



Disabled People's Reclaiming Our Futures Alliance

Disabled People's Manifesto 2019

Our vision for equality and inclusion

Our manifesto sets out our shared vision for an inclusive, fair and equal society free from barriers that exclude, discriminate and marginalise. It details sustainable and transformative approaches to key areas of our lives that will go a long way to securing Disabled people's equality and full inclusion in society.

Reclaiming Our Futures Alliance (ROFA)¹ is a network of disabled people and Disabled People's organisations (DPOs)² that aims to improve disabled people's lives. This manifesto details key principles and 16 key policy 'asks' that disabled people and our allies want our political parties and the next UK Government to adopt and implement including upholding and fully implementing the United Nations Convention on Rights of Persons with Disabilities (UN CRPD)³.

The manifesto uses a Social Model of Disability approach which holds that it is the economic, social, cultural, physical and attitudinal barriers operating in society that disable and exclude people with impairments. We use the term disabled people in this manifesto to include all people with impairments including: people with physical, cognitive and sensory impairments, people with learning difficulties; people who are neuro-diverse; Deaf people, deafened, hard of hearing people, mental health system survivors/people who experience mental distress and people with long term health conditions.

Things continue to get worse, not better for Disabled people

¹ <https://www.rofa.org.uk/>

² Disabled People's Organisations (DPOs) are organisations run and controlled by Disabled people with Disabled people representing at least 75% of Board /Management committee and 50% of staff teams. DPOs also use and follow a Social model of Disability approach.

³ The UNCRPD was ratified by the UK Government in 2009. It sets out the rights of disabled people see: <http://www.un.org/disabilities/default.asp?id=150>

Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights stated, following an extensive visit to the UK in 2018, that “People with disabilities are more likely to be in poverty, and are more likely to be unemployed, in insecure employment, or economically inactive. They have also been some of the hardest hit from austerity measures. As a result of changes to benefits and taxes since 2010, some families with disabilities are projected to lose £11,000 on average by 2021/22, more than 30% of their annual net income⁴.”

According to research disabled people have typically lost around £1,200 per year due to welfare reforms while non-disabled people have only lost £300 per year on average while households with one disabled adult and one disabled child have experienced an average loss of over £4,300 per year.⁵ According to Age UK more than 50,000 older disabled people have died waiting in vain for care during the 700 days since the Government first said it would publish a social care green paper. The number of people receiving publicly funded social care per year has dropped by around 600,000 since 2010.⁶ Many more people were admitted to hospital due to malnutrition in 2017-18 than in 2008-09.⁷

Our Vision

Our vision is a shared belief in a society based on the values of equality, and human rights, with equality of participation and inclusion for disabled people. To achieve this we need:

- A society where every person is equally valued and is recognised as contributing value
- A society that celebrates our intersectionality, diversity and the value and benefits diversity brings
- A society that actively eliminates discrimination and exclusion and actively invests in resources to enable full citizenship

⁴ Statement on Visit to the United Kingdom, Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights:

https://www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf

⁵ <https://disabilitybenefitsconsortium.wordpress.com/2019/07/16/has-welfare-become-unfair-a-new-report-by-the-disability-benefit-consortium/>

⁶ <https://www.ippr.org/research/publications/social-care-free-at-the-point-of-need>

⁷ <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2019-07-22/280427/>

There are 13.8 million disabled people in the UK. We want to see a society that supports and enables full citizenship for all. Well-resourced and efficient welfare and community infrastructure is necessary and achievable. Disabled people must have a legal and real right to live independently and to live a life of full inclusion, spontaneity, choice, of family, friends, education, work and community. The state must provide appropriate funding and support to enable disabled people and all people to live lives of equality, independence, and dignity in line with the UN CRPD.

We want to see real access to equality of opportunities and equality of life chances. Disabled peoples' inclusion must be a right and a reality from the beginning of our lives, not a continuous struggle in the face of daily exclusion, injustice, prejudice and discrimination.

Our Principles

- The UN CRPD and our human and civil rights must be fully implemented, promoted and enforceable in domestic law and policies
- Disabled people must have the right to enjoy the same degree of autonomy, and control over our day-to-day lives, and our long-term futures as non-disabled people
- Legislation and policy must support an inclusive society whereby disabled people are valued citizens and members of the community
- Disabled people must be provided with support, assistance and equipment that will enable us to participate with other citizens (both disabled and non-disabled) on equal terms, and with equal opportunities, across all areas of life.
- Disabled people must be centrally involved in legislation, policies, initiatives and services that affect our lives – Nothing About Us, Without Us.

