



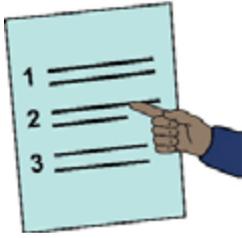
Reclaiming our Futures Alliance

An alliance of Disabled People and their organisations in England

Independent Living for the Future

Our vision for a national
independent living
support system





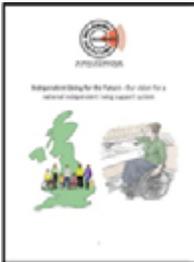
What is in this Paper



Meanings of some of the words in this paper



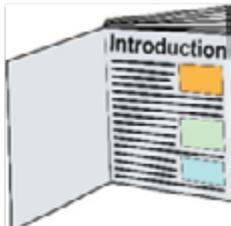
Background to this Paper



About this Paper



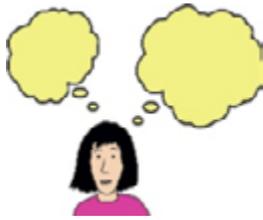
Disabled People's Vision of Independent Living Support for the Future



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Key Demands in short



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Key Demands



A right to independent living



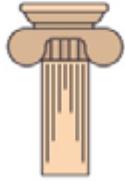
National independent living Service



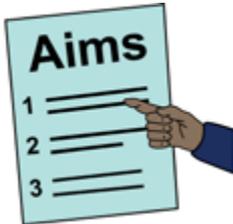
Steps to making our vision real



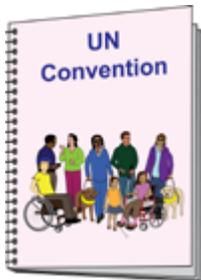
Changing the law



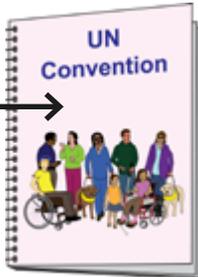
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WORD**Meanings of some of the words in this paper****19**

Article 19 – is the section of the United Nations Convention on the Rights of Persons with Disabilities that is to do with independent living.



Asylum seeker – is someone who leaves their own country, often for political reasons or because of war, and who travels to another country hoping that the government will protect them and allow them to live there.



Benefits – are payments to help people who do not have enough money coming in to live on. Benefits can be for people because they are out of work or because they are disabled.



Benefit assessments – are tests that people have to go through to see if they will be given benefit payments.



Chronic illness – is a health condition that lasts for a very long time and cannot be completely cured.



Co-production – is working together to make something happen. The word is often used to talk about decision-makers working together with disabled people to plan services.



Disabled people – includes people with physical disabilities, sensory disabilities, learning difficulties, mental health support needs, autism and chronic illness.



The Economy – the state of a country in terms of goods and money.



Foodbanks – are charities that give food to people who do not have enough money to buy their own.



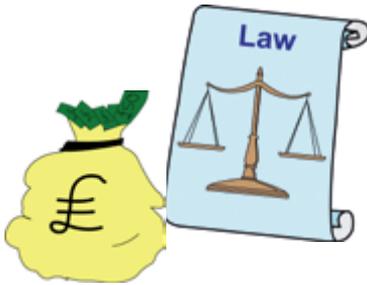
Inclusive education - is education that includes everyone, with non-disabled and Disabled people learning together in mainstream schools, colleges and universities.



Independent Living - is when disabled people have the support we need to live life how we want, with the same chances as other people, and to choose where we live and who we live with.



Independent Living Fund (ILF) – was a pot of funding for disabled people with high needs to live in their own homes. The Government closed it at the end of June 2015.



Legal aid - is funding for legal cases for people who cannot afford their own legal support.



National – covering the whole country.



Office for Disability Issues (ODI) - is the office in central government that is in charge of looking after disability issues.



Peer counselling – is when people who have had similar experiences listen to each other and share their experiences.



Personal Assistant – is someone employed by a Disabled person to provide support with daily living tasks.



