**Shaping Our Lives**

**Campaigning for the Future: How can we work better**

**to secure our rights?**

**Summary**

This report offers the views of a wide range of disabled people about present UK disability policy and how they may best work to improve it. In 2011 Jenny Morris wrote a Viewpoint report, published by the Joseph Rowntree Foundation[[1]](#footnote-1) called Rethinking Disability Policy (see footnote). Shaping Our Lives have facilitated two meetings to enable disabled people to discuss what they think about the findings of the report and look at ways in which disabled people can lead improvements to policy and practice as experts by experience – disabled people living and working in austerity Britain from 2012 through to mid-2015.

At the first meeting in September 2014 a diverse group of disabled people looked atwhat life is like for disabled people after four years of coalition government.Having had a rare opportunity for an inclusive discussion to rethink disability policy, participants next wanted the opportunity to discuss possible strategies for the disabled people’s movement to improve it. Shaping Our Lives responded by convening Campaigning for the Future – a workshop in June 2014 to explore this.

Since the first discussion meeting In September 2014 there has been a general election and a change from the Coalition government to a Conservative government. The long term impact of this is not yet known, but people fear that the austerity measures introduced by the Coalition government will continue and probably be more damaging to people from diverse and disadvantaged communities. The Queen’s speech in May referred to £11billion of cuts with no specific detail of how these would impact the welfare state, health and social care services, causing great concern for disabled people. The subsequent July budget and the Welfare Reform and Work Bill published after our meeting, confirmed fears that people already living in poverty and out of work would get no relief from continued austerity measures.

Everyone participating in the June 2015 meeting agreed things are getting worse for disabled people generally, from a lack of understanding about disabled people, to financial and welfare poverty increasing. At the end of that meeting participants were clear that they wanted action on these four areas:

1. Education – to tackle the prejudice and stereotypes created by misrepresentation of disabled people.
2. Build on what we have achieved as disabled people and what we offer.
3. Building a positive narrative to create positive statements that promote change for the better.
4. Campaign to get parity, and access to services which are accessible, inclusive, provide choice and give disabled people more control over their lives.

Participants were clear they wanted effective and efficient campaigns, that is campaigns that will work and work for disabled people. They identified both county/regional networks and national organisations as being important forces for change.

**Introduction**

On 4th June 2015 Shaping Our Lives organised a discussion meeting at Clement’s Hall in York. The aim of the discussion was to reflect on the concerns raised at a previous meeting examining the findings of the Viewpoint report by Jenny Morris and to explore ways in which disabled people and service users could work most effectively together to improve policy and practice.

The Jenny Morris report had been first published in November 2011 and on 12th September 2014, at a meeting convened by shaping our lives, 21 disabled people gathered to consider the relevance of the issues raised in that report in the context of current social and economic disability policy.

The main concerns and views from that 2014 meeting can be summarised as follows:

* Welfare reform is having destructive and wasteful effects across a wide range of disabled people. Participants see the welfare state as being undermined
* The meaning of ‘independent living’ which has been a rallying cry for disabled people to live in the mainstream and contribute like others has been undermined by government rhetoric and policy
* It is important to value diversity and see the contribution it can make to increasing a sense of solidarity and worth among disabled people, but current policies are having the opposite effect
* While the policy talk emphasizes getting people into employment, barriers have not been addressed, opportunities are restricted and a one size policy doesn’t fit all
* There are mixed views about direct payments and personal budgets, which can increase life chances for some but budgets are being cut at the same time as collective services are being lost leaving people isolated

Shaping Our Lives wrote and distributed their report on that 2014 meeting. It is called ‘Rethinking Disability Policy: Taking the discussion forward with disabled people’ by Peter Beresford and Becki Meakin. This is a link to that report [www.shapingourlives.org.uk/ourpubs.html](http://www.shapingourlives.org.uk/ourpubs.html)

Participants at that 2014 meeting wanted the opportunity to discuss possible future strategies for the disabled people’s movement. So the Joseph Rowntree Foundation agreed to fund a second meeting which was held on 4th June in York and chaired by Peter Beresford.

The discussion sought to represent voices that had not been heard at a previous meeting in September 2014and in previous activity that Joseph Rowntree Foundation had funded. To address this disabled people from the north of England and Scotland were invited to participate and most people who came lived, work or studied in those areas of Great Britain. There were 26 disabled people assisted by 12 personal assistants and support workers at the meeting and who represented a broad range of physical, sensory and cognitive impairments as well as people with autism and mental health service users. We were pleased that disabled students were represented and there was also experience of working with young disabled people in our group.

The framework for our discussion was the following areas:

* How we can campaign effectively to change to welfare reform, cuts in services and employment issues?
* Having control over words we use so they are not stolen from us to mean something else
* How we can do more to portray ourselves positively, for example, not as scroungers?

**The Discussion**

What is recorded here is evidence from disabled people who took part of their experience of living, working and studying in Great Britain in 2015 and of their recent past. It is direct evidence from people personally affected by changes to Government policy and cuts to services.

