



Consultation Response

Telling It Like It is 'TILII'



CONSULTATION ON THE MENTAL HEALTH STRATEGY 2021-2031

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. TILII recently facilitated a review of day services across their peer group who receive support from the Belfast Trust. TILII members also deliver a professional and efficient Easy Read service (TILII Translates) to all sectors, as part of our commitment towards improving access to information for all.

This response was developed and collated using the views of 51 TILII members (10 of which currently reside in a hospital).

Vision and Principles

TILII think it is really important to have a shared collaborative approach to meeting the mental health needs of all people living in Northern Ireland. TILII are pleased that you recognise people with a learning disability as part of this process as we need as much support with our mental health as everyone else, if not more.

One TILII member gave an example of how their Autism causes them to have really high anxiety levels. In fact, research shows that people with a learning disability with an Autism diagnosis do have higher anxiety levels than the mainstream population.

Mental health though more globally accepted than it used to be, still carries a stigma with it and people make judgements about people who have Mental Health problems. This is further added to for people with a learning disability, so TILII members feel it is really important that we help people to understand how difficult mental health can be, so we don't have to keep hiding our problem to protect ourselves from people who judge us or treat us badly. Covid is causing lots of people to struggle and have poorer mental health which is sad, but maybe it will help people be more understanding because they will have a greater idea of how we feel and see how hard life can be if you have a learning disability and a mental health problem.

Theme 1

Promoting wellbeing and resilience through prevention and early intervention

Prevention and early intervention is really important, all TILII members expressed agreement with this. One TILII member explained how tough their childhood had been and how the “trauma made me behave badly, and I was always getting into trouble”. This led to them being in a hospital before their 9th birthday. They moved from hospital to a care home and for a short time, they lived in the community but soon ended up in prison before being transferred to hospital because of their learning disability and mental health. They recognise they could not control their emotions or behaviour and for the short time in prison, they met other people like themselves who had a learning disability and mental health problem. These other people however were not transferred to hospital.

This TILII member went further to explain that they felt there was a lot of people in prison with mental health problems, and there needs to be more help to stop them offending again or going into hospital. They feel the trauma in their life has just made their mental health worse and they now hear voices which makes life even harder. They are not able to live in the community as they still feel unable to cope. They hope that by making sure families have early intervention this may lead to better chances for people as they would not wish anyone to go through the life they have.

Some TILII members also mentioned that sometimes people with a learning disability's mental health is overlooked. They said this was because their behaviours are put down solely to their learning disability and this is not always the case. Sometimes it is the way they feel and examples of anxiety or a trauma were given as causes of some of their inappropriate behaviours. That is why all TILII members agreed everyone's mental health should be looked at along with our learning disability and physical health. There are people with a learning disability who do have a mental health condition but do not have a mental health diagnosis.

The suggestion of more talking therapies is greatly received by TILII members. They all felt this was crucial, as having the ability to understand, control and express emotions can be difficult for us all but especially for people with a learning disability who may have not developed behaviour regulation or emotional resilience coping strategies, so more talking therapies is definitely a good idea. Making sure the therapies are inclusive of people with a learning disability, for example, the modified versions of CBT (cognitive-behavioural therapy) and also DBT (dialectical behaviour therapy) that is specifically adjusted for people with a learning disability. However, TILII want to make it clear that some of their peers who have no verbal communication must have alternative communication techniques, for example Makaton, Pec's, Talking Mats etc. and dependent on cognitive ability, other alternative therapies like art therapy, music therapy and relaxation therapies like mindfulness. TILII feel family therapy is also very important, especially for early intervention as it allows family members to express and explore difficult thoughts and

emotions safely, helping them understand each other's experiences and views, appreciate each other's needs and build on their strengths. It can help with many issues that affect the family unit, helping people make useful changes in their relationships and their lives. This would possibly have helped the TILII member spoken about earlier in this section, preventing him from spending most of his life in and out of hospitals etc.

Theme 2

Providing the right support at the right time

TILII agree that the treatment for mental health should be as important, as treatment for our body health. If your body is healthy but your mind is not you can still become really ill and die. Sometimes people are so ill in their head they become suicidal and take their own life. If we were treated at the same time for both, it might be less money in the long run as hopefully mental health problems will improve along with physical health. TILII feel it is crucial that experts/doctors with mental health experience, work with experts/doctors with learning disability experience along with experts that know how to deal with body illness so we have our whole well being dealt with in one go.

It is important that people with really serious mental health problems who are in a bad way can get immediate help, this could be done over the internet. It would need some background work as not all people with a learning disability are digitally active. Some TILII members only get access to WI FI/digital platforms when they are attending TILII meetings or day opportunities, so this would need to be addressed. TILII felt there should be an accessible expert either on the screen or on a phone ready to provide the appropriate support 24 hours a day in each Trust area. As well as being a quick way to access expert help it may also reduce suicide if there was help on hand 24/7. TILII also thought that support through the internet could help eliminate the stigma associated with accessing a community or hospital-based facility, as it can be accessed from your own home.

TILII felt the right hospital/treatment centres with a positive environment, well trained staff and experts on hand for people who are in need of treatment is really important. These hospitals/treatment centres need to be well run and TILII suggest all of them have a small team of experts. Experts should include a family member, a service user with mental health and a service user with mental health and a learning disability etc., who are specifically there to regularly monitor the hospital/patient experience to make sure we know the service is good. This will make sure we are meeting everyone's needs and address any issues that arise immediately and hopefully remove any culture of issues happening and going unnoticed because no one is asking or regularly checking patient experience.

Theme 3

New Ways of Working

TILII members agreed with a Centre for Mental Health and said that “any research that may help us find better ways to help everyone to have a more positive well-being must be a good idea”.

As already mentioned earlier, staff trained relevant to their job is absolutely essential. Staff need to be consistent in their practice, for example as this can help with anxiety. It is easier if we get to know someone and build a strong relationship of trust. Some TILII members also recognise that it is not good for anyone to become self-reliant on just one member of staff as if that member of staff is ill or leaves that could itself become a problem for someone’s mental health. TILII feel it is about having a team of people to provide individualised support as needed but also to offer a consistent amount of staff who people can get to know and trust.

Finally, it is crucial that Co-Production is there throughout all of the strategy. People who are experts by experience should be engaging with their peers to make sure the mental health service across Northern Ireland is a good service that helps people with or without a learning disability, to have their voice heard. This will help continued improvements of the service which in turn should help improve the mental health of everyone in Northern Ireland including people with a learning disability who have a dual diagnosis of a learning disability and a mental health condition.