



Consultation Response submitted by  
Telling It Like It Is (TILII)  
Proposed Closure of Muckamore Abbey Hospital  
January 2023

Our Telling It Like It Is project is a group of adults with a learning disability who are keen to have their voice heard. Originating out of the resettlement agenda and part funded by Belfast; South-Eastern and the Western Health & Social Care Trust, groups operate within local communities and hospital settings. TILII are highly experienced in delivering training, undertaking research, contributing to public consultation processes, and delivering workshops and presentations at events.

This response was developed and collated using the views of 50 TILII members.

For this consultation it is important to explain the lived experience of TILII members responding to this consultation.

15 TILII members are either current or previous patients at the hospital. Of those that are current patients, some have been a resident of Muckamore Abbey Hospital for decades however are currently feeling a growing pressure to move to a different place. There is heightened fear, anxiety and in some cases anger, felt by these individuals, many of whom have been institutionalised.

A further 7 TILII members have accessed facilities within the hospital on various occasions, for example the hydro pool.

The remaining 28 TILII members have not had any contact with the hospital but to varying degrees, are aware of recent media and news reports regarding the scandal.

In advocacy it is important that full explanation and transparency is provided to empower individuals to have their voice heard and most importantly understood. This consultation was very difficult to explain due to a lack of clarity of the position facing Muckamore Abbey – namely a full closure following resettlement of those ready for discharge, or a repurposing of services to resume to an Assessment & Treatment facility. The questions could therefore deliver a response which is misunderstood without a contextual understanding.

**It is important to start with the confirmation that all 50 TILII members felt that resettlement needed to be completed.**



**Furthermore all 50 TILII members felt there was a need to ensure that sufficient Assessment & Treatment services and support were available when a person with a learning disability required it.**

When asked their views on whether Muckamore Abbey Hospital should close, 48 TILII members said no. This was on the basis that some currently, and in the past, have needed to access treatment because they have become unwell. Nine TILII members who have not needed treatment in their lives said “It could happen to any of us at any time in our lives, so it is important the support is there.”

48 TILII members said they are aware, to differing degrees, of what is happening at the hospital with the allegations of abuse and ongoing police and public investigations. However, 11 TILII members said that a physical building cannot be held accountable for the alleged scandal and 15 TILII members said that the poor running of the hospital included management at the top, as well as some staff on the ground. They went on to state that it is unfair to assume or suggest that all staff and management had been poor during their time in the hospital.

1 TILII member (recently resettled) felt it should stay open because Muckamore has got a lot of fantastic services, facilities and staff. Examples given were day care. Physio, Speech and Language Therapy, Occupational Therapy, Alternative Therapy, clinics as well as the swimming pool. The TILII member went further and suggested a significant lack of learning disability (specialist) hospitals and community based services throughout Northern Ireland. “I feel if Muckamore Abbey Hospital closes it will leave a lot of pressure on staff and places that the patients are being resettled into, to the point that they can’t be staffed or the person’s support needs are not being met, and then what happens to the people who have resettled next?”

1 TILII member described themselves as ‘institutionalised’. They confirmed they were unsure if this was because they had been in and out of care since childhood, including a short stay in prison, or because of an extremely difficult home life. What they did confirm was that the few times they had been in the community, they struggled and stated the hospital feels safe.

TILII members recognise that each person is an individual and 19 TILII members fed back their understanding that if a person had felt happy living somewhere (in Muckamore) for over 25 years, why would they want to move?

23 TILII members felt that being forced to resettle when a person didn’t want to, could be detrimental to their mental health and as a result, the person could suffer more/further delays to a successful resettlement. 1 previous patient who uses the hospital facilities says they have seen some of their friends’ (patient) health suffer with the constant talk of the hospital closing alongside the fear they will be forced to leave (resettle).



TILII members consistently expressed a frustration of people having a view when they have never walked in the shoes of a Muckamore patient, stating that they were tired and annoyed that people who did not have lived experience were saying that a hospital should not be a home. This they felt could be experienced by patients as quite arrogant. 1 TILII member said “If you are in the hospital, then it is where you live and it is your home, especially if you have lived there for a long time like some of us have.” Another TILII member said “Who tells you where you should and should not live, how do you know your life in the community is better than ours was or is, in the hospital?” In short, TILII agreed that patients (past and present) are experts by experience.