Principle – is a basic idea to take into account when putting together bigger plans



Refugee – is someone who has escaped from their home country.



Social care – is support that helps people with daily living. People might need social care support if they are older or disabled. At the moment local Councils are responsible for social care for people who live in their area.

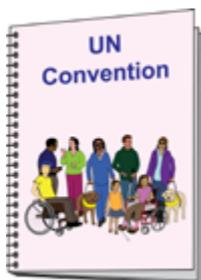


The Social Model of Disability

Social model of disability – is a way of looking at disability that says there is nothing “wrong” with disabled people: the difficulties we face are because of barriers in society and the way society leaves us out and is not accessible to us; it is society that needs to change to include us.



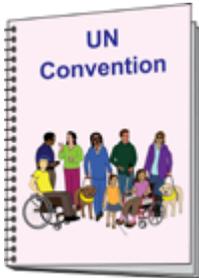
United Kingdom (UK) – is made up of England, Wales, Scotland and Northern Ireland. The UK Government rules over all the countries in the UK.



United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – is an international treaty that sets out how countries across the world should protect disabled people’s rights. It is known as the UNCRPD for short. The United Kingdom is signed up to the UNCRPD. This means it needs to report back every five years on how well it is doing what it says in the treaty. The UNCRPD is not law. This means the Government is not breaking the law if it does not do what it says.



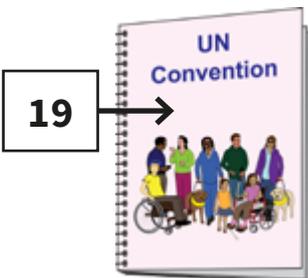
Background to this paper



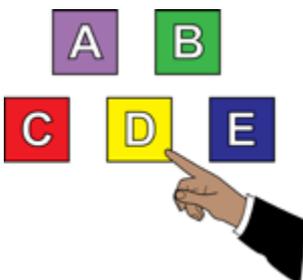
The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets out the rights that disabled people should be able to expect if they live in a country that is signed up to it.



The United Kingdom (UK) is signed up to the UNCRPD.



Article 19 is the section of the UNCRPD to do with independent living.



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.



Sometimes the Government and local Councils use the term “independent living” to mean people doing things without support. This is not in line with what the UNCRPD means by “independent living”. This can be confusing. We think it is important for disabled people to understand the UNCRPD meaning.



Cuts made by the Government have badly affected disabled people.



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.

Some examples of what the cuts mean:



- People who need mental health support being sent hundreds of miles away from home because there are no free beds in hospitals near them.



- 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 or borrow money.



Disabled people also face barriers because they belong to groups that are not treated fairly in society including:



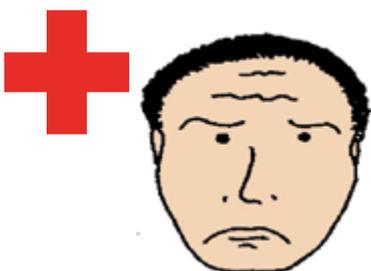
- Women



- People who are Black, Asian or from other minority ethnic communities.



- People who are Lesbian, Gay, Bisexual or Transgender.



There are also problems with the mental health system. The Mental Health Act is a law that makes it legal to hold people with mental health support needs against their will or to give them treatment such as drugs against their wishes in certain situations.



This goes against the UNCRPD.

Certain groups of people also face particular barriers with the mental health system including:



- People who are Black



- People with autism



- People with chronic illness



About this Paper

This paper has been put together by Disabled People Against Cuts as part of the Reclaiming Our Futures Alliance.



Disabled People Against Cuts is a campaign that was set up in 2010 to protest against the way cuts have badly affected disabled people.



The Reclaiming Our Futures Alliance is a network of organisations and campaigns led by and for Deaf and Disabled people across England.



In this paper we set out our vision for a national independent living support service. This service would provide support for disabled people that is in line with the rights set out in Article 19 of the UNCRPD.



The ideas in this paper have been shaped through meetings and discussions held by disabled people involved with the Independent Living Campaign.



