

# Effective engagement toolkit

How to ensure meaningful participation of people with disabilities in your work



**Leonard  
Cheshire**



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# Welcome

Hello, I have something I want to share!

**The way in which the disability sector works with people with disabilities and the organisations that represent them is changing. At Leonard Cheshire we believe that this is long overdue because the views of people with disabilities should be at the heart of everything that we do!**

The United Nations Convention on the Rights of Persons with Disabilities and its obligations for inclusive and accessible development creates many opportunities for Leonard Cheshire, those we work with and those we serve, to gain a deeper knowledge about the issues facing people with disabilities and respond confidently to these issues from a rights based perspective. However, in order to do this there needs to be a cultural shift in our behaviour, language and processes.

Despite our best efforts we know that making the adjustments needed is not always straightforward. This toolkit aims to be a practical 'living' resource for anyone with or without a disability, organisation or individual, committed to ensuring the voice of people with disabilities is front and centre of their influencing work.

These structured and simple to use guidelines have been developed in consultation with Leonard Cheshire's teams and partners, the Campaign Steering Group that supports us, and a diverse working group set up to lead a process toward greater engagement with Organisations of Persons with Disabilities (OPDs). It is hoped that this toolkit will ask more questions than it answers – opening the door for greater discussion, dispelling fear and encouraging creative thinking.

I very much hope that you will find this toolkit useful as well as helping you to reflect more deeply on issues of equity, inclusion and accessibility in your workplace, at home, and in the community.

**Dr Ruth Owen OBE**  
Chief Executive



## How to use this toolkit

**This toolkit is intended to be a guide that can be adapted as needed to fit project and collaborator's requirements and needs. It provides step-by-step guidance on influencing approaches and OPD entry points, quick guides on disability movement context, 'how-tos' and concise, good practice guidelines with links to in-depth information for further learning.**

As we hope this toolkit will be used by the widest of audiences, we have used the terms 'people with disabilities' and 'organisations of people with disabilities' throughout, since these are used by the international community. However we recognise that individual countries, such as the UK, have their own preferred and recognised terms such as 'disabled people' and 'disabled people's organisations' (DPOs).

Each section is a standalone printable guide. A list of useful resources and links for further reading can be found in the **resource appendix**.

Special thanks goes to members of Leonard Cheshire's Campaign Steering Group whose consistent support and enthusiasm has made researching, sourcing and drafting this toolkit an enjoyable project and a learning process for us all..

## Disability history

Historically, the treatment of people with disabilities has been far from fair. Aristotle was one of the first to denounce the validity of this marginalised group by 'proclaiming that deaf people do not have the same innate intelligence as a hearing person since they are incapable of language' (Rehabilitating Aristotle, Garret Merriam, 2010). Sadly this thinking has set the standard for how we view people with disabilities for more than a millennium.

It has taken the continuous effort and activism from the disability community to change the perceptions of people with disabilities in society today. But there is still much left to be done if we are to make the cultural shift needed to ensure people with disabilities enjoy the same rights as people without a disability. This section charts some key turning points in disability and Leonard Cheshire's own history over the last 100 years.

**1911**

**The National Insurance Act** passed, forming a system to fund health insurance for industrial workers and unemployment and sickness benefits. This marked the start of the modern social welfare system in the UK.

**1919**

In response to the thousands of injured soldiers returning from WWI, the **Central Council for the Care of Cripples** was set up. The organisation still exists today as Disability Rights UK.



**1944**

The **Disabled Persons Employment Act** was passed setting up a quota system for larger employers to hire people with disabilities as part of their workforce.

**1911**

**1919**

**1918**

**1944**

**1918**

**The Education Act** made schooling for all children with disabilities compulsory, giving them the right to education. However, many institutions that schooled children with disabilities were harsh and segregated them from the rest of society.



**1944**

The **Education Act** was passed, which accepted that mainstream education was the most suitable option for children with disabilities. Segregated schools were deemed a failure and hindered the development of children's interpersonal skills.



## 1946

The first Invacar was designed and built, a government-funded response to the lack of accessible transport for people with disabilities. It was scrapped and replaced by the **Motability Scheme** in 1977.

## 1949

By summer 1949, Leonard's home had 24 residents with a range of disabilities. More homes soon followed, and the charity now known as **Leonard Cheshire** was born.



## 1962

A protest by residents led to changes in the philosophy of the Le Court management committee and other Cheshire Homes towards the **social model of disability**.

## 1946

## 1949

## 1962

## 1948

## 1955



## 1948

**Leonard Cheshire's story starts!** Leonard Cheshire welcomes dying ex-serviceman Arthur Dykes (pictured left) into his home in Hampshire, 'Le Court', the first Leonard Cheshire Home.

The first Paralympic Games were held in Stoke Mandeville. This coincided with the 1948 London Olympic games.



## 1955

The first overseas independent home founded by Leonard Cheshire, **Bethlehem House**, opened in Mumbai, India.





## 1972

The **Disability Rights Movement** was birthed as a result of a letter by Paul Hunt (pictured above, centre) to the Guardian demanding equality and solidarity amongst people with disabilities. Read his story in **The history of disability activism**.



## 1981

The Disabled People's International group was formed with the slogan of **"Nothing About Us Without Us"**.

The British Council of Organisations of Disabled People was set up, the first national coalition of organisations controlled by people with disabilities to campaign for equality and human/civil rights.

## 1996

Due to campaigning from the **Independent Living Institute**, direct payments for social care were legalised, setting up the structure for the self-directed support of people with disabilities.

1972

1981

1996

1970

1976

1995

## 1970

The **Chronically Sick and Disabled Persons Act** was passed finally giving rights to people with disabilities to receive a range of services from local authorities, such as welfare and housing.

## 1976

'The Cheshire Foundation Homes for the Sick' was officially changed to **'The Leonard Cheshire Foundation'** recognising that people with disabilities did not wish to be referred to as 'the sick'.



## 1995

After countless protests and campaigning by people with disabilities, the watershed **Disability Discrimination Act** was passed, making it illegal to discriminate against people with disabilities in all civil acts. All service providers now must enable access to people with disabilities. Find out more in the BBC article **When disabled people took to the streets**.

## 1996

The **National Centre for Independent Living (NCIL)** was co-founded by Baroness Jane Campbell DBE of Surbiton, an active leader for the independent living campaign.



## 2011

**Hardest Hit** campaign was organised by the Disability Benefits Consortium and the UK Disabled People's Council, lobbying the government about the impact of welfare cuts. Around 8,000 people with disabilities attended the march on Parliament in May.

## 2014

**Change 100** was launched by Leonard Cheshire, a national programme matching talented undergraduates with disabilities to paid internships at some of the UK's leading companies.



## 2017

The United Nations Council on the Rights of Disabled People committee published a report on the UK government's violations against people with disabilities in the UNCRPD. The report criticised the government for failing to successfully implement policies protecting the welfare rights of people with disabilities. Access the **UN Committee ruling here** and the **UK government response**.

The struggle continues!

1998

2011

2014

2017

2010

2012

## 2010

The UK Government approved the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**, which was adopted at the UN in December 2006.

**The Equality Act** was passed, replacing the Disability Discrimination Act 1995. It broadened (some say weakened) discrimination legislation to include other protected characteristics including disability.

## 2012

The **Paralympic Games** was held in London and marked a watershed moment on mainstream TV coverage of athletes with disabilities. Pictured right is Paralympian and Leonard Cheshire ambassador Olivia Breen.



