



Inclusive Communities

A guide for Disabled People's
Organisations



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www.disabilityrightsuk.org/policy-campaigns/reports-and-research/inclusive-communities

Disability Rights UK 2014

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Introduction: action to create inclusive communities

Disabled people have long worked for full and equal participation in our communities – campaigning for equal rights and working practically through our groups and organisations on everything from more accessible transport to equal chances to stand for elected office.

We have achieved some legal rights. We campaigned for:

- Civil rights: equality in goods and services, employment, education, transport (gradually introduced from 1995 onwards).
- Positive public sector equality duties: to require public bodies to work positively for equality, not wait till discrimination has happened before they act. First introduced in the Disability Discrimination Act 2005 (and amended in the Equality Act 2010).
- Human rights: the UK ratified the UN Convention on the Rights of Persons with Disabilities in 2009.

These laws have been important for test cases:

Using the Law

In 2009, 17-year-old David Allen from Sheffield successfully challenged a high street bank for breaking discrimination laws by failing to provide wheelchair access to his local branch.

The bank claimed that other branches were accessible, and that they had offered Mr. Allen telephone or internet banking. The presiding judge criticised the bank for causing the teenager considerable embarrassment, awarding £6,500 in compensation and ordering the bank to install a platform lift.

“I only wanted them to comply with the law and provide disabled access so I could get into my bank like my friends.” (David Allen).

The case set a clear precedent to businesses and service providers that they had to make ‘reasonable adjustments’ to give customers access.

They are also important for generating 'system-wide' change: for instance, the Disability Rights Commission's Formal Investigation into health inequalities experienced by people with mental health conditions or learning disabilities led to new requirements in health services; the Equality and Human Rights Commission's Formal Inquiry into harassment and hate crime raised the profile of hate crime with police and prosecutors.

However, these laws are not perfect and any law is only as good as its implementation.

Disabled people have also worked for practical change both locally and nationally. When we asked for examples of inclusion in practice we heard from:

- Individual disabled people who have single-handedly and successfully campaigned to make everything from local coffee shops to buses accessible.
- Leaders who have introduced British Sign Language (BSL) signed services in a Mosque; and an organisation – Livability
 - working with churches to make them more inclusive.
- A Disabled People's Organisation – Disability Direct in Derbyshire – opening up opportunities to go to music festivals, by making them more inclusive
<http://tinyurl.com/l37sf5r>
- A South London group – Wheels for Well-being – teaching disabled people to ride bikes and gain greater participation
<http://tinyurl.com/maq7yn>
- Community Futures Kent working with District Councils, Police Independent Advisory Group, leisure centres, National Trust, Kent Libraries and many more to create welcoming attitudes, easy read information and greater access to premises via mystery shopping and whole community planning.
- Dementia Friendly Communities – involving people with early dementia as champions, and bringing together companies, public services and local people to make it easier for people with dementia to go out

and participate fully

<http://tinyurl.com/nfpfs8z>

- Disability Voice in Swansea, enabling disabled people to have a voice working alongside local decision-makers.
- Disability Wales co-developing with the Welsh Government a Framework for Action on Independent Living, committing to action across government to forge an inclusive and enabling society
<http://tinyurl.com/mcs34c7>
- NDTi's programme of developing Community Inclusion mentors which supports disabled and older people to engage in and contribute to their communities, and helps staff and organisations to understand how to build and support real inclusion
<http://tinyurl.com/kkmc7pw>
- DPOs and family networks who have worked for fully inclusive public education, right from the start, as in the London Borough of Newham. When disabled and non-disabled children learn together this can model inclusion from the youngest age and

positively influence everyone's attitudes and expectations.

- South Derbyshire CVS, which helped set up the 'Shout Out' forum for young adults with additional needs. Members of the Local Learning Disability Partnership and Shout Out Learning Disability Forum have been invited to take part in a review of South Derbyshire District Council's housing information, as a result.
<http://tinyurl.com/kw7fxvy>
- A non-profit Social Enterprise in South Wales – Digital Accessibility Centre - set up to address digital accessibility by employing disabled people from the local community to test websites and other digital products and offer advice on how to build accessible websites and mobile apps
<http://www.digitalaccessibilitycentre.org>

There is evidently a wealth of commitment and activity to increase participation, with disabled people often working with decision-makers to make

change happen. For instance, a DPO in Oxfordshire – OXTRAG (Oxfordshire Transport and Access Group) – worked with the local bus company to get clear signage in buses to show which areas were priority for wheelchair users, backed by training of bus drivers by disabled people, which made it easier for wheelchair users to travel.

This commitment to inclusion matters to whole communities. It is about making human rights real for everyone, every day.

We have undertaken research showing that inclusive local communities, with strong social networks ('social capital'), bring rewards for the whole community: strong political institutions, improved economic development, improved health and more effective public services. Some local DPOs have shown that supporting social participation is much more cost effective than measuring out small parcels of professional time: for example, Leicester CIL is undertaking work suggesting benefits of empowering models of independent living support.

However, disabled people do not have equal access to the processes that make this happen. At worst even our public spaces can exclude people who are 'different': through the physical organisation of space and/or through rules that exclude people who behave differently – the 'purification of space'. We want communities that include people unconditionally – not only if they 'fit in'. This may require new forms of community activity, open to all.

If local authorities work with Disabled People's Organisations (DPOs) and other partners to support new approaches to participation, there are benefits for everyone.

This guide points to opportunities to develop more inclusive communities – and provides examples of how it's been done, so we learn from each other's ideas and experience.

In a time of funding constraints there are many threats to disabled people's participation: poverty and reduced service support can impede participation; and 'status inequality' (being devalued) can mean disabled people's voices remain unheard.

Even in hard times there may also be opportunities – and this guide aims to identify how to seize them.

We have also produced a guide for local authorities, working with the Local Government Association, in which we encourage them to support and work with DPOs to fulfil core objectives like health and well-being, economic development, environmental protection and civic participation; and to meet their obligations under the Equality Act and the UN Convention on the Rights of Persons with Disabilities.

We outline approaches – from seeking feedback through to full decision-making and leadership by disabled people – and emphasise that to achieve fully inclusive outcomes (i.e. disabled people taking part in society) requires fully inclusive processes (i.e. disabled people participating at all stages in planning and decision-making).



European Network on Independent Living Campaigners

Citizenship and participation: identifying opportunities

An inclusive community is one in which everyone can exercise their citizenship rights to participate – socially, economically and politically. On each, there may be opportunities in local areas through recent changes.