This was a campaign set up in 2011 to fight against the planned closure of the Independent Living Fund (ILF).



This paper is also based on feedback from the following meetings and events:



- The independent living workshop at the National Deaf and Disabled People's Summit organised by the TUC Disabled Workers Committee and the Reclaiming Our Futures Alliance in November 2017.



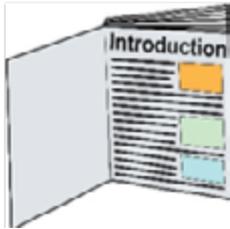
- The 2017 National Independent Living Campaign Conference funded by Disabled People Against Cuts (DPAC) and co-organised with the Reclaiming Our Future Alliance.



- A Reclaiming Our Futures Alliance independent living round table meeting held in May 2018 and follow up email discussions.



Disabled People’s Vision of Independent Living Support for the Future



Introduction



The social care and mental health systems are in crisis. As a result, disabled people’s rights are going backwards.



There is not enough funding for social care or mental health.



The social care system does not treat people fairly, for example some people such as those with chronic illness are less likely to be given support that they need.



We think that we need a new system that is based on the social model of disability. This is a way of looking at disability that says there is nothing “wrong” with disabled people: the difficulties we face are because of barriers in society and the way society leaves us out and is not accessible to us; it is society that needs to change to include us.



Our vision for a national independent living support system would get rid of the “post code lottery” we have now. This is where 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.



We believe that all independent living support should be free at the point of need. This would mean an end to all social care charging.



The national independent living support service would build on what worked well about the Independent Living Fund (ILF). The ILF was cheaper to run than social care support run by local Councils. Disabled people were also much happier with the support they got from the ILF than from local Councils.



Key Demands in short



1. Set up an independent living task force led by Disabled people. This group of people would put together plans for a national independent living support service.



2. Look at how to put Article 19 of the UNCRPD into law. This should be done working in co-production with Disabled people.



3. Make a case for spending more money on social care support. Spending more on social care could save money in other areas like the NHS and also build the economy through jobs in social care.



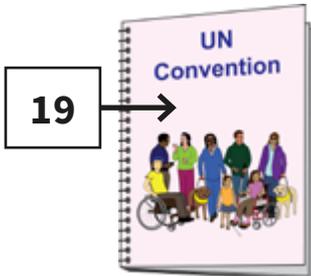
4. Work out how much funding needs to be spent on social care now and in the future. This is the amount of funding that would meet all Disabled people's needs.



5. Educate the public about why it is important to support Disabled people and how this is good for everyone in society.



Vision



Our vision is for what it says in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities to become reality.

Article 19 says that all Disabled people should:



- have equal rights to live in the community



- have the same choices as other people



- be fully included in the community



- be able to choose where they live and who with



- have a range of different types of support to choose from



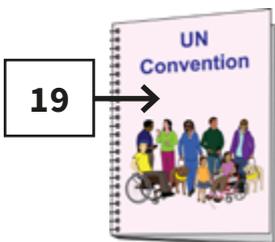
- be able to use the same community services and facilities that everyone else does.



Principles

There are a number of important ideas that should be behind the national independent living support service.

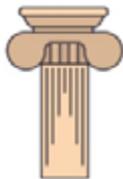
These are:



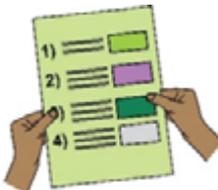
- Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)



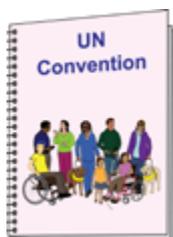
- The social model of disability



- The twelve pillars of independent living (see Extra Information A)



- The National Survivor User Network's Manifesto (see Extra Information B)



- The UNCRPD Committee's General Comment No 5 on Article 19 (see Extra Information C)



Key demands



We are asking for:



- A right to independent living that is in law



- A new national independent living support service that:



- has been set up by Disabled people working together with government



- is funded through taxes



- is managed by central government



- is led by Disabled people



- provides support for Disabled people through local user led services.