## Disability etiquette: Dos and don'ts

This quick guide provides some best practice tips for conversations about disability.



- Every person with a disability has an individual experience of how their impairment affects them. Therefore, don't make assumptions about how they want to be treated even if they have the same type of impairment as someone you have met before. **Just ASK!**
- Many people with disabilities live and work independently while others may require assistance. Making reasonable adjustments to enable participation is a legal requirement. Don't just assume a situation requires an adjustment, but equally be ready to discuss and provide it. **Just ASK!**
- Don't move or touch a person's mobility aid such as a wheelchair or cane unless asked to do so. If you're in any doubt... **Just ASK!**
- People with disabilities will prefer honesty and a genuine respect for their dignity, preferences and individuality. So if you're worried about how to behave or which language to use... **Just ASK!**



- Identify yourself when speaking to someone with a visual impairment. Remember to inform the person if you are moving away.
- If needed, support a person with a visual impairment to orient themselves within a space, and audio describe any printed information, or non-auditory communication such as videos, role play or images. Don't leave things on the floor which could create a trip hazard.



- Approach someone with a hearing impairment from the side or in front so as not to startle them.
- Ask someone with a hearing impairment what their preferred method of communication is eg sign language or lip reading.
- When communicating with a person with a hearing impairment, maintain eye contact and speak clearly. Don't hold anything in front of your lips or use over-exaggerated expressions.
- If a sign language interpreter is present allow time for interpretation.



- Speak directly to a person with a disability and not their personal assistant, companion or interpreter.
- Position yourself at eye level when speaking with a person who is using a wheelchair, or of short stature. This prevents a person straining their neck or being talked down to. If possible find somewhere to sit rather than hunker down. That way it's comfortable for everyone.



- Feel free to ask a person who has a speech difficulty to repeat themselves. They will be used to this and will appreciate that you value their contributions and ideas. Don't guess or nod comprehension when you have not understood what has been said.
- Speak clearly and in short sentences when communicating with a person with a learning disability. Don't be afraid to repeat or rephrase things to help give clarity. Don't be patronising, use a childish voice or expressions or exaggerate.

## Language dos and don'ts

The tips below on words or phrases to avoid and possible alternatives demonstrate our values. It is not about using politically correct language (that is covered on the **Quick guide on terminology**), it is about showing respect and maintaining dignity towards those with whom we work.

Avoid	Suggested alternative
The term 'suffer' – for example 'he suffers from epilepsy'.	'Has' or 'experiences' – for example 'he has epilepsy', as this is non-judgmental.
The term 'problem' – for example 'he has a mental health problem'.	'Difficulty' or 'challenge'. In this particular example it may be best to say 'he has a mental illness' or 'he has mild depression'.
The word 'only' can imply judgement if you're not careful – for example 'she can only sit on a till'.	Something like 'putting her solely on the till is the most effective use of her skills and abilities'.
Don't describe a person with a disability in terms of their condition – for example 'she is a diabetic'.	They are a person first. If you have to use a descriptive then say 'she has diabetes'.
Avoid 'mental handicap' as this is now considered offensive.	'Learning disability' is the term now used to describe a condition which results in an impaired intellectual ability.
Avoid terms such as 'wheelchair bound' or 'housebound' as these are judgmental.	Say 'uses a wheelchair' or 'doesn't leave the house' as these are factual.
'Crippled with' is still used to describe the effect of a disabling condition but not always appropriate.	Use phrases such as 'walks with sticks', 'uses a wheelchair' or 'has a condition which affects his mobility'.
Leaning on someone's wheelchair is imposing upon their personal space.	There isn't an alternative – just don't do it!

We would encourage you to talk to your colleagues about disability-related language and raise concerns if you have them. It's good to discuss any concerns rather than just guess.

### Quick links

- Differing Abilities have produced a great interactive etiquette quiz to help you make the best choice when meeting someone with a disability. [www.understandingdisability.org/Etiquette](http://www.understandingdisability.org/Etiquette)
- This is a short video from the D.C. Office of Disability Rights, discussing general rules of etiquette for interacting with people with disabilities. Watch it, it's hilarious! [www.respectability.org/inclusion-toolkits/etiquette-interacting-with-people-with-disabilities](http://www.respectability.org/inclusion-toolkits/etiquette-interacting-with-people-with-disabilities)

#### A couple of context specific guides on terminology and etiquette:

- **England Athletics Factsheet on Disability Terminology:** a concise guide to terminology in sports
- **CBM Disability Inclusive Development Toolkit:** this toolkit includes a helpful section on language and communication (1.3) in the international development context

# Terminology: What's in a word?

Language matters. It is not simply a matter of 'political correctness'; this is a real issue that affects people's lives.

## Why is language important?

Historically, people with disabilities have been the subject of discriminatory and offensive terms that, thankfully, are no longer acceptable. However, language is always evolving and it is essential that the words we use to describe disability and individuals with disabilities are appropriate, respectful, inclusive and contextual. Some words, such as 'Crip' and 'Crippled' may still be the chosen words by people with disabilities themselves as a way of reclaiming and repurposing the power of those terms. This doesn't mean it's okay for those without disabilities to use those words, even if it is repeating a quote from someone else.

Using the right terminology in internal and external communications, whether that's in reports, briefings, articles or social media, can empower and enfranchise people with disabilities; but equally using outdated and inappropriate terms will reinforce prejudice and discrimination.

Getting the language right should go hand in hand with a genuine change in attitudes and practice. We know this doesn't happen overnight. But if we are using the right language, along with other changes in approach outlined in this toolkit, a cultural shift should eventually happen.

## Getting the language right has to go hand in hand with a genuine change in attitudes and practice



## Where it worked: A collective voice for change

The National Youth Leadership Network (NYLN) and Kids as Self Advocates (KASA) teamed up to produce a very helpful guide: "**Respectful Disability Language: Here's What's Up!**". Using their collective voice to challenge how people with disabilities are talked about, they have helped influence a generation of journalists in the USA, with many institutes adopting more positive language and promoting good practice. For example, the National Centre on Disability and Journalism, headquartered at the Walter Cronkite School of Journalism and Mass Communication at Arizona State University, has developed an online **Disability Language Style Guide**.

## Terminology dos and don'ts

The table below lists some terminology dos and don'ts when writing about people with disabilities. Please note this is not an exhaustive list.

Disability	Outdated language	Respectful language
Blind or Visual impairment	Dumb, Invalid	Blind/Visually impaired, Person who is blind/visually impaired
Deaf or Hearing impairment	Invalid, Deaf-and-Dumb, Deaf-Mute	Deaf or Hard of hearing, Person who is deaf or hard of hearing
Speech/Communication disability	Dumb, "One who talks bad"	Person with a speech/communication disability
Learning/Cognitive disability	Retard, Mentally retarded, Slow, Brain-damaged, 'Special ed'	Learning disability, Cognitive disability, Cognitively/Developmentally disabled, Person with a learning or cognitive disability, Person/someone who is neurodiverse
Long-term condition	Long-term health condition	Person who has a long-term condition, as not all long-term conditions relate to health, e.g. autism
Mental health disability	Hyper-sensitive, Psycho, Crazy, Insane, Wacko, Nuts	Person with a psychiatric disability, Person with a mental health disability
Mobility/Physical disability	Handicapped, Physically challenged, Special, Deformed, Cripple, Gimp, Spastic, Spaz, Wheelchair-bound, Lame	Wheelchair user, Physically disabled, Person with a mobility or physical disability
Emotional disability	Emotionally disturbed	Emotionally disabled, Person with an emotional disability
Short stature, Little person	Dwarf, Midget	Someone of short stature, Little person
Health conditions	Victim, Someone 'stricken with' a disability eg 'someone stricken with cancer' or 'an AIDS victim'	Survivor, Someone 'living with' a specific disability eg 'someone living with cancer or AIDS'



**Remember: What is 'okay' for some people is not 'okay' for others. If you don't know what to say... Just Ask!**

### It's not just about ramps!

What is the first thing that comes to mind when considering disability access? Often it will be level access or a ramp. Yet we know that in reality accessibility is not just about having a ramp or level access into a building. This quick guide will take a broader look at the meaning of accessibility and how to deliver it in practice.

