

Slide one Presentation to the Social Care Commission.

Produced by the Cheshire Disabled People's Panel

Slide two - The Cheshire Disabled People's Panel.

- Disabled People's Organisations—DPOs—are managed by, and for, disabled people. Founded in 2021, the CDPP is an alliance of DPOs from across Cheshire: Cheshire Disabled People Against Cuts (DPAC), the Deafness Support Network, Dial West Cheshire, the Disability Information Bureau (DIB), Disability Positive and the Peoples Choice Group.
- Approximately 1 in 5 people in England are disabled or have an impairing long-term condition or chronic disease (we will refer to these groups collectively as "disabled people").
- Too often, disabled people routinely face barriers in dealing with public organisations, environments, and transport.
- Yet, in 2021, it is still common for there to be no disabled people participating in public sector decision-making that directly affects our lives. This must change.

Slide three - The Cheshire Disabled People's Panel.

- The Public sector equality duty (PSED) obliges central and local government to carry out impact assessments when they plan to introduce measures, including legislative measures, to ensure that groups with protected characteristics—among them disabled people—are properly consulted and any adverse impact on them is properly justified.
- Our position is that the best way for Cheshire West and Chester Council to uphold this duty is via co-production.
- Co-production of policies and services is not the same as consultation.
- Co-production requires leadership by those most impacted

Slide four - The Cheshire Disabled People's Panel.

- Co-production provides the pathway to transforming social care into an empowering and rights-respecting model of independent living services that centres the lived experiences of the person with care needs, offers them genuine choice and control, and upholds their rights
- ...including those set out in the provisions of the Care Act (2014); the Equality Act (2010); the Mental Capacity Act (2005); the Human Rights Act (1998); and the United Nations Convention on the Rights of Disabled People (UNCRDP).

- It is imperative that disabled people from all walks of life are centred in our local democratic processes, in all matters that directly affect our lives.

Slide five - The Cheshire Disabled People's Panel.

- We cannot emphasise enough how critical it is for that to be the case with local authority social care policy and practice.
- CDPP offers senior public sector decision-makers a single point of access to enter into equal partnership with disabled people on the design, implementation, and reviewing of social care and other policy and practice.
- At our July 2021 launch, politicians, and public sector managers from across Cheshire committed to work in equal partnership with us to deepen organisational understanding of the rights of disabled people, co-production, and the best ways to dismantle the barriers disabled people still routinely face.

Slide six - Our origins: the Disabled People's Rights Movement.

- In the 1960s and 1970s, inspired by the civil rights movements of the time, disabled people started to question their life experiences and why so many disabled people were institutionalised and excluded by charities claiming to represent us.
- Disabled people started to discuss and develop an understanding of disabled people's experiences that radically questioned society's assumptions about what disabled people could and could not do, and how and where disabled people should live.
- Disabled people began to challenge the exclusion, discrimination and lack of choice and control they experienced in daily life, and the prevailing negative attitudes in society. This was the beginnings of the 'Disability People's Rights Movement'.

Slide seven - Structural barriers to inclusion.

[image of the social model of disability]

The social model of disability states that the oppression and exclusion people with impairments face is caused by the way society is run and organised.

The problem is the disabling world

Examples are:

Badly designed buildings, stairs not ramps or lifts

Special schools

Lack of sign language interpreters

Discrimination

Inaccessible transport – no parking places

Isolated families

Poor job prospects

Slide eight - Structural barriers to inclusion.

- Barriers “disable” us, by creating exclusion, discrimination, and disadvantage for people with physical or mental impairments.
- Key disabling barriers for the Social Care Commission to be aware of:
- Attitudinal barriers: social and cultural attitudes and assumptions about disabled people that explain, justify, and perpetuate prejudice, discrimination, and exclusion in society
- Physical barriers: physical and built environment barriers that prevent equal access, such as stairs/ steps, narrow corridors and doorways, inaccessible toilets, poor lighting, broken lifts or poorly managed street and public spaces.
- Information/Communication barriers: linked to information and communication, such as lack of British Sign Language interpreters for Deaf people, lack of provision of hearing induction loops, lack of information in different accessible formats such as Easy Read, plain English, and large font.