1. Social citizenship

Disability Rights UK's research shows that contemporary local communities can only be strong if their diversity is considered and valued:

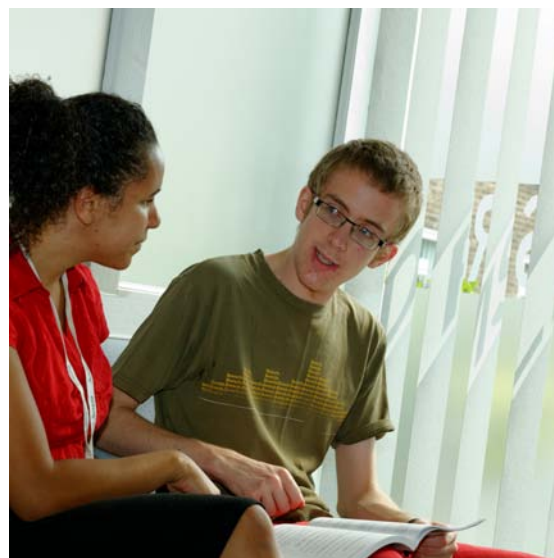
- The idea that a local community is either strong or diverse is a myth. There is a need to move beyond idealised, traditional notions of homogeneous 'community'.
- One in five of the population lives with disability or a long-term health condition; and in an age of 'superdiversity' many families live with multiple experiences of disability, as well as diversity of faith, ethnicity and sexual orientation.
- Strength comes from shared activities and goals – from solidarity – not just similarity. People may come together in identity groups (as 'disabled people') for particular ends but joining forces across differences of identity, on specific topics, can be at least as important. How local people come together to forge common perspectives, and who is included or excluded, is important.
- Contact between disabled and non-disabled people, on equal terms, with common goals, tends to change attitudes and behaviours towards disabled people.
- Public authorities can enhance social well-being by fostering strong, inclusive local communities.

In England, every local authority area has set up a Health and Well-Being Board, a partnership of clinical and local authority

leaders, with Healthwatch (the consumer champion) involved. This Board oversees local work to set priorities for commissioning health and social care and improve the health and well-being of the whole local community. Each Health and Well-being Board identifies top priority issues – for instance, improving the health of those with poorest health, active participation in the community, overcoming isolation, improving access to fitness and good health.

Organisations led by people with lived experience of disability or long term health conditions can – and often do – promote social networks and mobilise the power of community and peer support, overcoming isolation, enabling disabled people (who often experience inadequate health care) to achieve better health and opportunities.

If DPOs can influence and work with the Health and Well-Being Boards there is a chance of enhancing ‘social citizenship’. According to the Kings Fund, the success of these Boards will rest not on their formal meetings, but on how they relate to people using services and the public (see Richard Humphries, 2014 at <http://www.kingsfund.org.uk/blog/2013/03/how-are-health-and-wellbeing-boards-shaping-their-new-responsibilities>). Local DPOs are in a position to help make that happen



Mental Healthwatch

National Survivor User Network (NSUN), led by people living with mental health challenges, recognised that when people with lived experience are properly involved in shaping their services and communities they live in, their own health and the support available usually improves. NSUN therefore designed the Mental Healthwatch scheme – supporting people with lived experience to get involved with Healthwatch, the health and social care consumer champion, involved in everything from being trained to do ‘enter and view’ visits to local services, to advising on service improvements. By 2014, 150 volunteers and 50 local Healthwatches had got involved in the programme

(NSUN 2014 Mental Healthwatch Handbook: improving mental health with your community. <http://tinyurl.com/l3jy7n8>)

A local DPO could:

- Make contact with their local Health and Well-being Board – see contact list at <http://www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map> – and offer to help with engaging service users and the public. Consider approaching the individual from Healthwatch sitting on the Health and Well-Being Board, or other contacts you may have.
- Aim to offer advice on how people living with impairments/long-term health conditions can feed into priority setting and good practice participation processes.
- Explore opportunities to help shape the priorities for local commissioning of health and social care; and to undertake shared work to enable disabled people locally to improve health, well-being and social citizenship.

In Scotland a series of pop-up think tanks have focused on independent living 'solutions' that make recommendations for seizing the opportunity of integration of health and social care, always linking independent living to human rights. See: <http://tinyurl.com/l1sn7lh>

Partnerships for inclusion

ecdp, a DPO based in Essex, is working through its Big Lottery Lived Experience Volunteer Mentoring Project with a wide range of statutory and voluntary sector partners to promote active citizenship and disability confidence. The project recently brokered new volunteer placements and disability awareness with the National Trust in Essex. Volunteers with differing impairments are using their 'lived experience' to champion access, equality and diversity issues for a local National Trust renovation project. Their input will make the property open to all individuals from all walks of life.

2. Economic citizenship

A successful economic recovery quite simply is an inclusive recovery. As the Prime Minister put it, "What hope do we have in this global race if we lose out on the skills and talents of one fifth of our population? It would be like competing with one hand tied behind our back. What hope do we have as a country if a fifth of our people are excluded from mainstream society?"

Too often disabled people have not benefited even when jobs and skills come on stream in a local area. Disabled people are left till last – either out of work or stuck in low paid, low skilled, insecure employment. Many people living with disability or health conditions want decent employment – a real opportunity of a career (not just a job), with equality, and flexibility if needed to accommodate impairment, such as being able to work when well if you have a fluctuating condition.

We have heard from organisations opening up opportunities for disabled people, including the chance to become gym instructors, or apprentices in banks.

Across England there are 39 Local Enterprise Partnerships (LEPs) – championing economic growth, working with partners to develop skills for employment and create new business opportunities and new jobs. Local Authorities co-own the LEPs with local businesses, and link with partners typically including colleges, universities, chambers of commerce and others [See <http://www.lepnetwork.net/leps/> for a map of the LEPs].

Where local authorities and DPOs have linked up with this mainstream agenda of economic growth it has sometimes paid dividends. For instance, Hartlepool Local Authority had a team supporting people with learning disabilities or mental health challenges into employment, based in social services. As in most areas, employment rates of these groups were very low.

They made a simple change – integrating the team with the economic regeneration department, linking their employment support to actual local opportunities for new jobs, using their relationships with businesses to create new opportunities. As a result the employment rate of people with learning disabilities known to social services reached nearly double the national average – still low in absolute terms, but better than many areas.