### Universal design theory

Universal design ensures that products and buildings can be used by virtually everyone, regardless of their level of ability or disability. It means designing all products, buildings, and information so that they are usable by all people to the greatest extent possible. The theory is based on these principles:

- Disability is not a special condition of a few.
- It is ordinary and affects most of us for some part of our lives.
- If a design works well for people with disabilities, it works better for everyone.
- Usability and aesthetics are mutually compatible.



### Quick facts

Fewer than 17% of local authorities in England have plans to build accessible housing (Equality and Human Rights Commission)

45.3% people with disabilities compared with 31.7% people without disabilities reported difficulty accessing services in the areas of health, benefits, tax, culture, sport and leisure (Access England 2014)

### The Equality Act 2010

The UK Equality Act 2010 came into force on 1 October 2010. It combines almost all previous anti-discrimination laws, including the Disability Discrimination Act 1995, in a single piece of law. The general duties of the Equality Act are to encourage service providers to consider how they can positively contribute to the advancement of equality and good relations. Equality considerations should be reflected in all policies and services, including any internal consultations and reviews.

Whatever activity you are engaged in – be it delivering a programme, consulting on a document or running a campaign – there are some minimum standards that should be upheld as part of a commitment to accessibility and inclusion. The following guidance is by no means exhaustive. And it is good practice to review each situation's accessibility considerations separately as unique circumstances may arise.

### Universal design means it is:



Equitable



Flexible



Simple and intuitive



Perceptible information



Tolerance for error



Low physical effort



Size and space

## Accessibility: what you need to know

- Any publicly funded entity has a legal obligation to make reasonable adjustments so that their goods and services, programmes and events are accessible to anyone who uses them.
- Think about how people with disabilities might access and participate in any activity before it is designed, built, or delivered.
- Make sure you budget for accessibility. This might include paying for specific access needs, but might also be a bigger project such as carrying out an access audit of operational practice.
- Create an Accessibility Checklist as part of the planning process – the below information on accessible documents and events should be helpful for this.
- Delivering accessibility is the whole team's job not just one person's responsibility.

## Making your documents accessible

- All documents should be written in plain, common sense English. Minimise the use of unnecessary jargon and acronyms. If technical terms are necessary, explain their meaning clearly.
- Use an accessible font, such as Arial, with minimum font size 12.
- As a general rule, use dark type against a light background for good colour contrast.
- Documents should be provided in accessible formats such as large print, easy read English and other agreed languages eg Welsh. They should be made digitally available both in PDF and Word and formatted for accessibility for those using screen readers. All available formats should be released together.
- It is good to allow enough time for the development of easy read English, Braille and audio versions.



## Making your meetings and events accessible

The following list is by no means exhaustive, and should be seen as good practice guidance rather than a list of must dos!

- Check your venue beforehand – wherever possible you should visit the venue in advance and ensure it is accessible for all users. **Use the Accessible venue checklist** template in the Appendix and ensure you provide access details in the information sent to participants.
- All meeting and event invitations should indicate whether support such as BSL interpreting, assistive listening devices, real time captioning and personal assistance workers will be provided. Participants should be asked to indicate when they register if they would like any extra support in order to participate.
- Participants who have indicated that they require support should be contacted by phone within three working days to discuss the details of what they require.
- All materials used at meetings and events should follow the guidance above for making your documents accessible.
- For longer meetings, a room should be provided where people who need a break from chairs can lie down and rest or take a break.
- Generally, time your meetings and events to avoid any major holidays and religious events.

# Meaningful engagement with OPDs

Organisations and legislation often use the phrase ‘meaningful engagement’ when referring to involving specific groups. But what does it really mean? The truth is that meaningful engagement will look slightly different depending on the context.

**In international law** the United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets the tone on what meaningful engagement means in **General Obligations 4.3**. This calls on States to ‘closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations’ in the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to people with disabilities. Article 33 further outlines specifically how people with disabilities and OPDs should be consulted on national implementation and monitoring of the CRPD, ensuring that mechanisms are in place for this to happen.

**Domestically**, the role of the UK Government’s **Disability Unit**, based in the Cabinet Office, is to consult with OPDs and other UK government departments on coordinating the implementation of the CRPD. It also supports the cross-governmental role of the Minister of State for Disabled People, Health and Work in providing guidance on how to meaningfully engage people with disabilities in determining government strategy such as the upcoming National Strategy for Disabled People. In June 2020, the Disability Unit launched a Disabled People’s Organisation Forum which aims to bring the views, insights and lived experience of people with disabilities to the centre of policy making.

**At community level**, local authorities have an obligation under the Equality Act 2010 and the CRPD to ensure participation by people with disabilities in development and decision-making processes, and ensure an inclusive approach to this. To support this, Disability Rights UK issued guidance on **how local authorities can work with OPDs** which explores how they can facilitate the development of inclusive communities, and includes helpful examples of where this has worked.

At Leonard Cheshire we believe that meaningful participation is an approach that puts people with disabilities at the front and centre of our work. We aim to ensure that people with disabilities are invited to **purposefully participate** in our influencing and decision making processes.



**“I know, as a person with a disability, that I am fully capable of bringing about change; I am an expert of experience and that is powerful. So many new networks have opened up to me... I have formed incredible partnerships with DPOs, other brilliant disability and inclusion activists, media personalities and high profile people.”**

Maria Njeri, one of the youth reporters from Leonard Cheshire’s 2030 and Counting project, relays her own experience

Meaningful engagement may involve, but is not limited to:

**Participating** in decision-making processes (eg membership on Boards, Committees and Advisory groups)

**Promoting** advocacy (eg speaking engagements, being a media spokesperson, participating in pre-election activities, organising a public awareness event)

**Working** in programmes (eg peer mentorship, group leadership or facilitation, participating in fundraising activities, developing volunteer training materials)

**Reviewing** materials (eg reviewing drafts of publications)

**Assisting** with the operation of the organisation (eg participating on a staff hiring team, facilitating a component of new staff orientation and ongoing staff training, helping with office tasks)

## Who benefits when engagement is meaningful?

Striking the right balance so that meaningful participation has mutual benefit is important. Some positive benefits for both OPDs and partnering organisations when working together include:



### Partnering organisation:

- Provides credibility and legitimacy that the organisation represents and supports the 'voice' of people with disabilities
- Increases capacity by capitalising on skills and abilities of people with disabilities
- Doing work that is relevant
- Decision-making is informed
- Easier to identify gaps in approach
- Ensures work is appropriate and addresses real concerns/issues of people with disabilities
- Adds depth to the organisation's culture, dispelling myths and stereotypes
- Should impact staff positively

### OPDs:

- An opportunity to address issues related to living with disability
- May gain recognition for skills and experiences shared
- Provides opportunities to influence policies and programmes which can have an impact
- An opportunity to provide the perspective of people with disabilities and affect decision making
- An opportunity to develop personal/organisational strategy/activities
- May receive financial recompense for services provided

### Quick links

- CRPD General Obligations 4.3: [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html)
- CRPD Article 33: [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-33-national-implementation-and-monitoring.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-33-national-implementation-and-monitoring.html)
- Disability Unit: [www.gov.uk/government/organisations/disability-unit](http://www.gov.uk/government/organisations/disability-unit)
- Disability Rights UK's Inclusive Communities: A guide for Local Authorities: [www.disabilityrightsuk.org/sites/default/files/pdf/1%20%20InclusivecommunitiesLAGuidance.pdf](http://www.disabilityrightsuk.org/sites/default/files/pdf/1%20%20InclusivecommunitiesLAGuidance.pdf) (the PDF takes a while to load but stick with it!)