* 1. **What we are concerned about**

The disabled people who attended the meeting are more concerned than ever about access to employment and education. In particular the changes to Access to Work support that enables disabled people to work equally with non-disabled people and the removal of central government funding for support workers for disabled students by the last government. Almost immediately on coming in to power the new government announced changes to Access to Work support worker funding which will have an impact on how employers view disabled people. For people with learning disabilities Access to Work is essential to support the co-worker model.

One participant reported recent experience of an Access to Work assessment that recommended £470 of equipment, whereas the recipient stated they only wanted equipment that was much cheaper.

*‘I feel I am being made disabled by people telling me what I need and not listening to what I need.’*

The participants felt that the measures in place to help disabled people into work are insufficiently funded and sometimes ineffectual. For many people volunteering is an important first step into employment but Access to Work is not available for volunteers. The Work Trial programme was described as providing

*‘the minimum amount of support possible, expecting employers to pick up the rest’.*

This makes employers very worried about how support will be provided if they offer a permanent position to a disabled person and can lead to humiliating questioning for the prospective employee, described at the meeting as being like the ‘Spanish Inquisition’.

The difficulties in getting long term employment were also raised. A permitted work programme at a Local Authority had ended after 12 months employment for a disabled person with no offer of a permanent job or any training or development whilst doing the permitted work. The line manager responsible for the employee had apparently not realised it was a permitted work arrangement and so when the disabled person could not continue beyond the allowed time they also lost their Access to Work support.

One participant had helped about 7,500 disabled people into work and had much more success than the Job Centre, it could be viewed that this is because of a better understanding of the capabilities of disabled people. It was agreed that Access to Work staff and employers need training by disabled people.

Disabled Students Allowance cuts were announced 18months ago but the information has now gone underground preventing effective campaigning. There is concern that non-medical help for invisible disabilities is likely to be cut.

Students have fears about disclosing their disability when applying for jobs despite equality legislation, and it is thought disclosure may be better received for some disabilities than others.

**2 What can we do about it?**

Everyone agreed things are getting worse for disabled people generally, from a lack of understanding about disabled people, to financial and welfare poverty. The discussion moved to how can we tackle these problems. A number of suggestions were made and have been grouped as follows:

Education

* There is a need to educate government, statutory, public and private organisations about disabled people as a group rather than focusing on the ‘inspirational’ and the ‘scroungers’. This would give hope to more disabled people. It was suggested that trends towards devolution may provide more opportunities to influence other governments.
* Evidence how many people are employed through Access to Work. This is not just the disabled person who receives the support, but the additional workers they employ as support workers, personal assistants, coaches etc.

For example, one business owner appealed 3 times against a cut to their support worker hours. They employ 7 disabled people and 6 personal assistants who would probably not be working without her business.

* Change the perception that disabled people cost more and are of little value to businesses. As employees reframe the proposition of integrating disabled people into the workforce in terms of being better for the business by adding diversity, new market opportunities social awareness and inclusivity.
* Work to raise the expectations of young disabled people. Although it was recognised that parents will fight to get the best for their children this tends to be done individually and it was felt that we need parents to act together. We need to influence the aspirations of young people through schemes such as job coaches so they can realise their potential and ambitions.

Campaigning

* Campaign on rights based issues where there is a higher chance of success such as wheelchair access to premier league football stadiums. For campaigning to be successful we need a collective body/national organisation that can generate positive stories for the media and take this above the political framework.

Creating a narrative

* Create a simple narrative to counter the government line that disabled people are scroungers. Linked to this was the suggestion that we need to look and act like other people in positions of power, for example, by wearing suits and carrying business cards. This view was not shared by all as some felt that we should be proud to be who we are, like people from the lesbian, gay, bi-sexual and transgender communities.
* Speak in the same language as government and evidence the business case for putting disabled people in a fundamental role at all levels.
* Bring stories together of the positive contribution disabled people can make given the right support. Demonstrate that disabled people do not fit the media stereotype image of only being able to work in limited roles and the assumption that if you are not working you are not contributing to society. A blog was suggested to do this along with mobilising support from organisations who have a good record of employing disabled people, for example, the BBC.

Solution based responses

* Demonstrate how the ‘purple £’ can be more effectively used such as current work on streamlining direct payments (without local authority involvement) to increase efficiency and cut costs.
* Show how disabled people are a valuable market that can be reached through accessible practice and highlight the growing contribution they make as micro-employers.

*‘Our organisation has survived by not having contracts with Local Authorities. We are running 10 events this year to encourage businesses to see disabled people as customers. The message is that disabled people do have money, but cannot spend it where they want, so why not make your business accessible to get more business?’*

Parity

* Integrate disabled people’s rights into the commissioning process by ensuring our voices are heard on commissioning boards.

For example, in Sheffield disable people have been discussing influencing commissioners to introduce a policy to use ‘two tick’ suppliers that meet recognised standards for meeting customers care needs.

* Use legislation and standards such as The Care Act 2014 and the Autism Act to ensure health and social care providers are providing adequate services and make local commissioning structures more accountable when outsourcing services to commercial providers.

