

Intellectual Disabilities and the UNCRPD

My name is Brian Hayes.
I am the Chair of the National Platform of Self-Advocates.

I am also on the Disability Advisory
Committee advising IHREC on monitoring
the government's implementation of the
CRPD.



I'll talk about the National Platform later, but first I want to talk about
my personal experience of the CRPD.

Independence

I'm lucky that I've always been fairly independent.
I have a job with Kilkenny County Council.

I have my own place to live.
I have a good life in the community.
I do what I want and I go wherever I want.

I wasn't always like this, and I see some of my friends and colleagues who still can't do like I do.

Making a Difference

Because I'm one of the lucky ones, I need to feel that I am making a difference.

What I have personally achieved

I have learned to become an advocate for myself and for others.
I have learned how to do public speaking.
I fit in with a lot of different groups and meetings.

I have been part of meetings in the Dáil and have met with ministers and CEOs of services.

I've learned to speak up even when it is uncomfortable.
I haven't been in my comfort zone for years!

What the CRPD means to me

I think the CRPD is like a guarantee for me.

It means that I have a right in the law to have independence, choice and freedom.

It also gives me hope that I can influence policies that affect me, and that I can build up some power.

People with intellectual disabilities haven't had much power in the past, but the CRPD is like a set of instructions that tell the government and the community how this should change.

How the CRPD can become a reality

We all know the saying 'nothing about us without us'.

The different articles of the CRPD tell us how that can become a reality.

They say that people with disabilities must be the ones making the decisions.

People with disabilities must be the ones deciding what issues are priorities, what policies need to be changed, and what research needs to be done.

Policy and Practice

Our experiences and what we need must be what policy and practice is based on.

The National Platform of Self Advocates

I'll talk a bit now about the Platform and DPOs and the challenges we face.

The National Platform as a DPO

The National Platform of Self Advocates was set up in 2011.
It was the first organisation formed as a DPO in Ireland.

From our very first meeting, our steering committee has been made up only of people with intellectual disabilities.

Our members are people with intellectual disabilities.
Only people with intellectual disabilities have voting rights at our meetings.

Challenges as a DPO

We still face some challenges when we try to participate in getting laws and policies changed.

I want to talk about 4 of them here:

1. Many people don't understand what a DPO is and why it is important
2. We speak up but we are still not being heard
3. Funding
4. Many people don't understand that disability is about rights, not just health.

The CRPD and DPOs

The CRPD is a roadmap for change.

As a DPO, our role is to make sure that new laws and policies are based on our needs and that they respect our rights.

What is a DPO?



We are worried that some people don't understand what a DPO is.

It's about who is in charge as well as who the members are.

DPOs must be led and directed by people with disabilities.

The CRPD Committee defined what a DPO is and what it isn't.

If you are an organisation and more than half of your final decision-makers are not people with disabilities, then you are not a DPO.

It's as simple as that.

Supports for DPOs

There is a place for other disability organisations and for non-disabled people who want to support people with disabilities.

They can work with us to see what campaigns we need, what changes we need, and do lots of important work.

But they can't speak for us. Only we can do that.

When the CRPD was being written they had to separate supporter groups from people with disabilities to make sure that people with disabilities had their voices heard.

Our Voice

As Chair of the National Platform of Self Advocates, I have been involved in a lot of policy consultations and high-level meetings.

I am in the room, but I don't always feel included.

When you have an intellectual disability, people don't always hear you.

Not being heard

People talk over us.

People nod and smile, but you know that they haven't understood what you are trying to say.

At the end of their project they may say they have included people with intellectual disabilities in their process, but we still don't feel that we are included in making decisions.

Tokenism and different disabilities

We don't want to be put on boards and brought in to research projects just so that someone can tick a box somewhere.

Some people working in the disability area just don't understand how it's different for people with intellectual disabilities.

They don't understand how to be fully inclusive.

What does inclusion mean for us

It's not just about ramps and having documents in plain English.

We need to change how meetings are held.

We need to change who leads meetings.

We need to change who is speaking.

We need guarantees that our voice is being heard and our ideas are understood.

Most of all we need to change how decisions are made.

The way things have been done up until now hasn't given people with intellectual disabilities any more control over our lives.

We need the whole thing to change.

Funding

The National Platform was funded by Genio and Atlantic Philanthropies until last year.

Minister Finian McGrath has kept us afloat on a month to month basis until now.

We have no funding now and we will close if we don't get funds.

What we mean by now is **this month** and not some time in the future.

Funding and the Government

There is a clear obligation in law for the government to fund DPOs.

We need core funding.

Minister Finian McGrath is trying to find funding for us.

The Department of Justice needs to accept that they have a responsibility to fund DPOs.

Rights are a matter for justice not health.

Rights

Disability has to stop being framed as a health issue.

I want to live my life based on my abilities, not my disabilities.

This is a matter of rights. The CRPD supports this.

The Department of Justice and Equality needs to accept that it is their responsibility to ensure that my rights are guaranteed.

**Conclusion:
Progress & what needs to be done**

I don't mean to be all doom and gloom.

There has been progress.

Understanding our contribution

Some facilitators and chairs of policy and research projects understand how the CRPD should be implemented.

They accept us as equals. They give us time and respect our views.

They take our experiences and put them at the centre of any policy decisions they make.

It can sometimes take a little bit of imagination to hear the point we are making.

Imagination needs empathy, patience and most of all respect for us as people who know what we want and what we need.

An example of being heard

An example of being heard is that we told the NDA in a recent consultation that we wanted them to include speakers with intellectual disabilities in their events and conferences.

They listened, and here I am today.

True inclusion

When you include people with intellectual disabilities, you include everyone else too.

People with intellectual disabilities can have autism, or use a wheelchair, or have hearing impairments.

We are one of the most excluded groups.

We understand challenges from different perspectives like no one else.

Listening to people with Disabilities

If you listen to us, and to other people with disabilities, you will understand how the CRPD can help us all. It can be used as a roadmap to change.

We can understand what needs to be changed by taking peoples' experiences and connecting them to the different rights in the CRPD.

History is not to be ignored

We all have to know the history of how the CRPD came about.

We have to understand that power was given back to people with disabilities in that process.

We have to understand that 'Nothing about us without us' means giving us power, and letting people with disabilities lead the way.

Thank you for listening