DPOs may be able to link up with LEPs and local partners to open up opportunities, for instance:

- Finding out about local Labour Market Intelligence: where are jobs, apprenticeships, traineeships or other opportunities coming up? The database LMI for All provides access to data on this to help inform career decisions. <http://www.lmiforall.org.uk>
- Letting individuals who are in touch with the DPO know the opportunities likely to be available locally.

- Sharing available stories from disabled people who are working, or pursuing apprenticeships [For instance, see Into Apprenticeships at <http://www.disabilityrightsuk.org/news/2014/april/our-new-apprenticeships-guide>].
- Exploring potential funding or partnership opportunities so the DPO could support local employers to retain or recruit; and/or support individuals to keep or secure jobs, apprenticeships, traineeships, new enterprises – or gain new skills or qualifications. Consider mobilising the power of peer support and sharing of stories, as a ‘niche’ for DPOs.

DPOs can help local partners improve economic growth.

The power of peer support

Manchester-based DPO Breakthrough UK offers personalised employment support on people’s own terms ‘we’ll work with you, not make decisions for you’. Support is designed around the clients’ own employment goals and individual needs and is delivered by other disabled people who have lived experience of the barriers of prejudice, environment and lack of support. Policy and practice is based on the social model of disability and clients learn to understand how barriers can be removed to enable them to work in any role or workplace. Breakthrough UK also hosts a ‘Talent Match’ Coach to work specifically with young disabled people who are NEET (‘Not in Employment, Education or Training’) and support them to achieve their employment goals, enabling them to access apprenticeships, vocational training, work experience and volunteering on their journey to employment.

Working with the Local Enterprise Partnership

ecdp a DPO, has engaged with the South East Local Enterprise Partnership (LEP), with the aim of putting people with lived experience of disability at the centre of local enterprise development. ecdp Works is an award winning peer enabled employment training and work placement programme, delivered in partnership with business and the private sector. ecdp is engaged through the LEP with the Structural and European Union Investment Fund Strategy, with the aim of further building this work.

3. Political citizenship

As disabled people we want to move from being recipients of services to citizens, influencers and decision-makers. There has been much discussion in recent years of ‘shifting the balance of power’, ‘choice and control’ and increased power of the citizen – including the disabled citizen. But the experience on the ground is that power imbalances remain. There is a danger that those with greatest needs are least likely to benefit from local opportunities for participation.

Research confirms that disabled people need accessibility and often individualised support/adjustments to be able to contribute. Rights to support and adjustments are therefore important precursors to citizens’ participation.

There is also a need for an attitudinal shift: moving away from the discourse describing disabled people as either ‘productive’ (active citizens) or ‘parasitic’ (dependent); and instead thinking of disabled people in terms of the assets they bring and the contributions they make. For instance, disabled people are twice as likely to be carers as non-disabled people. When we asked for examples of inclusive communities we were told about inter-generational projects – for instance, young people with learning disabilities supporting older people attending lunch clubs.

Leadership support

When Radar (now Disability Rights UK) developed a leadership programme led by and for people with lived experience of disability, demand was strong: over 500 people took part over 4 years. Over 80% said the programme made them more likely to pursue their leadership aspirations. Many did. For instance, “Thanks to the programme, I have become a Trustee with the Milton Keynes Carers’ Group, Bucks Carers’ Group and ethnic minority organisations have contacted me to become a trustee” (Marzia Sayani).

Some DPOs have led changes in local (and national) debate about disabled people’s lives. Disability Cornwall & Isles of Scilly has created a series of films based on interviews with disabled people about their lives and history, which show powerfully ‘where we have come from’ as disabled people, and demonstrate both the sense of exclusion and the possibilities for change.

<http://www.disabilitycornwall.org.uk/research>



The concept of a ‘right to contribute’ places a helpful emphasis on the support and attitudes that enable people to contribute according to their potential.

Capacity building and community development can support disabled people’s participation, including by expanding the leadership base of disabled people, and connecting people through networks.

Local Leadership

Community Futures Kent facilitates local leadership by disabled people and runs adult learning programmes to support emerging leaders. The programme is called Getting on Board: Strengthening Communities and Local Democracy. They worked with 19 elected councillors and 7 members of Parliament, undertaking visits to local councils, parliament and 10 Downing Street. They received the Adult Learners' Week award for family and community learning 2014 and are keen to share their work with others <http://tinyurl.com/lof43sb>

Political citizenship

When Gavin Harding, who has a learning disability, was elected as a local councillor in Selby, Yorkshire, he brought to the role a history of activism both on behalf of people with learning disabilities and on behalf of the whole community. He was able to contribute beyond disability rights issues, moving into a position of wider influence.

'Partners in Policy-making' is a similar national programme which has helped develop a cadre of disabled people, including people with learning disabilities, and their allies who have both the understanding of policy processes and the self-confidence and mutual support to engage in policy advocacy in their local communities <http://tinyurl.com/pcvw8yt>

One approach is to aim for a critical mass of disabled people engaging with local authorities, advising and, crucially, becoming decision-makers. Arguably if more disabled people are in positions of influence across organisations, we might see a world that 'factored in' accessibility, equality and universal design from the outset. It is not enough to have one or two disabled people in senior positions - there is a risk they will 'pull up the ladder behind them' (as has sometimes happened with women leaders, for example).

But if we have more disabled councillors, school governors, non-executive directors and also have disabled people participating in major developments from the outset – then local decision making could really change.

The Local Government Association has a long-standing Be A Councillor campaign which recognises that local government is only as vibrant, effective and relevant as the people elected to run it. The campaign works to increase the talent pool from which councillors are elected and ensure councils better represent their electorate.

There is guidance available for people considering becoming a councillor – including a specific document for disabled people <http://tinyurl.com/ouw9yse> – as well as guidance for those talent spotting and recruiting candidates for election. Councils, regional organisations and local parties are encouraged to support the Be a Councillor campaign by running a local version tailored to their area.

The LGA is also working the Government Equalities Office on a pilot programme to encourage more disabled people to consider becoming a councillor. Potential candidates will be mentored by councillors and political experts <http://tinyurl.com/a33czuv>

If more disabled people do become local councillors and non-executives, we might see a change in the conversation: away from seeing ‘disabled people’ as ‘other’ (witness the Mayor of Swindon’s question in 2014 “Are we still letting Mongols have sex with each other?”) or a ‘vulnerable’ minority, and towards recognising that disability and health conditions are an ordinary part of human experience, which affects virtually every family, and absolutely every community.

