/2010/15/contents

[3] https://www.un.org/en/universal-declaration-human-rights/

[4] https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en

[5] https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx

[6] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/may2020

[7] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto15may2020

[8] https://www.disabilitynewsservice.com/coronavirus-control-over-support-is-helping-keep-disabled-people-safe-evidence-suggests/

[9] https://www.hee.nhs.uk/our-work/talent-care-widening-participation/supported-internships-project-choice

[10] https://www.ifs.org.uk/publications/14799