Slide nine - Our work: campaigning by Disabled People's Organisations.

- UK DPOs led the successful campaign for direct payments in social care, culminating in the Direct Payments Act 1996, and were also instrumental in their implementation as providers of information, advice, and advocacy to disabled people managing their own care and staff.
- DPO-gathered evidence of violations by the UK government of disabled people's rights resulted in a 2016 United Nations inquiry, which found that Britain's austerity welfare reforms “gravely or systematically violated the rights of disabled people.”
- DPOs are currently supporting four disabled litigants who have taken legal action against Secretary of State Therese Coffey on the grounds that the government

failed to adequately consult with disabled people and DPOs in the production of the National Disability Strategy.

Slide ten - Our work: campaigning by Disabled People's Organisations.

In the face of declining funding and limited resources— which have led to the closure of many DPOs.

DPOs are building our collective campaigning capacity and sharing resources and expertise through the creation of strategic alliances. DPOs are working locally, regionally, and nationally for disabled people's rights in these key areas:

- Social care, reframed as disabled peoples' right to an independent life— supported by universal, publicly owned, uncharged services
- Inclusive education
- Accessibility: transport, housing, and public environments
- Increased accessibility of elections, and party-political engagement with disabled voters
- Disability Hate Crime awareness and prevention
- Digital inclusion recognising that disabled people are less likely to have access to the internet or be able to afford broadband or equipment.
- Legal challenges in support of disabled people's rights

Slide eleven - Reframing social care as the right to independent living.

- The UK became a signatory to the United Nations Convention on the Rights of Disabled People in 2007.
- Article 19: Living independently and being included in the community
- States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) disabled people have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.
- b) disabled people have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.
- c) Community services and facilities for the general population are available on an equal basis to disabled people and are responsive to their needs.

Slide twelve - Reframing social care as the right to independent living

[Image showing the twelve pillars of independent living]

1. Full access to our environment
2. A fully accessible transport system
3. Technical aids/equipment
4. Accessible adapted housing
5. Personal assistance
6. Inclusive education and training
7. An adequate income
8. Equal opportunities for employment
9. Appropriate and accessible information
10. Advocacy
11. Counselling
12. Appropriate and accessible health care provision

Slide thirteen - Impact of local authority cuts.

Examples of social care cuts and their impact:

- Local Councils setting limits on how much social care they will pay for. Sometimes it costs more for a disabled person to live in their own home with support than to live in a group home. Some Councils are telling disabled people they will have to move to a group home against their wishes because it is cheaper.
- Local Councils charging fees to disabled people who use social care. The cost of these fees are pushing some people to stop using social care support even though they need it and causing others to build up debts.

- Cuts to social care are on top of problems with benefit assessments. These problems mean that many people who need benefits are being turned down for them, leaving them without enough money to live on.
- Some disabled people no longer have enough money for food or heating and are having to use foodbanks, borrow money, get into care charge-related debt, or withdraw from care from fear of costs / debts

Slide fourteen - Reframing social care as the right to independent living.

- In response to the social care crisis, which results in the breaching of disabled people's rights, DPOs have created a model of social care based on the Social Model of Disability that upholds disabled people's rights: the 'National Independent Living Support Service' model (see "research resources" on final slide)
- Independent living does not mean doing everything for yourself.
- In the UNCRPD it means disabled people having the support we need to live in the community with choice and control over our lives.
- Cuts to social care have made it more difficult for disabled people to get the support we need to live in the community and take part in life the same as other people. They mean that our rights to independent living are going backwards.
- The current system of social care provision results in an indefensible "post code lottery": people get different levels of social care support depending on what area they live in. We think people should get the same type and quality of support wherever they live.

Slide fifteen – Cheshire Disabled People's Panel campaigning on social care

- We work collaboratively on social care / independent living campaigning with local and national DPOs including Disability Rights UK, Disability Wales, Inclusion London, the Greater Manchester Coalition of Disabled People, and the Bristol Centre for Independent Living

Slide sixteen - Cheshire Disabled People's Panel campaigning on social care.

