



Submission on the lived experience of disability to The Joint Committee on Disability Matters

The National Platform of Self Advocates is an independent advocacy organisation run by people with intellectual disabilities. We represent the voices of people with intellectual disabilities in Ireland.

[The National Platform of Self Advocates](#)

Profile

The National Platform of Self Advocates is an independent organisation run by people with intellectual disabilities for people with intellectual disabilities. We are a membership organisation with an elected steering committee working on our strategic plan. All of our members are unpaid volunteers. The National Platform is founded on the right of people with intellectual disabilities to be included as equal citizens with rights as outlined in the UN Convention on the Rights of Persons with Disabilities. The Platform aims to be the nationally recognised spokes organisation on policy and issues affecting the lives of people with intellectual disabilities. We aim to be involved through representation by our members in local and national policy making groups.

Communication

The State needs to communicate with people with intellectual disabilities in accessible ways. This means not just giving us information in accessible formats like easy-to-read English and videos, but also giving us time to respond to information. Calls for submissions should be published long in advance of deadlines.

As individuals many of us rely on supporters to give us the information. Then we need time to gather our stories and prepare our submissions. Finally, we often rely on supporters to assist us in telling our stories. This takes more time than is usually given.

As an organisation, the National Platform of Self-Advocates does not get any state funding. We used to have a paid facilitator to support our work, paid for by Atlantic Philanthropies. Since that funding ended, we rely on ourselves or on unpaid volunteers to assist us. The State does not seem to understand that many of us are not readers, do not write, or do not have access to technology. We are excluded from

participation when we are not given the time and the support we need to communicate.

The best way to engage with the National Platform of Self Advocates is to invite our members to a members' only meeting. This gives us the space to talk about issues that affect us. We usually find that when we are mixed in with other groups that people either do not give us a chance to speak, or else they speak for us or over us. We are well capable of sharing our own stories if small measures are made to include us. We feel we are regularly discriminated against around communication, consultation and public decision making.

We want the State to:

- Give us accessible information about public consultations.
- Hold accessible consultation processes that are designed by people with intellectual disabilities.
- Guarantee that our unique voice will be heard.
- Include us in policy-making from agenda-setting to implementation and evaluation.

Advocacy & Representation

People with intellectual disabilities need our own advocacy organisations. Research shows that when general disability groups try to represent us, our voices are lost. There are no elected politicians with intellectual disability who will speak up for us. There are even barriers to us voting.

When the National Platform of Self-Advocates was still funded, we were able to bring the voice of people with intellectual disabilities into lots of different forums. We had our say on Personalised Budgets, the Make Work Pay discussions, we have delivered training on the Assisted Decision-Making Act and been involved in trying to make Ireland fairer for people with intellectual disabilities since 2011. Lack of funding and lack of understanding of how we work means that most of our work has now stopped. We feel that we are being shut up on

purpose because including us requires more thought, funding and effort.

We want the State to:

- Give funding for a wide range of Disabled Persons Organisations so that unique groups can have their voices heard.
- Where there is competition for funding for advocacy activities, prioritise DPOs. This may mean taking money away from service organisations and giving it to volunteers in DPOs instead.
- Require that all official information is provided in accessible formats. This means every piece of information from every State department, not just information about disability issues. People with intellectual disabilities have the right to be included in every part of life.
- Require all political parties to publish their manifestos in accessible formats.
- Make polling stations accessible and make sure polling station workers know how to support people with disabilities.

Employment

Under the Comprehensive Strategy for People with Disabilities (2015-2024) the government is committed to increasing the public service employment target of people with disabilities to 6%.

There is no commitment to providing employment specifically for people with intellectual disabilities. Our needs differ greatly from people with physical or sensory disabilities. It is usually easier for employers to reach their quota by employing people with physical or sensory disabilities.

We want the State to:

- Measure the employment rates of people with intellectual disabilities separate from people with physical or sensory disabilities.
- Provide opportunities to meet the skills and expertise of people with intellectual disabilities.

Housing

The CRPD says that people with disabilities have the right to choose where we live and with whom we live (Article 19). We did research with people with intellectual disabilities to find out our experiences of housing across Ireland:

<http://thenationalplatform.ie/wp-content/uploads/2016/07/Our-Lived-Experience-of-Housing-and-Transport-The-National-Platform-of-Self-Advocates-2017.pdf>. Our research found that housing is much better than it used to be for people with intellectual disabilities, but that there are still some problems. People with intellectual disabilities are at higher risk of homelessness than the rest of the population, and many of us still live in shared settings that we would not choose.

We want the State to:

- Give us a say in the planning, design and development of housing and the community supports that are developed around new housing development.
- Make sure that every new housing development is designed in an accessible way.
- Provide supports (via local authorities) to help us get our own homes and become ordinary tenants.
- Make sure that new housing meets the emotional, social and physical needs of the people who will live there.
- Make sure that people with intellectual disabilities who are living in nursing homes because there is no suitable house for them are included in homelessness figures.

Transport

The CRPD says that the State should identify and eliminate obstacles and barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services (Article 9). In 2016 we did research with people with intellectual disabilities nationally to find out their experiences of using public transport. We experienced lots of barriers and discrimination in the transport system. The report can be found here: <http://thenationalplatform.ie/wp-content/uploads/2016/07/Our-Lived-Experience-of-Housing-and-Transport-The-National-Platform-of-Self-Advocates-2017.pdf>

We want the State to:

- Listen when people with disabilities tell about the barriers they experience.
- Include people with intellectual disabilities in the planning, design and operation of transport services and facilities in the future.
- Make all public transport - buses, trains, and taxis - fully accessible. There should not be limits on the number of disabled people who can travel at any one time. We should be able to travel without booking ramps and lifts in advance.
- Make all transport systems work together (integrated) so people with disabilities can travel safely and in comfort and be able to move easily between different types of transport.
- Improve communication by the bus and train companies about changes to services well in advance.