Through that lens, it simply makes sense to make all decisions inclusive decisions. Whether it is a planning decision on a new housing development, or a public engagement exercise on crime prevention, it will simply be more effective if inclusion is considered from the beginning. disabled people’s involvement in decisions is the simplest way of making sure that happens.

The characteristics of citizenship

Citizenship participation is about unconditional inclusion; not being 'included' only if we fit in. For instance, if you have a mental health condition and can succeed at work as long as you keep your condition a complete secret, that is not full citizenship participation; it is conditional. Our approach to citizenship is rooted in human rights, in particular the UN Convention on the Rights of Persons with Disabilities. Article 19 states:

'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'.

An inclusive community is one based on participation as a human right; and on the rights in the Convention to education, employment, housing, family life and more. It helps fulfil the spirit and requirements of the Public Sector Duty under the Equality Act, which expects public sector organisations (with partners) to advance equality, human rights and good relations.



Why would decision-makers listen?

One in 5 of us is living with a disability or long-term mental or physical health condition. Any decisions that exclude us mean we are less able to participate, as consumers and as citizens. And so, in many cases, are our families and friends – none of us go the restaurant that turns away our friend with a guide dog – we go somewhere else and do not return; none of us can live in the housing that is not accessible for our family member. The community is the poorer for losing our involvement. And changing the housing development / transport development / restaurant policy later, after realising it is not inclusive, is far more expensive and troublesome than getting it right first time.

All main political parties acknowledge the importance of listening to and involving disabled people, for instance:

"We want policy to reflect the real-world experiences of citizens, and harness public engagement with the policy-making process. We are therefore seeking to strengthen and broaden input to policy and strategy development from the lived experience of disabled people, and also from people with particular expertise on disability issues in accordance with the principles of open policy-making". (Mike Penning, former Minister of State for Disabled People, 2014)

"Engaging disabled people directly in the design and review of the policies that affect them, and devolving decision-making to local level, will ensure disabled people take a central role in the management of their own lives. (Kate Green, Shadow Minister for Disabled People, 2014, <http://tinyurl.com/ocgoblu>)

Disabled people are not a discrete, homogeneous group. We may move in and out of disability. And as the older population grows, more and more people are living with one or more impairments; it is part of life. The number of people with three or more impairments is set to rise by a third by 2018 (Department for Work and Pensions, 2013).

Local authorities have responsibilities under both equality legislation and the UN Convention on the Rights of People with Disabilities in relation to the participation of disabled people.

“The United Nations Convention on the Rights of People with Disabilities can be used by disabled people and their organisations as a framework to negotiate and influence national and local matters – for example when a local authority is proposing to withdraw essential social support services which will affect disabled people’s rights to live independently” (Equality and Human Rights Commission, 2010).

Local decision makers who genuinely think about their local population can only succeed if they consider this diversity, of which the experience of disability is one very common and important strand.



How can disabled people and DPOs be involved?

Our review of evidence and practice revealed different levels of citizenship participation:

- Engagement to seek feedback
- Focused participation
- Wider participation and decision-making
- Tackling barriers to participation
- Being at the heart of governance

These are vital to support local authorities in creating inclusive communities and to social, economic and political citizenship.

Within each there may be roles for DPOs with the appropriate skills, links into the local community and local knowledge to support the local authority and its partners. Whilst we have identified just some roles there may be many more for particular DPOs in particular areas. Our assumption is that a DPO could offer some roles as part of a voluntary sector grant or other funding arrangement, whilst others are projects which would

require distinct funding (see Appendix A). A DPO can influence local decision makers to allocate resources, as well as engaging in bidding or commissioning processes.

Different DPOs have different historical and current relationships with their local authority/s. Sometimes that is a relationship of voluntary support and advice in relation to local authority services, sometimes a relationship governed by generalist grant funding, sometimes specific funding to run services or projects and sometimes a professional relationship where the DPO bids to undertake specific advice or support roles.

Obviously that relationship will affect potential future roles. However, the first task will undoubtedly be to convince the local authority that engagement and participation in decision-making are valuable roles for disabled people.

Local authorities will be aware that only a few of them have an excellent track record in this respect, although some definitely do. Some may feel that this is not an area where they need to concentrate energy as the benefits are not obvious. DPOs are best placed to put the case that services, both specialist and general, are more effective, more efficient and make better use of public money when they are informed by disabled people as service users and local residents. And that the more disabled people participate in the local authority the more they are likely to understand and appreciate the organisation.

Disability Rights UK has produced a guide for local authorities on social, economic and political citizenship and the importance of making communities more inclusive. This spells out the value of disabled people's participation.

Some DPOs engage at a strategic level with local authorities and more widely with partners, to achieve multiple benefits.

Confident Commissioning (SENDPO 2014) describes a strategic partnership between Spectrum (a DPO in Hampshire) and the local council and examples of user-led commissioning.

<http://tinyurl.com/mvwo7ac>

Reporting hate crime

In Lancashire, joint work by DPOs and agencies including the police and Crown Prosecution Service has led to increased confidence amongst disabled people to report hate crimes and harassment. Disability groups worked together with multiple agencies to set up third party reporting sites i.e. safe spaces for disabled people to report harassment and hate crime, coupled with training for 3000 front-line police officers to respond to crimes as 'hate crimes'. Under section 146 of the Criminal Justice Act sentencing can be tougher if a hate crime motive is established. This collaboration between DPOs and statutory agencies has led to a significant increase in reporting in Lancashire: from 64 reports of disability hate crime in 2012-13 to 172 in 2013-14. Stephen Brookes, Co-ordinator of the Disability Hate Crime Network, and directly involved in the training and third party reporting developments, observes that the keys to success are a multi-agency approach and peer to peer reporting, where disabled people are trained as volunteers in DPOs to take reports on hate crime. Stephen comments that with third party reporting centres "you get disabled people talking to disabled people, the reports work and the police are involved so you get an increase in confidence and reports are taken seriously." The Disability Hate Crime Network set up an accessible website to share good and bad practice and outcomes relating to disability hate crime nationally. Disability Rights UK has produced guidance on how to set up third party reporting centres through a multi-agency approach. See:

<http://www.disabilityrightsuk.org/how-we-can-help/publications/lets-stop-disability-hate-crime-guidance>

Engaging with disabled people to get feedback

Public bodies including local authorities have a long history of engaging with residents including disabled people to get feedback on existing services. Many have officers and even teams dedicated to engaging with residents and gauging resident satisfaction.

