



TILII Response to the United Nations Convention on the Rights of Persons with Disabilities (Obligation on Public Authorities) Bill

Introduction

Since 1999, the Association for Real Change in Northern Ireland (ARC NI) has been bringing people together. We change thinking, change practice, and change the lives of people with a learning disability, autism, and other support needs. We work with Experts by Experience and the people, organisations, and communities that share our vision to put real change into action.

ARC NI facilitates the **TILII (Telling It Like It Is) groups**. These groups include advocates with a learning disability, autism, and other support needs living in the Belfast, Western, and Southeastern Trust areas. TILII also includes people currently living in Muckamore Abbey Hospital.

TILII members speak up for their rights, share experiences, and make sure their voices are heard in decisions that affect their lives. They create Easy Read materials, deliver training, take part in consultations, and produce films to share information in an accessible way. Advocacy is central to everything TILII does.

For this consultation, **47 TILII members** contributed. Members live in different settings, for example at home with family, in supported living, in residential care, and in hospital. This means their feedback reflects a wide range of real-life experiences from across Northern Ireland.

How to Read This Response

- The bullet points are TILII members' ideas and suggestions.
- The voices in quotation marks are TILII members' real lived experiences. They show *why* these ideas matter.

Q7. Tell us about your disability and experience

TILII members' ideas:

- TILII members experience includes having a learning disability, autism, a physical disability, mental health conditions, and chronic illnesses.
- Some challenges include understanding forms, using public transport, or accessing health care.
- Hidden disabilities can make life harder and sometimes lead to misunderstandings with the public.

TILII voices:

- “I can get very anxious in new places, and if it is noisy, it can become overwhelming. It would help to have more autism-friendly events and places.”
- “Hidden disabilities are a problem. Sometimes people get cross because they don’t understand us.”

Q8. How can we make sure voices are heard as the Bill develops?

TILII members’ ideas:

- Ask people with disabilities for their opinions often.
- Use Easy Read, pictures, and videos.
- Hold local meetings so people can attend easily.
- Support advocacy groups like TILII.
- Include people with a learning disability, autism, and other support needs on advisory boards.

TILII voices:

- “At ARC NI through TILII, we are often asked to give our ideas, and it makes us feel valued. More people should get the same chance. There should always be regular meetings with decision-makers, so our ideas are heard before decisions are made, not as a tick box or afterthought.”

Q9. Are there organisations or groups that have supported you?

TILII members’ ideas:

- Members live at home, in supported living, in residential care, and in hospital, and use many different services.
- Some examples include ARC NI, TILII, Positive Futures, Praxis, Mica Drive, and Fresh Focus.

TILII voices:

- “The TILII group helped me have the confidence to speak up about changes at my day centre.
- “I learned a lot from being part of TILII. They helped me understand my rights and speak up.”

Q10. How can more people understand why this Bill matters?

TILII members’ ideas:

- Share real stories showing barriers people face.
- Use Easy Read, pictures, and videos.
- Run workshops in communities and schools.
- Share on social media and in the news.

TILII voices:

- “People didn’t know I had the right to choose what support I wanted. I had to explain it to them. If more people knew, things would be easier for everyone.”
- “I want children and young people to learn about rights so they are respected from the start.”

Q11. The law is old. What do you think?

TILII members’ ideas:

- The Disability Discrimination Act 1995 is very old and out of date.
- All 47 TILII members said putting rights fully in law would remove confusion.
- A new Bill is needed to make services plan around our rights.

TILII voices:

- “Sometimes staff don’t follow rules. I get frustrated and upset because nobody checked my rights. A new law would stop this.”

Q12. Language – terms to include or avoid?

TILII members’ ideas:

- Use positive, respectful words: choice, rights, accessible, support, inclusion.
- Do not use words like handicapped or patients – see us as people!
- 28 members said human rights and inclusion should apply to everyone.

TILII voices:

- “I like it when staff use my name and ask what I want. It makes me feel included and respected.”
- “When letters are in Easy Read, I feel like my opinion matters just as much as anyone else’s.”

13. Who should check compliance with this Bill?

TILII members’ ideas:

- A board including NI Assembly members, disability organisations, and people with lived experience.
- People with a learning disability and autism should be part of the checking.
- Reports should be made public and in Easy Read.

TILII voices:

- “I would like to be part of checking the reports. It is important that people like me can say if services are really helping.”
- “If someone checks that staff are following the rules, it gives me more confidence to ask for what I need.”

Q15-6 Sanctions – what should happen if public authorities fail?