Disability culture and the way we work with people with disabilities and the organisations that represent them is changing. Below are the main considerations when thinking about the disability movement today. We hope this will serve as a guide for developing an approach to inclusive influencing in what has been a rapidly changing landscape for the disability sector and its relationship with the disability movement in the UK and globally.

- The involvement and participation of people with disabilities through ‘representative organisations’, traditionally called disabled people’s organisations, (DPOs) has now shifted towards the language of the UNCRPD, using the term ‘Organisations of Persons with Disabilities (OPDs)’.
- The disability movement accepts that articles 4.3 and 33.3 of the CRPD set the tone on meaningful engagement of people with disabilities in the development and implementation of legislation. This approach also applies to policies developed by States that relate to the CRPD. More crucially, it is increasingly the adopted language for other decision-making processes and service delivery mechanisms.
- The International Disability Alliance (IDA) sets the criteria that most INGOs seem to follow in terms of what constitutes an OPD, saying: “They are global or regional organisations whose mission and objectives are about the promotion of the rights of people with disabilities.” This approach also applies to the domestic OPD federated structure in member States.
- It is no longer acceptable for organisations in the disability sector to continue to view people with disabilities as passive recipients. In adopting the tone of the disability movement’s mantra, “Nothing about us without us”, organisations are making the cultural shift necessary to ensure people with disabilities are not just seen, and treated, as beneficiaries – but also as experts in providing solutions to influence the change needed.

Leonard Cheshire is currently working towards a number of commitments that will strengthen our approach on working with OPDs, individuals and groups of people with disabilities. Below are some guiding principles that will inform our planning as we move ahead.

1. Using the term ‘Organisations of People with Disabilities (OPDs)’ as this is the preferred international language of CRPD and related frameworks.
2. Stated recognition that OPDs are global, regional or national bodies whose mission and objectives are about the promotion of the rights of people with disabilities and influencing change to ensure their rights are upheld.
3. Progress towards the meaningful participation of OPDs in Leonard Cheshire’s policy influencing work and programme delivery through the development of working practices with clearly defined entry points.
4. Develop criteria for developing strong partnership relationships with OPDs, disability groups, and service providers and research institutions working with people with disabilities and OPDs.
5. Work towards a set of commitments by Leonard Cheshire on meaningful engagement with OPDs, supported by best practice guidelines outlined in this toolkit.

## Influencing cycle: OPD entry points

### 6. Review and evaluate

Debrief on process, what was achieved, immediate, long-term and unexpected results, share lessons learned.

### 5. Delivery

Release new research or policy positions, MP briefings, campaign actions and comms (inc press releases, blogs, social media, supporter emails).

### 4. Collect the evidence

Gather evidence and data focus groups, interviews, surveys, qualitative data in the form of life experiences and hold consultations.

### 1. Assess the landscape and context

Ask people with disabilities what is important to them, what is/isn't happening on the issue, where can your organisation add value to that issue and support their messages and further your objectives?

### 2. Collaborate

Identify who your OPD allies are. Ask, what are their key objectives, success, values? What expertise and credibility do they have on their specific area? What does their membership look like?

### 3. Agree the approach

Identify key shared messages, consultation process, methods of delivery, access support needs and shared benefits.



# Influencing knowhow

## Global platforms

The global shift towards recognising the rights of people with disabilities enabled many OPDs and their allies to positively influence a broad range of stakeholders and decision makers, not just in the UK but internationally.

We know that we cannot achieve genuine inclusion without involving the voices of people with disabilities, individually or through OPDs.

A couple of things to consider when thinking about OPDs in the international development context include:

- The involvement and participation of people with disabilities through ‘representative organisations’, or OPDs, is inherent to both Articles 4.3 and 33.3 of the CRPD.
- The CRPD is seen by the global disability movement as setting the tone on meaningful engagement of people with disabilities in the development and implementation of legislation and policies by UN member States. The disability movement has further adopted the language of the CRPD for other decision-making processes.

## International Disability Alliance

A key international platform is the **International Disability Alliance (IDA)**, born out of Disabled Peoples International (DPI) – who coined the phrase ‘Nothing About Us Without Us’. IDA’s unique network of leading international disability rights organisations gives it unrivalled ‘authoritative representation of persons with disabilities on the global level, and is acknowledged as such by the United Nations.’ (IDA website) Established in 1999, IDA brings together over **1,100 organisations of persons with disabilities** and their families from across **eight global and six regional networks** and represents an estimated **one billion** people worldwide living with a disability.



# The CRPD: The cornerstone of all global influencing on disability rights

The CRPD presents multiple opportunities for OPDs to engage in advocacy at all levels, including national implementation of the CRPD and with the human rights and sustainable development process at the UN.

**CRPD Committee:** This is a body of 18 independent experts which monitors the implementation of the CRPD. This committee reports on State progress and violations of the CRPD, and receives shadow reports and evidence from OPDs.



It was to this committee that UK OPDs sent their **shadow report** on welfare reforms in 2017 – providing an opportunity for people with disabilities to hold their government to account.

**Conference of States Parties (COSP):** This has been held annually since 2008 at the UN headquarters in New York, covering a range of themes and issues in roundtables, interactive dialogues and side events.



This is a key opportunity for engaging experts with disabilities and OPDs in developing **side event proposals** and organising side meetings with State delegates on specific issues relating to CRPD implementation.

**The International Day of Persons with Disabilities:** This day is held every year on 3 December since 1992. It is an opportunity to celebrate how far people with disabilities have come in gaining recognition of their rightful place in society.



**Support or co-host** OPD and people with disabilities led groups in activities that highlight key developments and achievements. These can range from developing **social media content** to co-hosting/participating in live/remote events.

**Civil Society CRPD Forum:** This UN activity is held annually ahead of the Conference of States Parties (COSP) and is facilitated by IDA through the **Civil Society Coordination Mechanism**. The Forum gives space for open discussion and sharing of a huge diversity of experience and perspectives from across the disability rights community.



There is an opportunity to organise **side meetings** to enable OPDs to engage with government representatives, UN bodies and others from across civil society to share ideas, approaches to inclusion, find allies and future partners.

**SDGs Stakeholder Group of Persons with Disabilities:** This globally recognised group was set up in 2016 to engage with the global reviews of the Sustainable Development Goals (SDGs).

**High Level Political Forum (HLPF):** This is the UN platform for the global follow-up and review of the 2030 Agenda. Each year a selected number of States report to the HLPF on their progress towards the SDGs through Voluntary National Reviews.