The benefits of this have been widely documented in terms of understanding from a user perspective the experience of a service. Disability legislation, including the Disability Discrimination Act and the Equality Act as well as the UN Convention on the Rights of Persons with Disabilities have encouraged and, in some cases, required public sector organisations to engage with disabled people particularly when looking at developments likely to have an impact on disabled people.

Radar (now Disability Rights UK) produced a substantial guide in 2009 for public bodies on engaging with disabled people: Lights Camera Action. Whilst the

law has changed slightly (from the Disability Discrimination Act 2005 to the Equality Act 2010) the examples and methods remain highly relevant. The guide provides very practical information for local authorities on engaging with disabled people to achieve impact and greater equality <http://tinyurl.com/l34vy59>

Local authorities often use cost-effective methods including online feedback, resident surveys and specific focus groups, sometimes run by large national polling organisations. Some authorities have concerns about this losing the local context. When feedback can be disaggregated to identify the responses of disabled people some authorities have found that their satisfaction levels are lower than non-disabled people. This disaggregation is useful to enable local authorities to understand whose satisfaction is low and why – and to take action as a result

Methods of engagement

In 2013-14 Disability Rights UK worked with Marie Curie, who wanted to find out the end of life, palliative care experiences of disabled people, from both them and their families. We sought to discover their experience of the transition from existing packages to those more relevant to end of life journeys. Surveys, focus groups and interviews were used. Disability Rights UK was able to draw on our experience and knowledge of disabled people's lives, and continued access to independent living during the final stages of life to inform the research design.

Marie Curie will draw on the results to shape future work and will make recommendations for change.

What are the potential roles for disabled people's organisations?

DPOs are well placed to advise local authorities on the best ways to gain feedback from disabled people in relation to both specific services and general satisfaction.

Many local authorities will be keen to improve how they approach disabled people for feedback to ensure they have good quality information, and will be looking for ways to improve their satisfaction rating amongst disabled people.

If the local authority is using an outside organisation, possibly a national one, to undertake larger pieces of work, such as resident satisfaction, then a DPO may be well placed to advise them on the procurement of such an organisation to ensure that it effectively reaches disabled people, or to advise the organisation commissioned to ensure that they effectively and positively reach disabled people. This could add significant value to such a process and ensure accurate and useful outcomes. DPOs can offer to work jointly to frame questions based on known concerns of disabled people, and can advise on the best ways of asking about disability in wider resident (or indeed local authority employee) surveys.

A DPO could be in a position to bid to run some of the engagement and feedback projects for a local authority. As a local organisation with good links into the community and appropriate professional expertise a DPO could run anything from questionnaire-based projects through to one-to-one interviews, focus groups or larger events. Disabled people can be more likely to open up to a focus group leader or interviewer who is also disabled.

Local authorities rank themselves in terms of their progress against national benchmarks – for instance the Autism Strategy <http://tinyurl.com/nltwmbw> - this includes rating on how well they are addressing criminal justice issues, employment and housing. This kind of rating of opportunities for inclusion is a further area in which DPOs could have a useful input. The UN Convention provides a set of standards against which a local authority can measure progress, which again DPOs can advise on.



Focused participation

Many local authorities have moved on from basic engagement/feedback requests to understanding the benefits of residents participating in service design, delivery and in some cases strategic policy development. This has been particularly true of work with disabled people and disability organisations. The significant benefits of real advice and participation by disabled people on specific issues are acknowledged by effective local authorities.

Many acknowledge that proactive, clearly focused, well-resourced participation, leading to specific outcomes, is the foundation of more effective services that help make communities inclusive for all. Having the service user, or simply those with personal and significant disability expertise, involved in service design or specific advice puts inclusion at the heart of the service.

In some local authorities this participation is long-standing and

relates to issues which have a well-documented impact on disabled people – such as the built environment and local transport plans. Whilst these may be seen as the ‘traditional’ areas for participation of disabled people, this does not reduce their importance for inclusion; a fact acknowledged by government who have identified both built environment and transport as key issues for inclusive communities.

Under equality legislation local authorities are obliged to pay due regard to equality in key decision-making. This public sector equality duty is regarded as a strong element of good decision-making and when not undertaken effectively has been the subject of a number of legal cases. The early participation of disabled people in considering the equality impact of key decisions can bring real benefits: ensuring that ‘due regard’ is effectively paid, bringing effective outcomes including improved decision-making and more inclusive communities.

City of London

The City of London Corporation is committed to making the Square Mile an inclusive environment for all and to eliminating any inaccessible design which prevents disabled people from participating fully in society. The City's Access Team promotes inclusive design principles to ensure that buildings and external environments meet the access needs of everyone including people with physical, mobility, sensory, cognitive and learning impairments. The team provides professional advice on access adjustments and improvements to the City of London's public buildings, as well as the City's Streets and open spaces, some of which fall outside the business district.

The Access team works closely with the City of London Access group (CoLAG) most of whose members have a disability and live, work or regularly visit the City. Ranging from when physical access improvements are under consideration through to public transport issues, the input of CoLAG members is keenly sought and their opinions have influenced some major initiatives. Views of the Access group are also requested when consultative documents present themselves, emanating from local policies, central Government or such bodies as Transport for London.

The Access team facilitates the group's bi-monthly meetings in suitable and accessible meeting rooms at the Guildhall complex. In addition to the 'main' meetings, the Access team professionals will often arrange a sub-group meeting to discuss a major planning application or transport issue as well as inviting members to accompany them when touring the City's construction sites as part of the Considerate Contractors Scheme Access Awards ceremony.

What are the potential roles for disabled people's organisations?

There are potentially straightforward roles for DPOs in relation to focused participation.

Many local authorities will only have engaged with a small number of disabled people and will be aware that if they require effective advice on new service or policy developments they need to engage a wider spectrum. Identifying that range could be both difficult and expensive for a local authority. A DPO is perfectly placed to work with the local authority to find a representative range of disabled people, reflecting the local community and different impairments and situations, providing of course that the DPO

itself both recognises the considerable diversity among disabled people and actively seeks to ensure everyone is included. The DPO could do this by sharing its expertise, or by itself being the conduit, the 'honest broker' who could improve the quality of the participation and, crucially, the advice and information obtained. This means understanding what the local authority requires as well as disabled people's aspirations. Disabled people are often much happier participating in discussions about services or policies conducted by an independent organisation than by the local authority itself. The DPO can propose that it be commissioned to take on this role.

