Joe McGrath Presentation to Oireachtas Committee on Children, Equality, Disability, Integration and Youth, 16 February 2022.

SHORT VERSION FOR ON THE DAY

My name is Joe McGrath and I am a Committee Member of the National Platform of Self Advocates. The Platform is an organisation for people with intellectual disabilities, run by people with intellectual disabilities.

On behalf of the Platform I have worked as a co-trainer with the Centre for Disability Law and Policy in Galway to teach staff in disability services about this law and what they need to do to get ready for it. I have been doing this for the past 4 years.

This law is very important for us, but we have not been given enough information about it.

Since the law was passed seven years ago, no one from government has told us what we need to do to get ready for it.

Now government is planning to make more changes to this law, before it will be fully up and running.

Government published a document with these changes that is almost 200 pages long. The language used in it is very complicated and so we don't know what these changes will mean for us.

This is not good enough. Everyone has the right to know what the law means for their life. There should be an Easy to Read version of the law so that we can understand it for ourselves.

Because there is no Easy to Read version, I worked with Eilionóir in the university in Galway to figure out what these changes will mean for the Platform and our members. But there are still a lot of changes that are very technical and hard to understand.

I think some of the changes the Government wants to make are good. Like changes to how complaints are handled, how expenses of people making decisions are paid, how a support person can be stopped by a judge if they are doing a bad job.

I think the decision about whether a court case is heard in private or not should depend on what the person with a disability wants. I think it is good that IHREC want to recognise their disability advisory committee in the law.

But I disagree with some of the changes the Government wants to make. I don't think people should be allowed to share information about a person with disability without their consent unless a judge says this is ok. Our privacy is very important to us.

I don't think people with intellectual disabilities should be ruled out of being on a jury just because someone thinks they can't understand what is happening in court. I don't think the NDA needs to be named in the law about IHREC monitoring the Government on disability rights.

There are other changes that I think should be in this law that are not there right now.

The law should make sure that people in charge – like the Minister, the Decision Support Service, and IHREC, talk directly to people with disabilities and the groups that represent them, like the Platform, to understand what we need to make the law work for us.

I think the Decision Support Service should write a new Code of Practice for people with disabilities to explain what the law means for us. They should also write one to explain the law to our families.

I think a lot of the changes Government wants to make to the old law will make it harder for people with disabilities to stay in charge of their own lives and keep making decisions.

I am not worried about people like me who can speak up and say what we want but I am worried about what might happen to people who are not able to talk for themselves.

Government has had a lot of time to come up with the changes it wanted to make to this law since it was first introduced 7 years ago. But in all that time, Government has not talked directly to people with disabilities to find out what changes we want to see.

In the Platform, we want to make sure that any changes to this law make it easier for people to make decisions and get support if they want to, not harder. We want Government, the Minister, the Department and the Decision Support Service to listen to us, and work with us. Nothing About Us, Without Us.