OPDs can be supported to gather evidence and content on nationally specific issues to contribute to civil society **statements to the HLPF**. See CBM/IDA's **Toolkit for DPOs on Voluntary National Reviews**.

The world is changing! No longer are people with disabilities and OPDs prepared to sit on the sidelines and let others choose what is important to them. This includes driving the message on what they consider is important to people with disabilities and influencing the change needed in response.



### Quick fact

Did you know that the phrase 'Nothing About Us Without Us' was first coined by Disabled People's International – the first global network of people with disabilities founded in 1982 after the UN led 'International Year of the Disabled' excluded them at its launch conference.

### Key policy moments

In the last 25 years people with disabilities in the UK and globally have influenced a radical shift in policy to ensure they are not left out of the policy making process.

**1995** The Disability Discrimination Act (DDA) makes discrimination against people with disabilities illegal in the UK (updated to the Equality Act in 2010).

**2000** The Disability Rights Commission is set up with people with disabilities being the majority of its commissioners.

**2009** The UK Government ratifies the UN Convention on the Rights of Persons with Disabilities.

**2017** CRPD Committee publishes its Concluding Observations based on a UN Committee inquiry into the UK Government's implementation of the CRPD. The Committee observations stated the UK's "recent welfare policies do not fully enforce the international human rights framework".

**2020** UK Government announces plans for a National Disability Strategy.

The empowering phrase 'Nothing About Us Without Us' "expresses the conviction of people with disabilities that they know what is best for them" (Nothing About us Without Us, James Carlton). It has formed a mantra that has fuelled the disability rights movement ever since the words were first uttered. Many have adopted it as their own, including civil rights movements, Black, Asian and minority groups, and governments keen to promote their commitment to inclusion.

### How to support this shift

At Leonard Cheshire we are committed to ensuring that people with disabilities are front and centre in all we do. Below are a few examples of how we are moving towards this commitment in our policy work.

- We take a **rights-based approach**, underpinned by the CRPD and globally agreed commitments including the SDGs.
- We are committed to **working with people with disabilities and their representative organisations (OPDs)** in key decision-making and influencing processes.
- We are **bringing together** Leonard Cheshire's domestic (UK) and international influencing approach.
- We are seeking to **forge new partnerships** and build our ability to effect change, including through the **meaningful engagement and leadership** of people with disabilities.
- We are committed to securing the rights of people with disabilities through more **collaborative working** (both internally and externally), greater **organisational resourcing** and a greater focus **on pursuing tangible, strategic changes** in policy and practice.

## Policy process and entry points

In general it is good practice to begin active engagement with OPDs and people with disabilities as early as possible, rather than just asking people to comment on work and contribute to policy messaging or ‘asks’ that have already been agreed. Building a close relationship with a number of trusted OPDs and individuals with disabilities and involving them at an early stage will help to secure the commitment of all parties involved, as well as improving your organisation’s credibility and showing that you are intentional about engaging them in a meaningful way. The following table lists some questions to consider when thinking through entry points.

Policy engagement process (use in conjunction with the Influencing cycle)		OPD entry points
	<b>Assess the landscape and context:</b> Identify and agree area of focus	<ul style="list-style-type: none"> <li>■ Who decides the area of focus? Are OPDs leading or participating on a shared priority? Or is the partner organisation aligning and supporting an OPD’s priority?</li> <li>■ What factors influence what is focused on? Disability movement priorities on social change, welfare reform or tackling stigma and discrimination, or political national interests?</li> <li>■ Who needs to be influenced (this can be several layers of audiences depending on priorities)?</li> <li>■ What shared benefits are there for OPDs involved in the process? What is the added value of each partner?</li> <li>■ Involve OPDs at executive level when deciding on which big themes eg education, employment and social care, and recognition of their engagement throughout the consultation process.</li> <li>■ Continue to engage with OPDs on deciding the policy sub-themes eg education for girls with disabilities, teachers’ training etc.</li> </ul>
	<b>Collaborate:</b> Identify contributors/sourcing evidence or ‘co-production’ partners	<ul style="list-style-type: none"> <li>■ Agree who the allies, supporters and sources of evidence are for a particular theme or topic, eg if it is a social care theme, which OPDs are working on similar priorities?</li> <li>■ Talk to partners. Ideally this would be from a developed list of OPDs, networks and ‘expert’ people with disabilities that relationships have been developed with.</li> <li>■ Set up an OPD Reference Group or Steering/Advisory Group to orientate on the issues and generate interest, as well as identify those with relevant experience.</li> </ul>
	<b>Agree approach:</b> Determine the terms of involvement	<p>Agree a Memorandum of Understanding, Terms of Reference or basis for working together. This might include:</p> <ul style="list-style-type: none"> <li>■ Identify roles and responsibilities – agree leadership and who the ‘expert’ is.</li> <li>■ Agree consultation ground rules on when people can comment eg skeleton, copy or full copy with images and graphs.</li> <li>■ Agree sign-off process factoring in enough space if a dual sign off for partner/OPD or reference group.</li> </ul>

Policy engagement process (use in conjunction with the Influencing cycle)	OPD entry points
 <b>Collecting content, evidence, narrative</b>	Involve OPDs and people with disabilities in social research and evidence gathering, analysis of data and making recommendations.
 <b>Delivery:</b> Drafting and consultation process, validation and sign-off	<ul style="list-style-type: none"> <li>■ Budget for accessibility for reviewing drafts and setting up meetings (see Quick guide on accessibility).</li> <li>■ Agree consultation dissemination strategy.</li> <li>■ Provide review guidelines on drafts and direct them to particular sections of interest. Avoid being selective about what to send to OPDs for review.</li> </ul>
 <b>Dissemination, review and evaluate:</b> Who conveys learning, evidence, messages at related events	<ul style="list-style-type: none"> <li>■ Mutually agree the relevant processes, events and opportunities.</li> <li>■ Ensure consistency of policy messaging and expertise of the partnering OPD – not just an opportunity to push own organisation’s profile.</li> <li>■ Identify spokespeople and media content and contacts with marketing and communications teams.</li> <li>■ Support speakers, allow adequate time for briefings, provide all material in accessible formats.</li> <li>■ Provide an opportunity for OPDs to feedback on the whole policy involvement process (eg what worked well, and what didn’t).</li> </ul>

## Quick links

- **Toolkit for DPOs on participating in VNR process:** This is a useful booklet by IDA for OPDs and NGOs working with OPDs on engaging with Voluntary National Reviews. [www.cbm.org/fileadmin/user\\_upload/Publications/IDA\\_CBM\\_DPO\\_VNR\\_toolkit\\_FINAL.pdf](http://www.cbm.org/fileadmin/user_upload/Publications/IDA_CBM_DPO_VNR_toolkit_FINAL.pdf)
- **Involving disabled people in social research:** Guidance by the Office for Disability Issues. This is a document published by the Office for Disability Issues, now the Disability Unit. It is several years old but is useful in getting an idea of government approaches to meaningful engagement of people with disabilities in research and consultations. [assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/321254/involving-disabled-people-in-social-research.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/321254/involving-disabled-people-in-social-research.pdf)
- **“Nothing About Us Without Us,” by James Charlton.** Article from New York Times detailing 16 moments in the Fight for Disability Rights. This can also be listened to. [www.nytimes.com/2020/07/22/us/ada-disabilities-act-history.html](http://www.nytimes.com/2020/07/22/us/ada-disabilities-act-history.html)

# Influencing knowhow

## Campaigns

Since the 1970s people with disabilities have campaigned for the right to be heard, calling for solidarity among people with disabilities and their allies without disabilities in the fight for equality in accessing education, employment and the built environment. As a result, the notion that people with disabilities are passive recipients of care has been dramatically overhauled. A growing and increasingly active disability movement, both in the UK and globally, has over the last 50 years brought people with disabilities from the fringes of society into the centre of change making. For a snapshot of how this happened look at the Disability history guide in this toolkit.



