

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](http://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)