- We successfully lobbied the Secretary of State to unfreeze the statutory component of the Minimum Income Guarantee (unfreezing in line with the current annual rate of inflation from April 2022, announced in the 2021 Command Paper)

- We gathered data showing significant variations in the amounts, disabled people are being left to live on after their non-residential care charges are taken by local authorities, via Freedom of Information Act requests to all councils and CCGs in England who exercise their discretionary powers under the Care Act (2014) to charge disabled people for meeting their statutory non-residential care and support needs
- The “postcode lottery” impact is very evident in the NW—we found considerable MIG variations across the 10 GM unitary authority areas
- The Cheshire West and Chester MIG data tells us the local rates have not kept track with the cost of living for disabled people

Slide seventeen - Cheshire Disabled People's Panel campaigning on social care.

- DPOs have worked with journalists to call for an end to social care charging by local authorities
- We lobby MPs, the Association of Directors of Adult Social Services, the Local Government Association and their President Tanni Grey-Thompson, Secretary of State for Health and Social Care Sajid Javid MP, Minister of State for Disabled People Chloe Smith MP, Minister of State for Care Gillian Keegan MP, and APPG on Adult Social Care Damien Green MP.
- We are calling on local authorities to urgently uplift MIG at the discretionary level, and to commit to ending non-residential care charging practice: which is an unfair and punitive tax on disability
- Our primary campaigning goal is to ensure the political parties commit to universal provision of social care free at the point of need, reframed as the right to independent living (in line with Article 19)

Slide eighteen - Best-practice from Greater Manchester and Hammersmith and Fulham.

- DPOs work in equal partnership with council officers and elected representatives in other local authority areas—including Hammersmith and Fulham, and across Greater Manchester.
- This brings about inspiring, transformational changes to the lives of disabled people.
- CDPP was developed in consultation with the Greater Manchester Mayor’s Disabled People’s Panel (GMDPP).

“The Greater Manchester panel was the first of its kind and, from the beginning, was developed in partnership with disabled people’s organisations here in our city-region.

“I am proud that here in Greater Manchester we are leading the way on tackling inequalities and adopting pioneering approaches to democratic engagement and policymaking with disabled people.

Slide nineteen - Best-practice from Greater Manchester and Hammersmith and Fulham.

“They’ve been a powerful voice in vital conversations about inequalities and accessibility, and the work of the panel shows our continued commitment to working with disabled people to bring about transformative change to our public institutions, environment, and transport systems.

“It’s great to see that the Greater Manchester Disabled People’s Panel has provided a model for our colleagues in Cheshire.

“I wish our colleagues in Cheshire all best in their work.”

- Andy Burnham, Mayor of Greater Manchester

Slide twenty - Best-practice from Greater Manchester and Hammersmith and Fulham.

[Image of Andy Burnham – mayor of Greater Manchester with an excerpt of a speech]

“On International Day of Persons with disabilities we celebrate the contribution of disabled people to our society and communities, and renew our commitment to fight for equal rights, opportunities and protections for all.

Disabled people are among those who have been hardest hit by the pandemic, because of both the threat to their health and the restrictions imposed on their lives.

Greater Manchester’s Disabled People’s Panel has shown admirable leadership in recognising and responding to that impact and in championing the rights of disabled people, not only in our city-region but across the country”.

Slide twenty-one - Best-practice from Greater Manchester and Hammersmith and Fulham.

- DPOs in England consider Hammersmith and Fulham Council’s co-production of policy – including social care – to be the benchmark of good practice for local authorities.

- Hammersmith and Fulham are the first local authority in the country to commit to co-production across a whole council

“Co-production must be one of our cornerstones of equality and inclusion. I’m really committed to supporting a whole new way of working with residents – one that truly respects diversity and lived experience.”

–Kim Smith, Chief Executive of Hammersmith & Fulham Council

Slide twenty-two - Best-practice from Greater Manchester and Hammersmith and Fulham.