### Quick facts

**41% of stations in Britain don't have step-free access, or let down passengers with disabilities by poor design and services. (Leonard Cheshire analysis of data from Network Rail)**

**Coronavirus has had an impact on the work of 71% of people with disabilities who were employed in March 2020. (Leonard Cheshire/Savanta research 2020)**

Rights, experiences and opinions of people with disabilities and OPDs should always be at the heart of campaigning. This goes hand in hand with policy and research work which informs campaigns. Meaningful engagement with OPDs and people with disabilities should start at the very beginning of any campaign, from deciding on the issue, shaping the strategy, through to delivery and evaluation. This ensures the campaign mission is accountable to the disability movement as well as bringing credibility to the work and greater opportunities for collaboration and reach. Fully inclusive outcomes can only be achieved through fully inclusive processes.



### Where it worked: The Hardest Hit Campaign

In 2011 the Hardest Hit Campaign was a protest march organised by the Disability Benefits Consortium and the UK Disabled People's Council, objecting to the benefit cuts in disability allowance and local service cutbacks. Working alongside people with disabilities, Leonard Cheshire volunteers and staff supported campaigners to participate in a march across London.

The campaign, led by people with disabilities, operated at all levels from collecting data on the lived experiences of people with disabilities of how the proposed benefits cuts would affect lives, providing evidence to underpin policy asks, ministerial questions, petitions and the protest march. We held focus groups and consulted on the best way forward.

While the campaign was successful in overturning the benefit cuts, the key outcome was to have far wider impact, as Steve Winyard, co-chairman of the Hardest Hit Coalition noted: "The proposed cuts had brought together disability charities and disabled people's organisations into a single united force where previously we've had a difficult relationship with differences on policy and ideology."

## Campaign process: OPD entry points

Influencing campaign process	OPD entry points
 <p><b>Assess the landscape and context:</b> Identify what key change or response is needed to improve the situation.</p>	<ul style="list-style-type: none"> <li>■ Horizon scan on what people with disabilities, disability movements and researchers are saying on the issue.</li> <li>■ Build relationships with OPDs, local groups of people with disabilities and service user groups:               <ul style="list-style-type: none"> <li>- Find out what is important to them, and what is/isn't happening on the issue from their perspective.</li> <li>- Are there OPDs working on a similar area? If so, what is their approach, what are their successes/ challenges, what is the potential for collaboration on this campaign? What is the potential for building a longer partnership?</li> </ul> </li> <li>■ Assess how you can share resources, information and value (both ways), to help identify the key issues, activity already taking place, and potential solutions.</li> </ul>
 <p><b>Collaborate:</b> Authentic relationships create the best campaigns, so it is important to make the right choice.</p>	<ul style="list-style-type: none"> <li>■ Identify who the OPD allies are: Who should be involved? Who can help make the change required? Ask:               <ul style="list-style-type: none"> <li>- What are their key objectives, success, values? What expertise and credibility do they have on their specific area?</li> <li>- What does their membership look like?</li> <li>- What OPD connections are there already with your organisation?</li> <li>- What relationships do OPDs already have with key decision makers?</li> <li>- How will they bring greater credibility to the campaign?</li> </ul> </li> <li>■ Collaboration with OPDs will provide stronger and more authentic messaging, which both supports the wider disability movement and builds trust.</li> </ul>
 <p><b>Agree approach:</b> Now you know what you want to change and have identified allies, you can map out your campaign approach, strategy and set objectives.</p>	<ul style="list-style-type: none"> <li>■ Set up a Campaign Group:               <ul style="list-style-type: none"> <li>- Involve everyone in the campaign ensuring accessibility in terms of face to face, virtual and written activities.</li> <li>- Consult and develop plans with OPDs to see if there are areas to combine resources/activity.</li> <li>- Developing messaging: Identify what the messages are for different audiences and how to inspire them to act.</li> </ul> </li> <li>■ Develop tactics to reach new audiences and identified targets: Identify how to get people involved, support the campaign and add pressure to make the change happen.</li> <li>■ Share resources, data, contacts and ideas as this will generate more content and widen the reach of the campaign.</li> </ul>

Influencing campaign process		OPD entry points
	<b>Collect the evidence:</b> Both qualitative and quantitative.	<ul style="list-style-type: none"> <li>■ The sky is the limit in gathering evidence but ensure that whatever method used is inclusive and respects the dignity of those participating.</li> <li>■ Ensure people with disabilities are equally and meaningfully engaged in the data collection process and not just providing the data.</li> <li>■ Set up data focus groups, interviews, surveys, and collect qualitative data in the form of life experiences.</li> </ul>
	<b>Campaign delivery:</b> Co-produced campaigns result in two-way benefit as they promote each other's messages and build alliances.	<ul style="list-style-type: none"> <li>■ Budget for accessibility for face to face events, virtual and written information (See Quick guide on accessibility).</li> <li>■ Agree spokespeople who are appropriately briefed and supported.</li> <li>■ Disseminate the pre-agreed campaign actions, eg research, policy positions, MP briefings, press releases, blogs, social media, supporter emails.</li> </ul>
	<b>Review and evaluate:</b> Evaluation of collaborative working and activities from both sides.	<ul style="list-style-type: none"> <li>■ Schedule a debrief on the process, what was achieved, immediate and long-term, unexpected results and lessons learned.</li> <li>■ This rich feedback can then be used to further develop and positively shape future campaigns.</li> </ul>

## Quick links

- Develop a charter with those you want to work with. Disability Rights UK have created this: [www.disabilityrightsuk.org/about-us/our-customer-charter](http://www.disabilityrightsuk.org/about-us/our-customer-charter)
- NCVO have created a visual campaign cycle to help think about the process of campaigning. This can be adapted to include entry points for OPDs and individuals. [knowhow.ncvo.org.uk/campaigns/campaigning-and-influencing/what-is-campaigning/the-campaign-cycle](http://knowhow.ncvo.org.uk/campaigns/campaigning-and-influencing/what-is-campaigning/the-campaign-cycle)

# Influencing knowhow

## Public affairs

It is a well recorded fact that people with disabilities make up the world's largest minority group. Currently around 15% of the world's population, or roughly 1 billion, live with a disability (World Report on Disability, 2011). Comparative studies show that out of 195 countries, 119 have anti-discrimination and other disability-specific laws in place compared with 45 in 2006 when the CRPD was passed. (UN DESA)

While this increase is a dramatic step in the right direction on the legislative rights of people with disabilities, the greater impact has been on the critical role political and civil stakeholders have in ensuring that legislative measures required by the CRPD are adopted. Even more crucial is the effectiveness of an organisation's public affairs team in building strong relationships with all the stakeholders involved, turning key messages into political action. This is a particularly important aspect as influencing policy and effective campaigns go hand in hand when it comes to disability rights inclusion.