1 other TILII member who has resided in the hospital for a long time said the hospital is their home and they do not want to leave. They went on to confirm they have capacity, they understand what they want and stated the anger felt when others who have not lived their life, make decision including trying to force them to move out. They stated, “It should only be current patients, previous patients and carers/staff who have worked in or with the hospital, or have been involved with patients for resettlement etc., who should have the right to make comments or suggestions about where I should live.” They went further and acknowledged whilst they had witnessed some poor practice there has also been some excellent staff and management who have gone above and beyond to support patients.

Those 48 TILII members felt a solution was to use the current site but to ensure that the hospital is run with proper oversight, to include accountability, well trained staff and strong management. 18 TILII members suggested that if remaining open, there should be a Board which must include a patient representative and a parent carer. This would ensure any information can be discussed with all patients, and any decisions can take into account the views of all patients. 1 previous patient also highlighted that some patients due to mental capacity may be involved to differing degrees, but that all patients need to be heard.

11 TILII members suggested that the hospital grounds are big and have some buildings that are no longer used. These could be refurbished to ensure there is room for long term patients who want to stay. This way they continue to use hospital facilities and services whilst not bed blocking for any new patients coming in needing treatment.

2 current patients and 1 previous patient went further and stated their feeling that if their choice is to live in the hospital what right does anyone have to deny that. They went on to say that people have the right to choose their living option they feel is right for them.

1 patient said it should be closed, though they confirmed they have had only good experiences at the hospital. They are unsure the hospital will be able to get past the stigma of the abuse scandal and suggested closing Muckamore Abbey Hospital and



re-opening a hospital in a different place and with a different name. 1 other TILII member who had some negative experiences in the hospital many years ago also felt this was a good idea.

## **Resettlement**

The delays and failures to complete resettlement for individuals, and their families, has been an ongoing issue that needs to be addressed with everyone working together.

All 50 TILII members stated that every patient must be treated as an individual and that any transition requires a lot of care, thought and understanding. They went on to confirm this must be done in partnership with open and honest communication, including and especially with, the person whose resettlement journey it is.

15 TILII members shared their view that parts of the community are still not ready for people who present with behaviours that challenge. An example described from personal experience of a TILII member was as follows, "Neighbours did not like the noise my house mate made in the garden. Neighbours did not like the number of cars (staff) parked at my home and neighbours were hostile towards us because they did not want to take the time to get to know us and give us a fair chance to be part of the community."

9 TILII members who lived on their own or in a group setting however commented on their positive experience of living in the community, including what good neighbours they had.

11 TILII members said there is not enough accommodation and staff to support people with a learning disability, and those with complex needs living independently in the community.

9 TILII members went further and shared their personal experience, or that of their friends, in having to return to the hospital because their homes in the community did not work out for them.

12 TILII members, both past and present patients, also wanted to highlight that they were involved in hospital resettlement discussions including being part of the Community Integration Project (CIP), which saw providers, NI Housing Executive, HSC Trusts and the former Health & Social Care Board working together to monitor the progress of resettlement. At these meetings, TILII members as patients shared their own and other patients' stories to highlight both good and bad resettlement stories. The idea of this was twofold - to make sure patients voices were heard and to ensure any positive stories were highlighted and any poor stories were discussed so that lessons were learnt to help improve other patients' resettlement journeys.



When the CIP meetings abruptly stopped, TILII challenged this but to little effect. 1 TILII member stated “It is embarrassing that the people who are resettling are not involved in meetings about their own lives!” 12 TILII Members went further, stating their involvement should have never been stood down and this poor practice is at a time when the Trust, staff and communities constantly talk about co production, including services should be led by the people who use and need them!”

TILII members who are current patients of Muckamore Abbey Hospital have written to the Chair of the Oversight Board to say they need to be involved with any ongoing resettlement meetings again to ensure their views are heard.

### **Do you have any further comments?**

#### **Trauma**

All 50 TILII members also wanted to state that any patients who have been on the receiving end of abuse and their families should be supported to allow them to get through the trauma. 18 TILII members went further acknowledging the impact felt by victims and their families could require years of expert support. TILII felt this should be provided no matter the time or financial cost.

TILII would like to thank you for giving us the opportunity to respond to this consultation.