A right to independent living



The UNCPRD is not bound in UK law. This means no action can be taken against the Government if it acts in a way that goes against what the UNCPRD says.



The Care Act 2014 does not do enough to protect Disabled people's rights and make sure we have the social care support we need.



We are calling for a new law that would give Disabled people a right to independent living.



Information about the new law should be widely communicated to make sure Disabled people are aware of their rights under it. This information should include what Disabled people can do if their rights are being broken. The information must be available in different accessible formats.



The law should apply to all Disabled people living in the UK including Disabled refugees and asylum seekers.



National independent living service



The social care support that Disabled people need in order to live independently will be provided through a new national independent living support service.



The service will be funded through taxes.



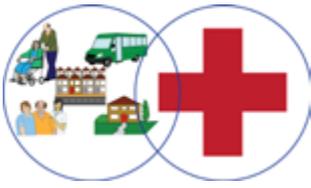
Central government will be responsible for the new service



but social care support will be provided by local user led organisations.



There will be no charges for social care support, it will be free.



Social care will sit alongside but be independent from the NHS.



The new service will build on what worked so well about the Independent Living Fund.



Disabled People’s Organisations and user led groups will have a say in how the new service is set up and run.



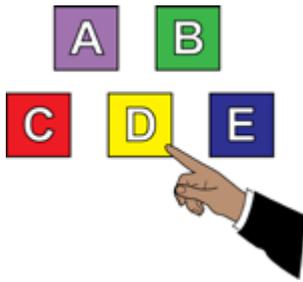
The national independent living support service will be responsible for supporting Disabled people through assessments to check what social care support they need.



The new service will also be responsible for giving out payments to Disabled people to pay for their social care support. Disabled people will not have to manage their own support payments themselves if they choose not to.



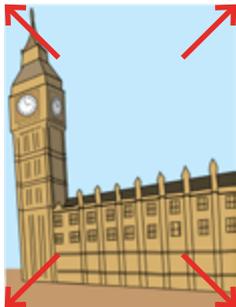
Funding will be put into local user led services so that in each area Disabled people can choose from a range of different types of support.



These services will support Disabled people to have choice and control. They will support Disabled people with finance, administration and legal duties as employers.



Local Disabled people will have a say in funding decisions for local services. Disabled people who are involved will be representative of different backgrounds and groups.



The national independent living support service will be based in a cross-government body so it is not tied to any one Government department but has links with all departments that are relevant to Disabled people's lives.



Co-created with Disabled people



The national independent living support service will be co-created by Government working with Disabled people through an independent living task force. The task force will be led by Disabled people who need/use independent living support.



Anti-discriminatory



The service will be designed to be anti-discriminatory and to treat all Disabled people fairly and equally.



Funded through taxes

Social care should be funded through general taxation like the NHS is. This means that funding for it should come out of the general pot of money that is raised through tax. There should not be a new tax introduced for the specific purpose of raising money for social care separate from other taxation.



Managed by central government

The national independent living support service will build on lessons learned from the Independent Living Fund. It will be independent from local Councils. This will help get rid of the “postcode lottery” we have now where people in some areas get better support than in others.



Led by Disabled people

Disabled people will have a say at all levels within the national independent living support service. The board that is in charge of the service will have a majority of Disabled people on it. Non-user led charities and disability organisations will only be able to play a limited role.



Delivered locally

The new service will be delivered locally through user led organisations. Funding will be put into local user led services so that in each area Disabled people can choose from a range of different types of support.





These services will support Disabled people to have choice and control in all areas of their lives including:



- Access to Work



- Housing



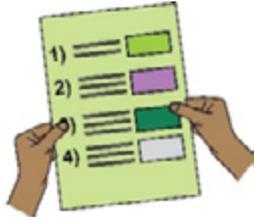
- Benefits and money



There will be ways to check that the same types of locally based support are available in different areas, so that Disabled people can move to a new area without losing support.



There will be a full range of services that meet the needs of Disabled people from different backgrounds.