Wider participation and decision-making

Whilst the participation of disabled people on issues with a clear 'disability impact' is of tremendous value, there can be even more value for us, as disabled people, participating in wider issues: for instance, the work of the local authority around economic growth, health & well-being and environmental protection.

Many local authorities have taken the decision to facilitate the participation of disabled people in wider decision-making and scrutiny functions. This recognises that any development (not only those 'obviously' of significance to disabled people) will work best if it works for everyone, and that disabled people are diverse and multifaceted, experience barriers in a variety of ways and can make a valuable contribution by looking at the full spectrum of local authority activities. This is one of the most effective ways of building inclusion into local services and also promoting social, economic and civil citizenship.

London Borough of Sutton

The London Borough of Sutton's Equality and Diversity Forum is a formal advisory mechanism of the Council that includes representatives from the Borough's equality and diversity groups, such as Sutton Centre for Independent Learning and Living (SCILL), Sutton Vision, and the Smart Enterprise. The Forum meets up to four times a year and is chaired by Councillor Adrian Davey.

The Forum provides advice to the Council, its committees, officers of the Council and to other public service providers on equality and diversity issues. Recently, the Forum has considered issues such as Sutton Station Redevelopment and disability access, and developed a programme of equality and diversity events [<https://www.sutton.gov.uk/index.aspx?articleid=18683>].

London Borough of Hackney

A project by the Scrutiny Committee in Hackney was successful in winning an award from the Centre for Public Scrutiny in 2013. This focused on the take-up of youth services by young disabled people. Rather than spending time in the town Hall having meetings, councillors found innovative ways to hear the views of young disabled people first-hand. This included Members attending Hackney's Primary and Secondary Disabled Forums to hear about the activities they take part in and the barriers to accessing the services they want. Members also attended two site visits to Hackney Ark, Hackney's Children and Young Person's Centre for Development and Disability, and attended an 'Activity for All' event at Britannia Leisure Centre

As a result of that close listening, the committee's recommendations were clear and smart and led to changes such as improved training for staff and outcomes such as a higher take-up of services by young disabled people.

The 2012 Legacy

The London Legacy Development Corporation aimed to create the most accessible park in the UK (the Queen Elizabeth Olympic Park), as well as local developments including life-time homes (readily adaptable) and jobs for a diverse range of local people. All projects, from the velodrome and stadium to cafés, had to meet their inclusive design standards; some had specific access features, like a pool pod lift. This approach was developed through involving disabled people across the work. By 2014 over a million people had visited the park. All contractors working on the projects had to meet targets for employing disabled people: some were above target, employing (for instance) 10% disabled people or above. Using the power of contracting to drive up disabled people's participation can be a helpful lever.

When disabled people work with the local authority in making decisions about key services and policies, this can impact directly on citizenship opportunities.

Transport for London Independent Disability Advisory Group (IDAG)

Serious moves have been taken in London to make transport more accessible – from creating the largest fleet of accessible buses in the world to some operating companies, like Docklands Light Railway, offering disabled people a test journey, with someone to show them the route, to try a whole journey and make sure it's feasible. These developments would not have happened without the participation of disabled people.

Transport for London has developed IDAG, which is an independent group whose members are recruited on a formal basis for their expertise in relation to disability equality. They are all disabled people.

The remit of the group is across Transport for London, and agendas and work programmes are set by the group members themselves.

The independent structure of IDAG is one of the first of its kind in a transport organisation – TFL take the view that this is about putting into practice the principle of involving disabled people in all services.

This is a new, and sometimes challenging approach for local authorities. If undertaken effectively it can result in high calibre and well informed decision making which strongly supports the development of inclusive communities. It takes 'nothing about us without us' to its logical place.

Obviously, each local authority has ultimate decision-making mechanisms which cannot be overridden by other arrangements or structures, but by including disabled people within decision-making processes and transparently and carefully considering any recommendations, there can be real benefits to the outcomes.

This approach, more than all others, is likely to lead to more inclusive communities because it cuts across all the key areas of social, economic and political citizenship and ensures that disabled people are at the heart of decisions. The decisions which disabled people make can have a significant impact on social and economic citizenship, to support more inclusive communities.



London Borough of Hounslow

London Borough of Hounslow set up a Disability Community Forum (DCF) to act as a vehicle for local disabled residents to register their concerns on issues which impact on the quality of their lives. The forum also assists, advises and supports the Council to meet the general and specific duties arising from the Equality Act 2010.

The forum is a sub- committee of the Cabinet and has a membership which includes councillors and 5 user representatives from the community and voluntary organisations operating within the Borough.

This structure increases access to democratic participation for disabled residents in council functions and services. Representation from all the parties also means ownership and commitment to disability equality from all political parties. It also provides the committee with clout and ensures officers attend and act on promises made to the community.

As an advisory body the DCF advises and make recommendations to the Cabinet and refers matters to other relevant council bodies, as appropriate. There are four meetings per year. Special focus groups are set up between meetings to consult and engage local disabled residents on key changes the council is proposing, such as changes to web page design, customer access to Hounslow council, and town centre regeneration.

The DCF is also supported by partner agencies like the police, Healthwatch Hounslow, Hounslow Homes, Transport for London, pan disability organisations, organisations representing residents with a learning disability, blind and partially sighted residents, and residents with autism. Partners may propose items to be considered by the DCF and request opportunities to respond to public concerns or policies affecting their organisations.

At the AGM, disabled residents set the forward plan and priorities for the coming year. About 45 members of the public attend the meetings regularly. They include those with physical disabilities, learning disabilities, mental health issues, blind and partially sighted and deaf residents. Each meeting covers priorities identified at the AGM but special topics such as access on the buses and hate crimes have been additionally hosted at the request of disabled residents at these meetings. These special topic sessions are joint partner events and have secured optimum attendance from 250 disabled and elderly residents.

What are the potential roles for disabled people's organisations?

This kind of broader participation and decision-making can bring a range of roles for DPOs.