Our Priority 'Asks'

1. **End austerity:** The disproportionate way that austerity has been imposed has had a profound and devastating impact on disabled people of all ages, our families and the services and community support we need. The UN Disability Committee and the Special

Rapporteur on Poverty have both evidenced the discriminatory and detrimental impact austerity has caused to disabled people's quality of life, inclusion and dignity. Cuts to entitlements and services for disabled people must be reversed.

2. **A planned programme of strategic, national and local investment** in support for Disabled people, co-produced with Disabled people and DPOs, must be implemented to address the impacts of austerity and get progress towards our equality and inclusion back on track. This investment should progressively realise our rights under the UNCRPD and bring these rights into domestic law.
3. **A legal right to Independent Living:** We need specific independent living legislation that fully enacts and enforces, as domestic law, Article 19 of the UNCRPD, incorporating the 12 pillars of independent living⁸ as its key goals and principles. In parallel, we need the implementation of a National Independent Living Support Service (NILSS)⁹ based on an expanded version of the Independent Living Fund (ILF) that will work alongside the NHS, free at the point of need/use and paid for from direct, progressive taxation. The service will be delivered locally through a network of DPOs, cooperatives, not for profit organisations and the public sector.
4. **Urgent action to tackle the Social Care crisis:** While NILSS and a legal right to independent living is being enacted urgent short-term measures are required to tackle the current social care crisis and ensure continuity of care for existing service users and those in need not currently receiving support . This will involve investing to bring funding back to 2010 levels, ending social care charging and restrictions on people who use self-directed support, such as the compulsory use of prepaid payment cards; extending and ring-fencing the 'Former ILF Recipient Grant' for another four years and urgently introducing an appeals system for social care (independent living support).

⁸ "12 Pillars of Independent Living" are:

Appropriate and accessible information, An adequate income, Appropriate and accessible health and social care provision, A fully accessible transport system, Full access to the environment, Adequate provision of technical aids and equipment, Availability of accessible and adapted housing, Adequate provision of personal assistance, Availability of inclusive education and training, Equal opportunities for employment, Availability of independent advocacy and self-advocacy, Availability of peer counselling.

⁹ <https://www.rofa.org.uk/independent-living-for-the-future/>

5. De-institutionalisation and the closure of residential institutions and hospitals for disabled children and adults: The Equality and Human Rights Commission (EHRC) research shows that “Despite the government’s Transforming Care agenda to move people with learning disabilities and autism out of inpatient units and into community living, as of the end of February 2019, 2,295 were still in inpatient units in England, of which 1,330 (58%) had a stay of over two years in length.” The abuse, and to all intent and purposes, the torture of disabled people, particularly people with autism and/or learning difficulties, as uncovered in the Winterbourne View, Whorlton Hall, County Durham and Muckamore Abbey NHS hospital, County Antrim, Northern Ireland, has to end with the immediate closure of these hospitals and institutions. Urgent action must be taken to develop, resource and put in place appropriate community support, particularly non-clinical, user-led and culturally appropriate services, which promote the right to independent living of people who experience mental distress, people with learning difficulties and autism.

6. Radical reform of mental health and mental capacity laws: People who experience mental distress/use mental health services and people who have autism and/or learning difficulties should have full human rights drawn from the UN CRPD. There needs to be a radical shift in approach to mental distress, which should include accepting it as part of human diversity and a strong emphasis on addressing intersectional and structural discrimination and disadvantage. Substitute decision-making, detention in psychiatric institutions, involuntary treatment and community treatment orders must end. The government should implement radical reform of mental health and mental capacity laws based on the principles enshrined in the UN CRPD. There must be a statutory right to advance choice decisions, which include the right to refuse detention, involuntary treatment and community treatment orders. There must be access, as needed, to supported decision-making and peer advocacy. There must be resourced and well supported co-production and DPOs should have an equal say in the development of those policies.

7. Welfare Support: All disabled people must have a right to inclusive and adequate welfare support. The fundamentally flawed and failing system of Universal Credit and benefit sanctions must be scrapped immediately and benefits restored to 2010 levels and upgraded for inflation. The assessment process for disability benefits must be

redesigned in line with the UN CRPD and brought back into the public sector. A new benefits system must be co-produced with disabled people that recognises and addresses the barriers to full inclusion and the extra costs of impairment.