Steps to making our vision real



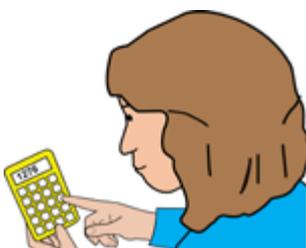
- Move the Office for Disability Issues (ODI). The ODI is the office in central government that is in charge of looking after disability issues. At the moment it sits within the Department for Work and Pensions. We think it should be in a different department that would give it more reach, such as the Treasury, the Cabinet Office or the Government Equalities Office.



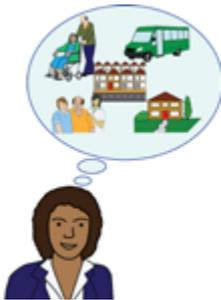
- Set up an independent living task force. This will be led by Disabled people who need/use independent living support from a range of different backgrounds.



- Fund research work to make a case for spending more money on independent living support. This will look at how social care can make money for the economy and how spending money on social care can make savings in other areas like the NHS.



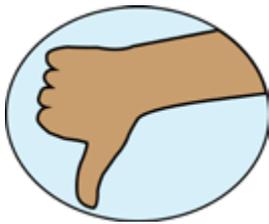
- Work out the amount of funding needed to make sure all Disabled people have the independent living support they need now and in the future.



- Fund user-led research into different types of independent living support that can meet the needs of Disabled people from different backgrounds.



- Make a communications plan for how to raise awareness about what we mean by independent living, Disabled people's human rights and the role of Personal Assistants.



- Deal with bad attitudes towards Disabled people at all levels in society.



- Fund training for people working in government and running services so they understand what Disabled people mean by “independent living”. The training should be led by Disabled people.



- Make a plan for how to fund more local services run by Disabled people and by local Councils, to replace social care services that are run privately for profit.



- Make a plan for closing long stay hospitals and units where Disabled people are sent away from their communities, to be replaced with independent living services in the community.



- Make a plan for housing to build more accessible homes. This should include building more Council housing that is accessible.



- Fund work to draw up a case for spending more money on Access to Work. This should look at how more money comes back in taxes for every pound spent on Access to Work.



- Make Access to Work part of the national independent living support service.



Changing the law



- Make a new law that gives Disabled people a right to independent living. This should include a right to inclusive education.



Care Act 2014

- Bring into force the appeals process under the Care Act 2014. The appeals process is a system so that Disabled people can challenge their local Council if they thin the Council has not given them the social care support they need.



- Bring into force Section 1 of the Equality Act 2010. Section 1 is part of the Equality Act that is not yet set up to be followed. If it was in force all government departments and local Councils would have to follow it. They would need to check what impact new policies will have on society and the amount of money people have.



- Stop the changes to legal aid that have made it more difficult for Disabled people to get. Legal aid is funding for legal cases for people who cannot afford their own legal support.



- Stop the reservation that the UK government has on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities. Article 24 is the right to inclusive education. The reservation means that the government is not fully signed up to this as a right. We think all Disabled people should have a right to inclusive education.



Mental Capacity Act 2005



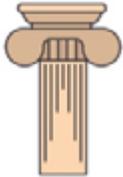
- Change the Mental Capacity Act 2005. At the moment we think this law gives too much power to other people to make decisions on behalf of Disabled people. We think it should be changed to make sure that decisions are in line with what the Disabled person and their family want. We also think there needs to be an accessible system so that people can challenge decisions made about them with which they do not agree.



- Bring an end to practices that mean Disabled people can be held against our will, have decisions made against our wishes and be forced to take treatment.