Local authorities may not understand the benefits of disabled people's participation beyond 'traditional disability issues' or those services used by disabled people in higher percentages than non-disabled people. So a local authority Environment Department may not even consider that talking to local disabled people about how to improve waste collection would be beneficial. In fact some local authorities who have done this have discovered that removing some of the barriers experienced by disabled people to recycling and refuse services

benefit the whole population. So there is a potential role for DPOs in making the 'business case' to local authorities for facilitating the participation of disabled people across a wide range of services.

Once a local authority is convinced of the benefits, then there is a definite role for the DPO in helping and supporting the local authority to facilitate inclusive participation.

How this happens would depend on the particular areas that the DPO highlights benefiting from participation and the approach selected by the local authority and DPO. This could be something as simple as the DPO negotiating with the local authority to facilitate focus groups on a particular service or policy area. It could be the DPO

working with the local authority to set up specific advisory groups. It could focus on ensuring that the Local Enterprise Partnership (LEP) has the input of disabled people or that there are disabled people represented on the Health & Well-Being Board.

It could be, as with Blackpool Disability First, the DPO convening a group of senior players from local public sector organisations (local authority, police, health, education and more) to take forward effective partnership work to increase inclusion, resulting in everything from more accessible trams to bus driver training.

It could be DPOs getting involved in commissioning, from identifying local needs to co-producing the commissioning strategy to meet them. Recent work by nef on 'Commissioning for outcomes and co-production' helpfully draws attention to the importance of initiatives that both meet specific 'service objectives' (like mental well-being) and contribute to 'high level' strategic objectives, like social, economic and environmental progress (the so-called 'triple bottom line').

SENDPO (the South East Network of DPOs) has produced a toolkit for DPOs and commissioners on how to take forward disability confident commissioning <http://tinyurl.com/mvwo7ac>

The huge advantages that DPOs have is their knowledge and links to the local community of disabled people, and their independence.

It is important that disabled people and the DPO are at the heart of identifying which policy and service areas would benefit from participation. It is disabled people themselves who understand which policies and services need particular attention. Of course, the UN Convention offers a comprehensive set of rights-based standards from which to assess current performance.

In reality local authorities will have identified themselves which areas they will review. In that case, the participation of disabled people may be more reactive. It is essential that disabled people asked to participate are not just asked to comment on a done deal! Whether they already have

a long-standing relationship with the local authority or not, DPOs need to be able to explain why that approach would not necessarily be effective in improving services or inclusion.

The scrutiny function of local authorities is one of the most wide ranging opportunities to influence policy, service design and delivery. The vast majority of local authorities will have scrutiny committees which look at different services and are predominately made up of councillors. In some areas they also undertake in-depth scrutiny enquiries or have scrutiny commissions.

All these structures can co-opt, or call as witnesses, expert individuals who cannot vote but who can provide evidence to the committee. The participation of disabled people within the scrutiny function can bring very significant benefits and there is a clear opportunity for DPOs to support the local authority through:

- identifying which elements of the scrutiny function would benefit from participation by disabled people

- helping them find appropriate disabled people to be co-opted onto committees or called as witnesses in scrutiny enquiries
- supporting the function themselves and
- ensuring that scrutiny officers who provide information for the councillors are well briefed on disability issues. The DPO could be in a position to undertake this service.

Being at the heart of formal decision-making is just a step further than active participation. Where DPOs can support a local authority in setting up a local disability forum this formalises the forum so it goes beyond advice to become part of the local authority structure, and therefore the advice has to be formally considered and reported upon.

In some local authorities there have been specific forums to look at key issues of interest to disabled people, for example disability transport forums and care user forums. Some have been constituted as part of specific council structures. Whilst

local authorities are trying to reduce bureaucracy and cost they are also trying to increase accountability. DPOs have a potential role in ensuring that the value of such forums are recognised in terms of their ability to increase accountability, improve services and make communities more inclusive whilst at the same time not

setting up an additional layer of expensive bureaucracy.

DPOs may wish to consider discussion with their local authority about forums to address both 'traditional' disability issues, like transport, and wider forums which allow disabled people to be involved in decision-making.



Tackling barriers to participation

Traditional and even less traditional methods of engaging with residents often present particular barriers for us as disabled people. Efforts to identify and overcome barriers, working with disabled people, are well-documented. Overcoming barriers often centres on early discussions with disabled people about positive participation, accessible and focused communication, removing physical barriers, providing appropriate adjustments for face-to-face participation and necessary support and resources.

Some Local Authorities have found that simply removing barriers may not necessarily bring disabled people flooding to participate. Outreach work, building confidence and making the case for how participation may improve services and make communities has been needed.

Increasingly, service delivery, engagement and participation across local authorities take place electronically, through

online services, electronic communication or social media. Some disabled people appreciate this: it is how some younger people expect to participate. It can be helpful, for instance, for people who find face to face contact more challenging (like some people with autism) or who are unable for health reasons to travel. For others it creates significant new barriers, with access issues relating to new technology, costs of accessible technology and unfamiliarity.

Many local authorities have gone beyond simply removing the barriers and have worked with disabled and older people to identify issues in using electronic communication, and to find ways to encourage their use, maximising the benefits both for individuals and for the community more broadly. Being on-line is one important part of social and economic citizenship, offering access to everything from cheaper shopping deals to knowledge and social opportunities.

Leicester on line

CareOnLine is a free service provided by Leicestershire County Council which introduces computers and the Internet to disabled adults and their carers, especially those with no previous experience or who cannot leave home.

CareOnLine is an outreach service providing a complete package of advice, technical support and training into people's homes, to help overcome fear of technology and encourage learning. Their website provides a wealth of information and advice for the community. Learning to use new technology gives disabled people equal opportunities and the chance to communicate and take part in their local community and more widely which they might otherwise find extremely difficult.

Just one example is that CareOnLine consulted Blaby District Council and the Tenants Association at Jubilee House Sheltered Housing scheme on whether they would like a computer. Colin Norman, the chairman of the association organised a meeting between CareOnLine and residents to discuss the idea and agree what the residents wanted.

CareOnLine installed a computer in the community lounge and residents were offered training. Fourteen people aged 65 to 85 attended the first course to begin developing skills in internet use, e-mail and word processing.

What are the potential roles for disabled people's organisations?

With the opportunities that online participation, social networks and electronic communication present at low cost, this is inevitably a growth area.

However, there is a strong awareness that this often excludes some groups including some disabled and older people and those with English as a second language.