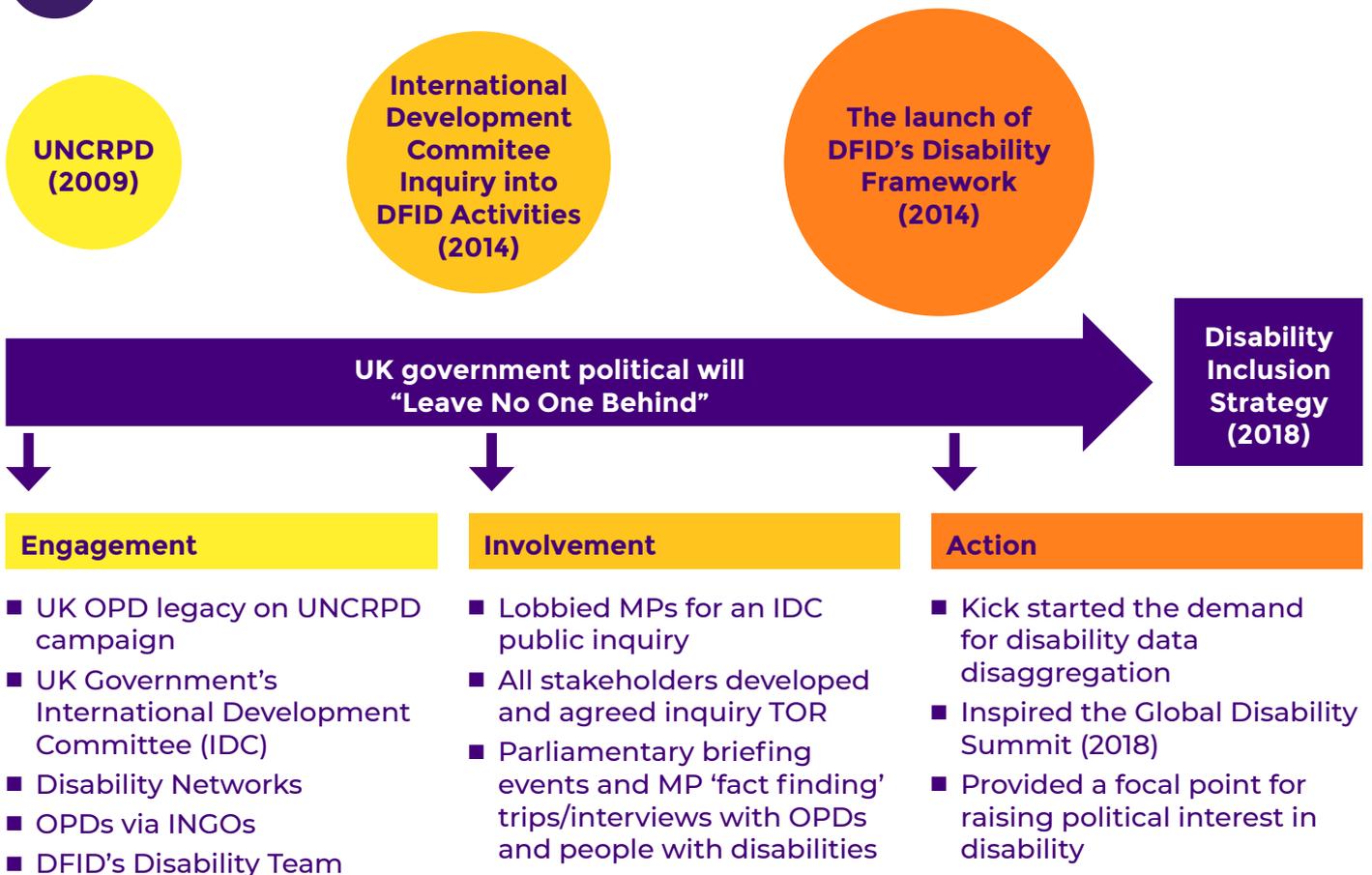
### Quick facts

In the UK women with disabilities were more than twice as likely to have experienced domestic abuse (17.3%) than women without disabilities (7.0%) (ONS, 2019)

13.3% of people with disabilities report regularly feeling isolated, almost four times that of people without disabilities (3.4%), with the greatest disparity aged 16 to 24 years (ONS, 2019)



## Where it worked: Disability inclusion in UK aid policy



# Public affairs process: OPD entry points

Ideally OPD partners and people with disabilities would already be engaged in any change making campaign by the time the political landscape is assessed for allies.

Public affairs engagement process		OPD entry points
	<b>Assess the landscape and context</b>	<ul style="list-style-type: none"> <li>■ Once a policy 'ask' or the mission of the campaign has been decided, scan the horizon to expand OPD engagement opportunities in parliamentary activities:               <ul style="list-style-type: none"> <li>- Devise a stakeholder list</li> <li>- Develop schedule of parliamentary questions</li> <li>- Identify any relevant All Party Parliamentary Group events</li> <li>- Identify any external media hooks and any debates that the policy could be linked to</li> </ul> </li> </ul>
	<b>Collaborate</b>	<ul style="list-style-type: none"> <li>■ Scan of stakeholders – what do you want to push on together? This is similar to horizon scanning but more about identifying who is doing the same thing.</li> <li>■ Set up a stakeholder group with a variety of interested stakeholders including OPD partners working on this policy area.</li> </ul>
	<b>Agree approach</b>	<ul style="list-style-type: none"> <li>■ Agree campaigning tactics and a process for developing accessible public affairs activities.</li> <li>■ Agree common ground with OPDs.</li> <li>■ Agree with all stakeholders participating on specific coalition activities eg create an open letter.</li> </ul>
	<b>Collecting content, evidence, narrative</b>	<ul style="list-style-type: none"> <li>■ Embark on informal intelligence gathering – finding evidence to support policy messaging, sharing information between stakeholders.</li> <li>■ Monitor the political environment, including what OPDs are saying and seeing – does it still support messaging?</li> <li>■ Monitor OPD and stakeholder activity.</li> <li>■ Identify compelling qualitative evidence 'stories' to support messaging.</li> </ul>
	<b>Delivery</b>	<ul style="list-style-type: none"> <li>■ Create MP briefings, blogs and co-hosted parliamentary events with OPDs and people with disabilities.</li> <li>■ Authenticate the messaging by agreeing OPD spokespeople who can convey the messaging.</li> </ul>
	<b>Review and evaluate</b>	<ul style="list-style-type: none"> <li>■ Develop lessons learned internally and externally by way of follow up with OPDs, to inform future campaigns and relationships.</li> </ul>

# Appendix: Accessible venue checklist

Checklist	✓	Comments/Notes
<b>Transportation to venue</b> <ul style="list-style-type: none"> <li>■ Note nearest tube stations and bus stops/bus numbers</li> </ul>		
<b>External environment</b> <ul style="list-style-type: none"> <li>■ Is venue located on a busy road</li> <li>■ Are blue badge car parking spaces nearby</li> </ul>		
<b>Approach to premises</b> <ul style="list-style-type: none"> <li>■ Is the main entrance level access</li> <li>■ If not, where is an accessible entrance located – suggest as an alternative route if appropriate</li> </ul>		
<b>Entrances</b> <ul style="list-style-type: none"> <li>■ Are there steps (even small changes of level over the doorframe)</li> <li>■ Is the entrance ramped</li> </ul>		
<b>Reception areas</b> <ul style="list-style-type: none"> <li>■ Where is the event check-in going to be</li> <li>■ Is it low level</li> <li>■ Will there be badges or information handed out</li> </ul>		
<b>Internal access/circulation</b> <ul style="list-style-type: none"> <li>■ Which floor is your event on</li> <li>■ Is access by lift</li> <li>■ What type of lift, platform or elevator</li> <li>■ How many lifts</li> <li>■ It would be good practice to include a route guide to the main room and breakout rooms in the information sent to the participants</li> </ul>		
<b>Toilets</b> <ul style="list-style-type: none"> <li>■ Note where the toilets are:</li> <li>■ For ambulant users</li> <li>■ For wheelchair users</li> </ul>		