Reclaiming our language

The chair asked the members their thoughts on the feeling that the Government have taken over certain words such as Independent living, direct payments, peer support etc. Some suggestions were made as follows:

Several participants referred to existing guidelines on language such as those developed by Greater Manchester Coalition of Disabled People and the Samaritans which provide appropriate language to describe service users in an positive way and guard against statements such as ‘committing suicide’ which suggests someone has committed an offence. One member reported that they attended the Conservative Party conference to talk about the work they do with learning disability communities and they were asked if they had ‘mental health’-

*‘I was shocked they did not know the difference.’*

Another participant raised the poster campaign that pictured Ed Milliband and asked ‘Do you think this man has had a stroke’. Although the Department of Work and Pensions are still trying to get people involved in politics it was generally agreed that nobody would want to experience this type of abuse.

There is a need for much more training and involvement of disabled people in what language to use and what is acceptable.

There is an idea that independence is having to do everything yourself. This is wrong for the entire population; no-one is independent of other people. There is also an idea that disabled people are passive recipients in care. The United Nations convention for people with disabilities states independent living as ‘living independently’ and the Care Act rejects the this definition and leaves it undefined. With the right support we can live on our own and support other people. We can help with action plans. There was concern that if we rejected the language ‘independent living’ we would also lose our rights to live in the community.

Language has been manipulated to meet government agendas. When an MP was challenged to explain what a personal budget was they referred to a direct payment.

*‘We are a commodity that a number of people benefit from.’*

Contributing to society

We need parity by being represented at every level. Concerns were raised about the discrepancy in support for mental health services compared to other health and care services. It was felt we need to work together to get influential positions on committees, in statutory bodies, public sector organisations and government. However, barriers to involvement were raised again such as inaccessible times of day for meetings and a tokenistic approach. One participant reported that a local authority had agreed to involve people with autism on a committee, but then requested that only one person attended at a time.

Prejudice is still there and Kate Greenwood’s 15 year plan to tackle this was referred to. We need to find a way to overcome this and having equal rights does mean that we can be treated differently.

It was stressed that we need to be valued and we should be more confident about the value of our contribution. Involvement should be funded and not a voluntary activity. We should also question why they want us to be involved and ensure it is not just because we are disabled.

**3. How can we do it?**

At this point there had been a lot of discussion about what can be done and what we are doing. Our capacity in terms of wealth and power is very LIMITED and inequality is growing. We looked at what we could do to bring about change.

Social media was suggested as an inexpensive and useful tool for people to rally together remotely. However, some people voiced concern that social media can be isolating as it is an individual event and we need to use our networks and encourage disabled people who are meeting and working with other disabled people to communicate key messages so that all people, including those that do not get to meetings like these, to get involved.

Younger people may be particularly interested in using social media and blogging was suggested a simple way to get stories out. There was also discussion about a central resource of accessible rights based materials to enable people to be more aware of what they should expect and be entitled to.

*‘I talk about my experiences in work and inspire young people (with learning disabilities) – means young people think they can do it. Can we go into schools and help young people see what they can achieve?’*

Many people felt events were an effective way of raising awareness and we should build on the events that are happening all the time through disabled people’s organisations as well as consider specific larger events.

**4. Priority areas for action**

The following areas were identified as being the most important to take forward and develop practical actions around:

a) Education – to tackle the prejudice and stereotypes created by misrepresentation of disabled people. This covers a broad area of work including informing disabled people of their rights, raising the expectations and ambitions of, in particular young disabled people, challenging inappropriate language and depictions of disabled people, whilst also improving access to services.

b) Build on what we have and solution based responses – communicate the value of disabled people as employees, micro-employers and an under used market for goods and services. Promote our value and be confident to seek positions of influence on an equal basis.

c) Building a positive narrative – develop short and simple positive statements that promote change for the better for disabled people and counteract the over simplified narratives often used by government and the media that seek to depict disabled people as not adding to society.

d) Parity and access to services – work to use legislation and our knowledge to influence the commissioning of services so that they are accessible, inclusive, provide choice and give disabled people more control over their lives.

**Next steps**

How can all this be achieved? Shaping Our Lives explained that this was one of three events looking at similar strategies to take forward. The three different organisations holding these events will hopefully be able to provide a summary of the common themes and priorities for actions.

At this time resources and funding are very scarce in the disability movement and it will inevitably be small actions by existing disabled people’s organisations, local networks, country networks and national organisations as the driving forces behind change. However, Shaping Our Lives will endeavour to keep these important themes alive by continuing the discussion through our network, with the other organisations holding similar activity and the Joseph Rowntree Foundation who have funded this work to date. In particular, Shaping Our Lives will look for support to develop some of the service user driven elements such as building a forum to share our contribution, tell our stories and create a strong narrative for the future.

These inclusive meetings of disabled people were made possible by funding from the Joseph Rowntree Foundation and we would like to extend our gratitude for their support.

1. Rethinking Disability Policy; a Viewpoint paper published Joseph Rowntree Foundation November 2011 [↑](#footnote-ref-1)