This offers a significant potential role for DPOs in ensuring that the online and electronic communication utilised by local authorities meets the highest access standards. This may mean offering a service to local authorities in terms of auditing the accessibility of their websites and offering suggestions for improvement. DPOs are likely to be the only people who could provide a range of local disabled people to user test websites and electronic communications. In many ways this is the new version of access auditors and whilst there are commercial organisations to offer this service they are unlikely to draw in the skills of local disabled people who know the services well.

DPOs would obviously need to ensure that their testers were well skilled in identifying access barriers within websites and online/electronic communication, to ensure that they were providing a high level service.

The other potential role is in supporting the local authority to provide, or providing for them, projects to increase the skills of local disabled people in utilising websites, social media and electronic communications. There are many examples of local authorities doing this, but sometimes without the input of disabled people. This kind of project is much more likely to be successful if it involves those with strong links to local disabled people, a user based view of the challenges, and expertise in accessibility.

Disabled people at the heart of governance

Engagement, participation and involvement in decision-making are of immense value in ensuring that services and decision-making foster inclusive communities. However, the ultimate role in decision-making within local areas is through the ballot box and standing for election. A truly inclusive community is one which has maximum participation by disabled people in democratic processes and ensures that disabled people are represented within governance structures.

Some of the barriers for disabled people to participating in elections are cultural or relate to the nature of political engagement – for instance, it is only recently that some elected officials have begun to feel safe to be open about hidden impairments like mental health issues – whilst others may be practical or physical.

Work undertaken by the charity Scope during the 2010 election identified that there were accessibility barriers at 67% of

polling stations surveyed. That's an improvement of only 1% on the previous general election, and just 2% on the election before. 47% people who told them about their postal voting experience reported accessibility issues. In some ways, things had got worse: in 2005 70% of polling stations had large ballot papers on display, but this dropped to only 49% in 2010.

Significant work has been undertaken by the Electoral Commission to identify the barriers for disabled people. They suggest straightforward and more innovative ways to tackle them and ensure disabled people are aware of the adjustments which can and have been made.

Whilst democratic participation is a cornerstone of an inclusive community, a further indicator is the number of disabled people who seek to become elected representatives. Disabled people are actually better represented as local councillors than in many other professional roles: the annual survey undertaken each

year normally records in the region of 10% reporting experience of disability. However, it is widely felt that this is related to the fact that councillors are much older than the general population on average. The representation of young disabled people amongst councillors is very low.

What are the potential roles for disabled people's organisations?

There are several potential roles for DPOs in relation to participation in voting and standing as councillors, police and crime commissioners, elected mayors and other public roles.

On voting, DPOs could advise local authorities on ensuring programmes to encourage voter registration succeed in increasing the number of disabled people registered. They could also provide expert advice on accessibility of not only polling stations but also publicity about the election and postal voting. They could advise on access issues relating to the counting of the vote to ensure that disabled staff can undertake this role and

that disabled people can observe.

When it comes to encouraging more disabled people to stand for elected office, DPOs are perfectly placed to advise local authorities on accessible publicity, to ensure this reaches and encourages disabled people and to run events for disabled people to provide them with information about what standing for elected office and being a councillor means. Mentoring and shadowing to build confidence and knowledge can also be very useful.



Access to elected office fund

The access to elected office for disabled people fund was set up by government in 2012 to run until March 2015. The fund offers individual grants of between £250 and £40,000 to disabled people who want to be considered for selection as candidates for an election, or are planning to stand for election.

The fund will cover certain costs that a disabled person who wants to stand for elected office will have to pay, to help fund the additional support that they may need when trying to get elected. Without this support, a disabled person may face an extra barrier that a non-disabled person would not face.

The fund covers the following types of costs:

- transport-related costs (for example, the cost of using private taxis if you cannot use public transport or drive, or extra parking charges if you have limited mobility)
- support-related costs (for example, the cost of extra train tickets or another hotel room for your personal assistant)
- communication-related costs (for example, a British Sign Language interpreter)
- technology-related costs (for example, a screen reader or voice-recognition programme)

Conclusion

DPOs are centrally placed to support social, economic and political citizenship by linking to the priorities of local authorities and other local partners, from business to health and skills bodies.

In the past, DPOs typically had strong links with Social Services Departments – and many still do have important relationships with them. But the world has changed:

- Priorities for commissioning health and social care services are set by Health and Well-Being Boards – and commissioning is done by Clinical Commissioning Groups (CCGs)
- The economic agenda – jobs and skills – is taken forward by Local Enterprise Partnerships (LEPs), which are co-owned by local authorities
- There are opportunities to influence and get engaged across a much wider agenda than ‘traditional’ disability issues, from the environment to major infra-structure developments.

Inclusive communities benefit everyone: they contribute to the area’s health, economic growth, and strength of democratic engagement. DPOs can promote these benefits to local authorities and play major roles in helping to make them happen. This can be done through different levels of participation of disabled people; from consultation on pre-existing plans through to decision making and democratic engagement. The higher the level of participation, the fuller the inclusion is likely to be. It is by public authorities working with disabled people and our organisations that we are likely to see a step change in inclusion.

This is about making human rights real for everyone, every day.

Appendix A: Funding opportunities

The Disability Action Alliance publishes funding opportunities useful to DPOs [<http://disabilityactionalliance.org.uk/funding-opportunities-for-members/>].

Locally, it can be useful both to influence priorities of the Clinical Commissioning Group and the Local Enterprise Partnership (see sections above), and to identify opportunities and explore ways of seizing them. Building partnership can be very useful.

Going forward, Disability Rights UK is campaigning for better opportunities for grassroots organisations in both independent living and employment and skills support, through peer support and genuinely personalised support led by disabled people.

In 2015 the Big Lottery will be launching a new independent living research fund.

Appendix B: Reflective questions for DPOs

What are the enablers of inclusive communities?

You may want to consider:

- The opportunities and priorities locally: for instance, what are the priorities of the Local Enterprise Partnership and the Health and Well-being Board? Are there opportunities to get involved in local Scrutiny?
- Frameworks of rights: the UN Convention, the new Care Act, the Equality Act – and how to make them real for everyone, day to day
- What you can offer specifically
- The support disabled people may need to share their lived experience and ideas, from peer support and mentoring to leadership development

What are the barriers to inclusive communities and how might you overcome them?

You may want to consider:

- Access in every sense
- Financial inclusion, including welfare system complexity and resource constraints
- Geography
- Lack of support
- Who are your allies locally?