



## **Telling It Like It Is (TILII) Response**

Consultation on Learning Disability Service Model –  
'We Matter'

November 2025

## Introduction

Since 1999, the Association for Real Change in Northern Ireland (ARC NI) has brought people together to change thinking, change practice, and improve the lives of people with a learning disability, autism, and other support needs. We work with Experts by Experience, alongside individuals, organisations, and communities, to turn this vision into real, practical change.

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 South Eastern Trust areas. TILII also includes people currently living in Muckamore Abbey Hospital.

TILII members speak up for their rights, share their experiences, and ensure 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, **46 TILII members contributed.**

Members live in a variety of settings, including at home with family, in supported living, in residential care, and in hospital. Their feedback reflects a broad range of real-life experiences from across Northern Ireland.

Each session followed the same format:

- The Six Dreams (Ambitions) – what life should look like for people with learning disabilities.
- The Delivery Plan – how services plan to make those dreams happen.

At the end, participants were asked: “What should happen first?”

Members emphasised that while the six dreams sound positive, good ideas alone are not enough. Many have seen ideas before that never came to life. They want practical solutions, clear accountability, and sustainable change.

## **Part 1 – The Six Dreams: What Life Should Look Like**

### General Overview

TILII members agreed that the six dreams describe what a good life should look like but stressed the importance of practical delivery.

The biggest concerns were around consistency across Trusts, staffing, funding, and follow-through.

### **1. Life Changes**

#### **What is working well in services:**

- Named workers exist in some services and help with transitions.
- Early planning sometimes happens in schools.
- Families are occasionally involved in transition planning.

#### **What is not working well in services:**

- Transitions between child and adult services are inconsistent or missing.
- Named workers change too frequently, reducing continuity.
- Plans are sometimes not fully implemented.

#### **Agreement: 41 TILII members support Dream 1 – 5 not sure**

#### What TILII members liked:

- Planning early, ideally from the start of senior school.
- Having a named worker to help people navigate services.
- Families being involved in planning and decision-making.

#### **Concerns / Reality Checks:**

- Transition support between child and adult services is often lacking.
- Named workers sometimes change, meaning plans are not followed through.
- Information Hubs could become overwhelming if not well designed.
- Plans exist but are not always implemented, which reduces trust.

#### **Ideas / Suggestions:**

- One easy-to-use central hub for service information and self-referral.
- Transition workers should remain consistent and communicate across services.
- Plans should be reviewed regularly and progress reported to families and individuals.

- Include peer mentors to support transitions.

## **2. Health and Wellbeing**

### **What is working well in services:**

- Annual health checks occur for some, especially those with complex conditions.
- Hospital Passports and liaison nurses exist in some areas.
- Some staff receive disability and communication training.

### **What is not working well in services:**

- Health checks are inconsistent; some people are missed entirely.
- Hospital Passports are often brief and impersonal.
- Reliance on a single Learning Disability Doctor is unrealistic.
- NHS delays and staffing shortages prevent ideas from being fully implemented.

### **Agreement: 46 TILII members support Dream 2**

#### What TILII members liked:

- Annual health checks, Hospital Passports, and liaison nurses.
- Linking health checks into care plans.
- Training for health staff in communication and disability awareness.

#### **Concerns / Reality Checks:**

- Health checks are inconsistent and some people are missed.
- Hospital Passports often feel short or impersonal.
- Relying on a single Learning Disability Doctor is unrealistic.
- NHS delays and staff shortages make some initiatives impractical.

#### **Ideas / Suggestions:**

- Make annual health checks mandatory.
- Provide communication and disability awareness training for all health staff.
- Easier booking systems with automatic reminders.
- Prioritise treatment for people with complex needs.
- Include older people and those with dementia in plans.
- Use digital solutions like apps and digital passports to improve accessibility.

### **3. Families and Carers**

#### **What is working well in services:**

- Some families have a named contact.
- Short breaks and respite opportunities exist.
- Carers are occasionally involved in decision-making.

#### **What is not working well in services:**

- Direct Payments are not available in all Trusts.
- Families can “slip through the cracks” when staff change.
- Ideas often exist on paper but lack funding or delivery.

#### **Agreement: 44 TILII members support dream 3 – 2 not sure**

#### **What TILII members liked:**

- Named contact for each family.
- Short breaks and flexible carer support.
- Recognition of the vital role of carers.

#### **Concerns / Reality Checks:**

- Direct Payments vary across Trusts, leaving some families unsupported.
- Families can slip through the cracks when staff change.
- Some carers fear losing respite if the person moves to supported living.

#### **Ideas / Suggestions:**

- Every family should have a named advocacy contact.
- Use carers registers actively to provide real support.
- Short breaks should be more frequent and flexible.
- Self-Directed Support should be clearly explained.
- Consult the person first, not only carers.
- Ensure funding and staffing are in place before introducing new initiatives.