TILII members' ideas:

- There should be consequences so organisations cannot get away with ignoring the Bill.
- Publicly name organisations who fail.
- Require action plans with deadlines.
- Use the law if services keep getting it wrong.

TILII voices:

- “Staff did not follow the rules about my support. Nothing happened. It made me upset. If there were rules, this could not happen again. I want to know that if a service ignores the law, something will happen, so people are treated fairly.”

Q17. What impact do you want from public services in day-to-day life?

TILII members' ideas:

- Support to live in the community and make choices.
- Equal access to health care, education, and jobs.
- Services that listen to us and act on feedback.
- Staff who understand our rights and communicate clearly.

TILII voices:

- “I want to be able to choose my activities at the centre. It makes me feel independent and happy.”
- “If doctors explain things clearly, I can make better choices about my health.”

Q18–20. How would you describe your disability? How can the Bill include all needs?

TILII members' ideas:

- Disabilities can be visible, less visible, or hidden.
- Hidden disabilities are important and should be recognised by authorities.
- Services should check all types of disabilities are included when planning support.

TILII voices:

- “People don't always see my learning disability. They expect me to do things quickly. I need staff to understand this.”
- “I sometimes get tired quickly, but people don't notice. The Bill should make services aware of this.”
- “12 TILII members said we sometimes get into trouble with the public because people do not understand our disabilities.”

Q21. Do reporting obligations go far enough?

TILII members' ideas:

- Reporting is important but must show real change.
- Reports should be Easy Read and involve people with disabilities in checking.

TILII voices:

- "I want to read the reports in Easy Read so I know if things are improving."
- "Reports should include stories from people like me, not just numbers."

Q22. Thoughts on 'Due Regard'?**TILII members' ideas:**

- "Due Regard" is a good first step but we want it to become law so everyone has the same rights
- It should lead to full UNCRPD implementation in law.
- Public bodies should actively show they consider our rights.

TILII voices:

- "If staff think about my rights before decisions, it makes life fairer for me."

Q23–24. Should the Bill commit to full UNCRPD implementation?**TILII members' ideas:**

- Yes. Full implementation means all rights are in law.
- Human rights should be strong so inclusion is real.
- Public services would be accountable and change would last.

TILII voices:

- "I want to know that my rights are protected. It makes me feel safe and included."
- "Full implementation will stop people being left out because they are different."

Q25. How to deliver the Bill without big new funding?**TILII members' ideas:**

- Use current staff and resources better.
- Train new and old staff on rights.
- Involve advocacy groups like TILII to monitor and advise.

TILII voices:

- “Use people like us to train staff so they can learn about rights instead of waiting for extra funding.”

Q26. How to make this Bill a political and funding priority?

TILII members’ ideas:

- Share real stories of barriers and successes.
- Show supporting people properly saves money long-term.
- Run public campaigns to show wide support.

TILII voices:

- “When politicians hear my story from my own mouth, they are more likely to listen and understand why this law is needed.”
- “If the public sees how this law helps people, they will support it too.”

Q27. Lived experiences of barriers in services, work, social life

TILII members’ ideas:

- Barriers include inaccessible information, poor communication, not being included, and delays in services.
- Hidden disabilities are often ignored, leading to unfair treatment.

TILII voices:

- “I got told off in a shop because I didn’t understand quickly. Staff didn’t know about my autism and learning disability.”
- “At the doctor’s, forms were too long and confusing. I had to ask my support worker to help every time.”

Q28. Positive experiences

TILII members’ ideas:

- Good experiences happen when staff listen, explain clearly, and ask what people want.
- Easy Read materials help with understanding and choice.
- Being asked for our opinion makes us feel respected.

TILII voices:

- “At my day centre, they asked what I wanted and listened. It felt good to be included.”
- “I get to choose my own activities because staff bother to ask me. It makes me feel respected.”

Q29. What would good communication look like?

TILII members' ideas:

- Clear, simple, Easy Read information.
- Share information in advance.
- Use pictures or videos.
- Use sign language
- Check that we understand.
- Give us time don't rush us, please have patience.

TILII voices:

- "I like when staff show me pictures of what is happening. It helps me understand."

Conclusion

TILII members live in many different places – at home, in supported living, residential care, and in hospital, and use a wide variety of services including ARC NI, Positive Futures, Praxis, Mica Drive, and Fresh Focus.

From this consultation, TILII members are clear:

- Rights must be protected in law and made stronger.
- Hidden disabilities and individual experiences must be better understood.
- Real inclusion only happens when people with lived experience are part of shaping services and decisions.

TILII believes that by listening to people with lived experience, the new Bill will be fairer, stronger, and more effective.