## Appendix: Accessible venue checklist

Checklist	✓	Comments/Notes
<b>Main room</b> <ul style="list-style-type: none"><li>■ Note layout</li><li>■ Fixed seating</li><li>■ Aisle width</li><li>■ Space for wheelchairs</li></ul>		
<b>Access to breakout rooms</b> <ul style="list-style-type: none"><li>■ Ensure adequate signage</li><li>■ This information needs to be included in route guide</li></ul>		
<b>Breakout room facilities</b> <ul style="list-style-type: none"><li>■ Induction hearing loop</li><li>■ Circulation (being able to move around furniture)</li><li>■ Space for wheelchairs at desk/worktables</li></ul>		
<b>Evacuation arrangements</b> <ul style="list-style-type: none"><li>■ Make a note of fire refuge points</li><li>■ Way finding and lighting</li></ul>		

# Appendix: Useful links and resources

## Terminology

### **Disabled People's Association Singapore: Glossary of Disability Terminology**

This is a complete guide to words and phrases acceptable to people with disabilities by people with disabilities.

### **Office for Disability Issues, Inclusive language**

The UK government's guidelines on words to use and avoid when writing about disability in government documents.

### **England Athletics Factsheet on Disability Terminology**

A concise guide to terminology in sports.

### **CBM Disability Inclusive Development Toolkit**

This toolkit includes a helpful section on language and communication (1.3) in an international development context.

## Accessibility

### **Accessible – access guide for venues**

This is an online venue database – but do not use this as a substitute to doing a venue visit and completing the venue checklist.

### **Disability and Inclusion: Universal Design Principles and Guidelines**

A guide to Universal Design Theory.

### **Planning and access for disabled people: a good practice guide**

Published by the Office for the Deputy Prime Minister, 2006.

### **Equality and Human Rights Commission – Equality Act Guidance**

An online guide to the Equality Act.

### **Equality and Human Rights Commission – Being Disabled in Britain: A journey less equal**

A review into disability inequality in Britain, published in 2017.

## Disability etiquette

### **Differing Abilities etiquette quiz**

Differing Abilities have produced a great interactive etiquette quiz to help you make the best choices when meeting someone with a disability.

### **Etiquette – Interacting with people with disabilities**

This short video from the D.C. Office of Disability Rights discusses general rules of etiquette for interacting with people with disabilities. Watch it, it's hilarious!

# Appendix: Useful links and resources

## Meaningful engagement

### **CRPD General Obligations 4.3**

Outlines what the CRPD means by meaningful engagement of people with disabilities.

### **CRPD Article 33**

Outlines what States have to do to ensure participation by people with disabilities in national implementation and monitoring of the CRPD.

### **UK Government Disability Unit**

The Disability Unit aims to break down the barriers faced by people with disabilities in the UK.

### **Disability Rights UK – Inclusive Communities: A guide for Local Authorities**

Guidance for local authorities on creating inclusive communities. The PDF takes a while to load but stick with it!

### **Global Consensus Statement: Meaningful adolescent and youth engagement**

A good checklist for youth engagement.

### **Next Avenue – How to create meaning in dementia care**

There has been a lot of work with dementia patients around meaningful engagement.

### **PMLD Link, Vol 17 No.3 Issue 52, Winter 2005, Meaningful Engagement**

A useful collection of mini-articles related to specific practices of meaningful engagement for anyone working with people with learning difficulties.

### **National Coordinating Centre for Public Engagement – Online engagement**

A good example of how meaningful engagement can be practiced in new environments such as Covid-19.

## Leonard Cheshire's Approach

### **UN Convention on the Rights of Persons with Disabilities**

Homepage for the CRPD, including a breakdown by Article.

# Appendix: Useful links and resources

## Global platforms

### **The 2030 Agenda - Comprehensive Guide for Persons with Disabilities**

This guide presents information about the 2030 Agenda, how it connects to the CRPD, and explores potential entry points for OPDs to influence and participate in implementation, follow-up and review.

### **CRPD Committee**

A body of 18 independent experts which monitors implementation of the CRPD.

### **Conference of States Parties to the CRPD (COSP)**

Annual meeting of States Parties to the CRPD to discuss matters relating to implementation.

### **Civil Society CRPD Forum**

This UN activity is held annually ahead of COSP and is facilitated by IDA through the Civil Society Coordination Mechanism.

### **SDGs Stakeholder Group of Persons with Disabilities**

This group was set up in 2016 to engage with the global reviews of the SDGs.

### **High Level Political Forum on Sustainable Development**

The UN platform for the global follow-up and review of the 2030 Agenda.

### **IDDA and IDC - The 2030 Agenda: Introductory Toolkit for Persons with Disabilities**

A toolkit that explains how SDGs connect to the CRPD, and explores how people with disabilities can be influential and participate in achieving the SDGs.

### **The International Disability Alliance**

An alliance of 14 global and regional organisations of persons with disabilities. They advocate at the UN for a more inclusive global environment for everyone.

## Campaigns

### **Disability Rights UK Customer Charter**

A model for developing a charter of those you want to work with.

### **NCVO - The Campaign Cycle**

NCVO have created a visual campaign cycle to help think about the process of campaigning. This can be adapted to include entry points for OPDs and individuals.

## Policy

### **CBM and International Disability Alliance - Toolkit for engagement of DPOs in the VNR process**

An exploratory and interactive tool for OPDs on the monitoring mechanisms of the SDG implementation, called Voluntary National Reviews.

### **UK Government guidance - Involving disabled people in social research**

Guidance by the Office for Disability Issues on how to involve people with disabilities in social research.

### **Nothing About Us Without Us - James Charlton, New York Times**

Article detailing 16 moments in the Fight for Disability Rights. This can also be listened to.

# Appendix: Useful links and resources

## Public affairs

### **United Nations: Disability Laws and Acts by Country/Area**

An overview of disability legislation across the globe.

### **New York Time's: 16 Moments in the Fight for Disability Rights**

Tracks the journey towards 'Nothing About Us Without Us.'

### **[www.w4mp.org](http://www.w4mp.org)**

This site is a good resource for people working in and around the UK Parliament. It offers 'explainers' on parliamentary procedures, as well as telephone numbers for useful contacts e.g. the events booking system if you wish to book a room or host an event in parliament.

### **[www.theyworkforyou.com](http://www.theyworkforyou.com)**

This site enables people to find out who their MP is and also look back at debates, voting records of MPs and written questions. So it's great if trying to compile a stakeholder list to see if MP's parliamentary records show that they would be sympathetic to your organisation's campaign aims.

### **[www.parliament.uk](http://www.parliament.uk)**

Gives the most up to date information on what's happening in parliament. You can find information about select committees, the order of the day in both Houses of Parliament, key votes, Bills, transcripts of the day etc.

### **UN Handbook for Parliamentarians on the CRPD**

Provides data and messaging on the CRPD for briefing Parliamentarian's responsibilities under domestic law.

**If you have any questions about anything in this toolkit, please get in touch.**

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