### **4. Meaningful Lives and Citizenship**

#### **What is working well in services:**

- Opportunities for work, volunteering, and social activities exist in some areas.
- Staff receive some training for complex needs.

- Day centres and local community engagement occur for some members.

**What is not working well in services:**

- Transport is expensive and inconsistent.
- Community activities may not support people with complex needs.
- Day centres remain essential; closures would reduce participation.
- Funding and staffing shortages hinder sustainability.

**Agreement: 46 TILII members support dream 4**

What TILII members liked:

- Access to work, volunteering, learning, and social activities.
- Staff trained to support people with complex needs.
- Being part of their local communities.

**Concerns / Reality Checks:**

- Transport is expensive and inconsistent.
- Community activities may not accommodate complex needs.
- Day centres remain essential for many people.
- Funding and staffing shortages threaten sustainable participation.

**Ideas / Suggestions:**

- Create paid work placements as well as voluntary opportunities.
- Build peer advocacy networks.
- Regional forums to co-design activities with people supported.
- Include friendships and relationships in care plans.
- Fund community initiatives long-term and address transport barriers.

## **5. Home**

**What is working well in services:**

- Supported living and adapted housing exist in some areas.
- Housing needs are sometimes reviewed.
- Accessibility adaptations occasionally happen.

**What is not working well in services:**

- Housing availability is limited.

- Adaptations can take months.
- Poor housemate matches can impact mental health.
- Supported living is difficult to sustain with current staffing levels.

**Agreement: 45 TILII members support dream 5 – 1 not sure**

What TILII members liked:

- More supported living and adapted housing.
- Housing needs should be regularly reviewed.
- Accessible and adaptable homes.

**Concerns / Reality Checks:**

- Housing crisis limits availability of suitable properties.
- Adaptations take months to complete.
- Poor housemate matches can affect mental health.
- Supported living can be difficult to sustain without proper staffing.

**Ideas / Suggestions:**

- Make accessible housing standard.
- Build small flats or shared homes with on-site staff.
- Create regional crisis housing to prevent unnecessary moves.
- Improve maintenance and adaptation times.
- Allow pets to support wellbeing.

**6. Mental Health and Behaviours of Distress**

**What is working well in services:**

- Some crisis services and specialist teams exist.
- Staff receive some behaviour support training.
- Links between learning disability and mental health services exist.

**What is not working well in services:**

- 24/7 crisis support is not consistently available.
- Waiting lists are long.
- Mental health services are already under pressure for all.
- Consistency varies across Trusts.

## **Agreement: 46 TILII members support dream 6**

What TILII members liked:

- 24/7 crisis services.
- Specialist teams and trained staff.
- Better links between learning disability and mental health services.

### **Concerns / Reality Checks:**

- 24/7 crisis support requires significant staffing and funding.
- Waiting lists are long.
- Mental health services are already stretched.
- Consistency across Trusts is unclear.

### **Ideas / Suggestions:**

- Mandatory behaviour support training, regularly inspected.
- Mental health specialists available at all times.
- Provide counselling, talking therapies, and WRAP plans.
- Mental Health Champions in every Trust.
- Use technology to monitor wellbeing.
- Expand specialist inpatient beds.

## Part 2 – Delivery Plan: How Services Will Make It Happen

TILII members felt the plan covered the right areas but questioned whether it can realistically be delivered.

Key points:

- Ambitions must be properly resourced.
- Clear accountability and timelines are essential.
- Progress should be reported back to people supported.
- A national database linking services could reduce confusion.
- More supported living and housing must be fully funded.

## Part 3 – Big Question: What Should Happen First?

TILII members ranked the six dreams in order of priority:

Dream	1s	2s	3s	4s	5s	6s	Total Score
Health and Wellbeing	12	10	8	6	5	5	198
Meaningful Lives & Citizenship	10	12	9	7	5	3	187
Families and Carers	8	9	12	7	5	5	177
Home	7	6	8	12	7	6	162
Mental Health & Behaviours	5	4	5	6	15	11	140
Life Changes	4	5	4	8	9	16	131

TILII members focused on practical, immediate supports for daily life. Health and social participation are the top priorities, while long-term planning (Life Changes) was ranked lower, reflecting that members want visible improvements now, not just aspirations for the future.

## **Summary**

TILII members strongly support the six dreams but want to see action, not just words.

Key messages:

- Health, social participation, and meaningful community life must come first.
- Ideas often fail because of funding, staffing, and inconsistent delivery.
- Solutions must be practical, sustainable, and monitored.
- Technology, peer-led initiatives, and local projects can support delivery if resourced.
- Involvement of people supported, families, and carers in planning and decision-making is essential.

TILII members are hopeful and willing to contribute to change, but they want proof that this time, the ambitions will be implemented.