- Leader Cllr Stephen Cowan’s relationships with local DPOs and campaign groups such the Hammersmith and Fulham Coalition Against Cuts led to his agreement to establish a Disabled People’s Commission in 2017.
- In 2018, the DPC recommendations led to:
 - i) the council’s commitment to co-producing policies and services with disabled residents
 - ii) a Co-Production Implementation Group, in which disabled residents, councillors, and senior council officers work in equal partnership to bring the DPC recommendations to life
 - iii) an end to the discretionary charging of residents by the council for meeting their non-residential statutory care and support needs
 - iv) a paid, senior role of Strategic Co-production lead created by the Council, job-shared by disabled officers Tara Flood and Kevin Caulfield

Slide twenty-three - Best-practice from Greater Manchester and Hammersmith and Fulham.

[Image of councillor from Hammersmith and Fulham Council]

“Our Co-Production Implementation Group ensures that in our local authority area, we are making decisions with disabled residents—not for disabled residents, to bring to life our commitment to doing things with residents—not to residents.”

- Cllr Stephen Cowan, Leader, Hammersmith and Fulham Council

Slide twenty-four - The co-production model in Hammersmith and Fulham.

[Image of co-production model from Hammersmith and Fulham Council 2017]

Nothing about disabled people without disabled people
Working together to transform services in Hammersmith and Fulham

Key findings:

Many say the quality of life has gone down.

Some feel they can't influence local decisions.

Councillors and staff want to work better with disabled residents.

Recommendations:

Take a human rights approach

Commit to coproduction (working together)

Skill up to work better to

Develop a communication strategy for co-production.

Strengthen Disabled People's Organisations or DPOs.

Make services deliver what disabled residents want.

Develop a budget.

Do independent monitoring.

Slide twenty-five - Our recommendations to the Social Care Commission.

- DPOs in England consider co-production of social care to be the benchmark of good practice for local authorities.
- The Social Care Commission provides an excellent opportunity for Cheshire West and Chester Council to work with Cheshire DPOs to embed Article 19 of the UNCRPD—the right to an independent life—into the local working culture, and by doing so, enhance the reputation of Cheshire as a trailblazing authority for the empowerment of disabled people.
- CDPP recommends that Cheshire West and Chester Council establishes a Disabled People's Commission, to begin its work in early 2022, whose terms of reference should mandate the Commission to design a pathway for the

establishment of a Co-production Implementation Group (CIG) led by disabled people and their organisations.

Slide twenty-six - Our recommendations to the Social Care Commission.

- Social care policy in Cheshire West and Chester to be designed, delivered, and reviewed in equal partnership with the CIG, and guided by a commitment to ending charging by the authority for meeting statutory care and support needs
- Recent research emphasises that cuts to social care lower the health and wellbeing outcomes of disabled voters and result in deaths in the disabled population (see the CDDP's Letter to Cllr Armstrong, Cllr Gittins, Andrew Lewis, and Peter Grime of 27 October).
- In recognition of this, we call on elected representatives and council officers to end the cutting ("efficiency measures," "streamlining of services," "rationalising" in the politically preferred language) of disabled people's services

Slide twenty-seven - Our recommendations to the Social Care Commission.

- We call on the council to raise the discretionary element of the Minimum Income Guarantee in our region to compensate disabled people for the real-terms reduction to the MIG created by the Secretary of State freezing of the statutory rates from 2015-2022 (we have statistical data for the commissioners)
- We call on the council to raise the Personal Expenses Allowance above the statutory minimum

Slide twenty-eight – The Cheshire Disabled People's Panel.

[Image of a hand-made campaign banner – saying nothing about us without us]

Final slide twenty-nine – Researched resources.

Internet links to research articles.

1. Hammersmith and Fulham – Coproduction- doing things with residents not to residents: <https://www.lbhf.gov.uk/councillors-and-democracy/co-production-doing-things-residents-not-residents>

2. Reclaiming our Future Alliance -Independent Living for the Future:

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

3. Disability Rights UK - Independent Living for the Future:

<https://www.disabilityrightsuk.org/news/2021/june/social-care-reform-improving-disabled-people%E2%80%99s-lives>

4. Scrap Care charges – Why we need change, Social Care on equal terms with the NHS: <https://www.scrapcarecharges.com/why-we-need-change>

Presentation ends.