Extra information A



The 12 Pillars of Independent Living



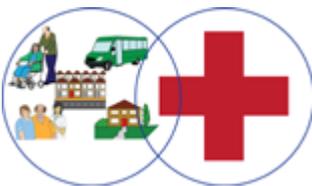
The 12 Pillars of Independent Living set out different barriers to independent living and how they can be removed. These are:



- Accessible information



- Enough money to live on



- Accessible health and social care



- Fully accessible transport



- Full access to the environment



- Aids and equipment



- Accessible housing



- Personal Assistance



- Inclusive education and training



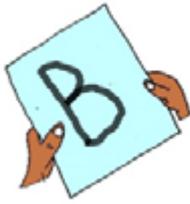
- Equal opportunities for employment



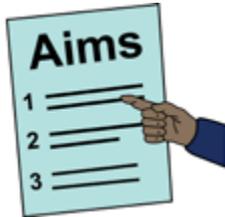
- Independent advocacy and self-advocacy



- Peer counselling



Extra information B



The National Survivor User Network's Manifesto: Our Voice Our Vision Our Values

We aim to:



1. Tackle the problems that have been caused by cuts to public funding and changes to the benefits system.



2. Make the policy of 'getting the right support, at the right time, in the right place, from the right person' a reality.



3. Put pressure on mental health services to include and listen to service users. They should follow the principle of 'nothing about us without us' at all levels of what they do, from involvement in decisions about our own individual care to decisions about how services are run.



4. Work together with people who are often left out of society to work out ways of meeting their support needs



5. Challenge discrimination, where certain groups of people are treated unfairly within mental health services.



6. Call for changes to the Mental Health Act 2007 to make it fit with human rights and make sure that people are not harmed or abused.



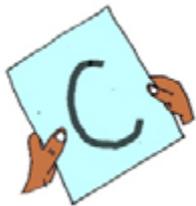
7. Follow the social model of disability and give proper choice to service users.



8. Take back control over research led by people with personal experience of mental health.



To see the full manifesto go to:
www.nsun.org.uk/our-manifesto



Extra Information C



Inclusion London Information about the UNCRPD General Comment no 5 on Article 19: Living independently and being included in the community



To read the full text of the General Comment go to:
<https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>



In August 2017 the UN disability committee published a “general comment” on Article 19. General comments give more information about specific sections of the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities).



The General Comment makes points about what the UN Disability Committee thinks about independent living that might be useful for campaigning. Some of these are listed below:



- Spending money on independent living saves money in the long run because it reduces poverty.



- The right to independent living applies to everyone – there are no Disabled people who cannot be supported to have independent living.

- It is important to address issues faced by Disabled people who are also:



- Women



- From Black, Asian and Ethnic Minority Communities



- Lesbian, Gay, Bisexual or Transgender



- Governments should not give too much power away to local Councils so that there is a postcode lottery for support.



- Independent living is not just about doing things for yourself.



- Independent living is about taking part in all areas of life including social life and leisure activities.



- “Institutionalisation” is not just when Disabled people are locked away in long stay hospitals. It can also happen when Disabled people are stuck in their own homes without the support they need.



- Disabled people should not be forced to share Personal Assistants.



- Funding for Personal Assistants must be enough to employ people in line with workers’ human rights.



- If a Government makes cuts that badly affect Disabled people’s right to independent living, they need to show that these cuts are really needed and are not treating some people worse than others.



- Governments must make sure that new settings are not set up that pretend to be about supporting Disabled people to live in the community but actually keep them apart from it.



- For Disabled people to live in the community, there needs to be enough accessible housing.



- It is against Article 19 to leave out Disabled people who need more support than others.



- Staff working in government departments and for local Councils should have training in what independent living is.



- An end must be brought to practices where decisions are made for Disabled people and where Disabled people are locked up against their wishes.



- There must be ways for Disabled people to appeal against decisions to do with their right to independent living and they must have rights to legal aid.



- Independent living is closely linked to inclusive education.



Picturebank from People First (Self Advocacy)

www.peoplefirstltd.com



Additional images from Bromley Experts by Experience

www.xbyxbromley.com/

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Alliance for Inclusive Education

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Cheshire Centre for Independent Living

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Disabled People Against Cuts

Greater Manchester Coalition of Disabled People

Inclusion London

Independent Living Action Group (Bristol Disability Equality Forum)

Mental Health Resistance Network

Merton Centre for independent Living

National Survivor and User Network

People First (Self Advocacy)

Reclaiming Our Futures Alliance

Shaping Our Lives

Sisters of Frida