Telling It Like It Is (TILII) Response

This Is Our Health Consultation

July 2026

Introduction

Since 1999, the Association for Real Change in Northern Ireland (ARC NI) has been bringing people together to change thinking, change practice, and change lives. We work with Experts by Experience, alongside individuals, organisations, and communities, to turn ideas into real, practical change that makes a difference every day.

ARC NI facilitates the TILII (Telling It Like It Is) groups. These groups are made up of people with a learning disability, autism, and other support needs from the Belfast, Western, and South Eastern Trust areas. TILII also includes people who previously lived in Muckamore Abbey Hospital and the one remaining patient still living in hospital.

TILII members speak up for their rights, share their experiences, and make sure their voices are heard in decisions that affect their lives. We create Easy Read information, deliver training, take part in consultations, and make films to share information in ways everyone can understand. Advocacy is not something TILII does, it is who we are.

For this consultation, 48 TILII members contributed. Members live in many different places, with family, in supported living, in residential care, and in hospital. Their views come from real lives and real experiences. They know what it feels like to be listened to and what it feels like to be ignored. They know what good support looks like and what happens when support is not there.

People with a learning disability, autism and other support needs still experience some of the biggest health inequalities in our society. Too often, information is not accessible, appointments are rushed, and decisions are made without us. We are living longer, and that is something to celebrate, but living longer must also mean living well.

1. What helps you to stay well?

The 48 TILII members who took part had lots of different ideas about what helps them stay well, but there were some clear messages.

All TILII members said that family and/or friends are what keep them well. They talked about the importance of having people around them who care, listen, and support them.

29 TILII members said that getting out and about, going to groups, volunteering, having a job, or taking part in activities helps their mental health and gives them a reason to get up in the morning.

23 TILII members said that feeling safe and having a good home helps them stay healthy.

15 TILII members talked about the importance of having enough money to buy healthy food, pay bills, and enjoy life.

36 TILII members said that being part of their community and not feeling lonely is important to their wellbeing. Some members said that loneliness can make people feel unwell.

Other things that TILII members talked about:

- Having information they can understand.
- Having support to make healthy choices.
- Being treated with dignity and respect.
- Having choice and control over their lives.
- Having people who know them and understand their needs.
- Doing exercise and going to the leisure centre.
- Eating healthy.
- Going to the doctor and taking the right medication.
- Good communication and understanding different people's communication needs.

Alex Belfast TILII said:

"Health is not just about doctors. It's about having a good life."

Joseph Belfast TILII member said:

"When I'm with my friends, I feel happier and healthier."

Overall, members said that staying healthy is not just about individual choices. It is also about having the right support, accessible information, opportunities in the community, and services that understand our needs.

2. If the health service could guarantee you something, what would you want that to be?

There was one message that came through very clearly. TILII want to be listened to and treated equally.

19 TILII members said they sometimes feel that people with a learning disability have to fight to be heard.

All TILII members said they want information in Easy Read so they can understand what is happening to them and make informed decisions about their own health.

ARC NI and TILII run the TILII Translates service, where Experts by Experience work alongside ARC staff to translate information into Easy Read. Members are incredibly proud of this work because they know that accessible information helps their peers understand their choices, have their voices heard, and make informed decisions about their lives and health.

For TILII members, Easy Read is not a nice extra, it is essential for equality, independence, and meaningful involvement in decisions that affect them.

All TILII members said they want doctors, nurses, and other professionals to understand learning disability and autism better, to be compassionate, and to understand people's individual needs.

17 TILII members talked about wanting more time at appointments and not feeling rushed.

Many members also said they want:

- To be involved in decisions about their own health.
- Reasonable adjustments to be made every time they use a service.
- Better access to mental health support.
- Access to annual health checks and screening programmes.
- Health services that work together and share information.
- Support that changes as people get older.

David Belfast TILII said

"Talk to me, not about me."

Corrina Bangor TILII said

"See the person, not the disability."

All TILII members want the same opportunities and the same standard of healthcare as everyone else. However, 27 TILII members also commented that healthcare needs to improve for everyone, not just people with a learning disability.

TILII Members felt strongly that everyone deserves good, accessible, and timely healthcare and that improving services for people with a learning disability would make healthcare better for everybody.

3. If the health service was able to make that guarantee, what could you do to help make that possible?

TILII members believe that staying healthy is everyone's responsibility and that we all have a part to play.

All TILII members said they would:

- Attend appointments and health checks.
- Take medication as prescribed.
- Ask questions if they do not understand.
- Try to eat healthy foods and stay active.
- Learn more about staying healthy.
- Support friends and family to stay healthy.
- Cancel appointments they cannot attend.
- Share their experiences to help improve services.
- Have patience.
- Make sure they are looking after themselves.
- Keep themselves safe.

5 TILII members also talked about the fact that some people have a fear of hospitals and may need support to overcome this.

However, members also said something very important: people cannot always stay healthy on their own. Some people need support to understand information, get to appointments, afford healthy food and activities, or stay connected to their communities so that no one feels lonely or isolated.

Jonathan Downpatrick TILII said:

"I want to look after my health, but sometimes I need support to do that."

Members felt strongly that staying healthy should be a shared responsibility between people, communities, and health services.

4. Any other comments?

There was a real sense of hope in this discussion.

All TILII members said they are proud that people with a learning disability are living longer and having more opportunities than in the past.

Several members who previously lived in Muckamore Abbey Hospital spoke about how much their lives have changed since moving into the community. They talked about having more freedom, making choices, and being part of everyday life.

However, four TILII members also said that they miss the sense of community and the friendships they had in Muckamore. They spoke about the importance of the relationships they built there and the sadness of losing regular contact with friends who were a significant part of their lives.

Their comments remind us that moving from hospital into the community is not just about changing where someone lives. It is also about helping people maintain important relationships, build new connections, and feel that they belong.

However, all TILII members said that living longer is only part of the story. People want to live longer and live well.

As part of Learning Disability Week 2026, TILII and ARC NI launched our Living Longer, Living Well campaign. Through films and personal stories, people with learning disabilities shared what growing older means to them and what helps them have a good life.

All TILII Members said that living well means:

- Having good health and being able to access healthcare when needed.
- Having friends, family, and people who care about you.
- Staying connected to your community and not being lonely.
- Having things to do and places to go.
- Having choice and control over your life.
- Being listened to and treated with dignity and respect.
- Getting the right support as your needs change.
- Having a learning disability is part of who we are and should never be seen as something negative.

27 TILII members said that people with a learning disability still face barriers that other people do not. They said information is often inaccessible, services do not always understand their needs, and sometimes they still have to fight to be heard.

TILII Members said they want:

- Better access to health information.
- Better mental health support.
- More opportunities to stay active and connected.
- Better support for carers and families.
- Staff who understand learning disability and autism.
- Services that work together and see the whole person.
- More focus on prevention and helping people stay healthy as they age.
- Decisions made with people, not for people.

Peter Bangor TILII said

"I don't just want to live longer. I want to live well and enjoy my life."

Martha Bangor TILII said

"We don't want special treatment. We just want the same chances as everyone else."

Richella Bangor TILII said

"Everybody deserves a good life, no matter what disability they have."

Living longer should be one of Northern Ireland's greatest success stories. The challenge now is making sure that people with a learning disability do not just live longer, but live well, stay connected, and enjoy the same opportunities as everyone else as they grow older.

Thank you for giving TILII members the opportunity to share our experiences and hopes for the future. We want a Northern Ireland where people with a learning disability do not just live longer but live well.