8. **Housing:** All disabled people must have a right to accessible housing under the principles of universal design. The Bedroom Tax which has such a disproportionate detrimental impact on disabled people must be scrapped. Urgent action must also be taken to tackle street homelessness for disabled people and people in mental distress. The acute shortage of accessible housing must be addressed in a house building programme, across both the public and private sector that is compliant with accessible housing building regulations and lifetime homes standards.
9. **A fully inclusive education system:** All children should learn and play together. The national Special Educational Needs and Disability (SEND) funding crisis must be ended and the increase in the exclusion of disabled children and the rising number of disabled children in segregated education must be halted. Disabled learners must have the legal right to attend and fully participate in all mainstream education settings within a fully inclusive education system that meets the needs of all disabled learners. The Government must end the dual education system which encourages the operation of segregated schools and colleges. The Government must also end the reservation and interpretative declaration of article 24 of UNCRPD and fully commit to the progressive realisation of inclusive education for every child and learner.
10. **Access to justice:** Disabled people need equal access to all aspects of our justice system. Cuts to legal aid must be reversed and there must be strategic investment to ensure provision of comprehensive, independent, accessible, free advice, advocacy and legal support. Disabled people must also be protected from adverse costs orders when taking legal action on discrimination. The EHRC need to have sufficient funding and capacity to pro-actively tackle discrimination including bringing back in-house equality and advisory support and ensuring provision of free mediation services for discrimination cases. Disability hate crime must also have parity in law with other hate crimes.

11. Inclusion and full participation: Disabled people experience discrimination and exclusion on a daily basis and the vast majority of us are unable to challenge this situation. The Equality Act 2010, which relies on individuals to take legal action is deeply flawed. Service providers know they can, to a large degree, get away with discriminatory practices as there is little incentive for providers to comply with their Equality Act duties. The Equality Act should primarily be enforced by public bodies, and public bodies with regulatory powers, should be obliged to take proactive steps to ensure goods, services, built environment and infrastructure comply with accessibility standards and promote inclusive practices. Infrastructure investment plans and regulatory measures must be put in place to ensure disabled people's access on an equal basis with others to the environment, public spaces, transport, information and communication, so that disabled people can participate in social, cultural, political and family life on an equal basis with others. Access must be an essential requirement in procurement, licencing and franchising. There also needs to be the creation of legal status for British Sign Language.

12. Employment, conditionality and sanctions: The UK labour market is increasingly one of low paid, insecure jobs in the gig economy with zero hours contracts. Managing an impairment or health condition requires a level of control over workload and environment and the less control someone has, the less likely they are to sustain employment. Insecure, low control jobs have also been shown to have a detrimental impact on psychological wellbeing and it is unlikely to be a coincidence that there has been a noticeable increase in the numbers of people claiming ESA (or its predecessor Incapacity Benefit) for mental health reasons. The current Work Capability Assessment (WCA) and wider regime of conditionality and sanctions is not fit for purpose and must be scrapped. It has been shown time and time again to be an approach which not only fails to understand the complex relationship between work and impairment /ill health, but which is actively causing harm to those who have to go through it¹⁰. The Government's focus on work as a health outcome and increasing use of conditionality, including access to health services has to be reversed. It is crucial that the principle of social security is restored. This means recognising that people have a right to an income replacement payment in order not to live in poverty

¹⁰ <https://www.inclusionlondon.org.uk/wp-content/uploads/2018/10/ESA-WRAG-Report.pdf>

when they are too ill and/or experience too many barriers to engage in paid employment. It means a move away from the assumption that waged work is the only 'meaningful activity' for human beings and that receiving benefits means a second-class social status.

13. **All disabled people should have a right to work and employment:** All disabled people who want to work and are capable of doing so should have the opportunity to do so. This means removing the complex structural barriers present in the labour market. A comprehensive and strategic plan of action to tackle the discrimination and exclusion disabled people face in employment and work must be developed and resourced by Government and co-produced with disabled people and DPOs. This requires an expanded and improved Access to Work (AtW) scheme, investment in high quality employment support and legally enforceable duties on employers in both public and private sectors to reflect the diversity of the UK population in their workforce.
14. **Real and effective co-production with Disabled People's Organisations (DPOs) across the UK:** Ensure meaningful, well-resourced and accessible engagement and co-production with disabled people and our organisations (DPOs) at local, regional and national levels on all issues affecting us as required by UN CRPD. The Government needs to work with DPOs to co-produce a comprehensive strategic policy and action plan for achieving disability equality over the next ten years.
15. **Brexit:** Membership of the EU and the European Court of Human Rights affords disabled people in the UK rights and protections which need to be guaranteed if Brexit happens. Any changes to legislation and rights for disabled people as a result of Brexit must guarantee to be replaced with legal protections in line with the UN CRPD and other human rights treaties and laws.
16. **Climate emergency:** Disabled people are made vulnerable by changes to the environment and the UK Government's failure to act to reverse climate change. The declaration of a climate emergency and the development of a climate emergency plan must ensure the needs of Disabled people are recognised and addressed.

For further information about the Reclaiming Our Futures Alliance (ROFA) please go to

<https://www.rofa.org.uk/>

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