

# **The use of restrictive interventions, restraint and seclusion**

## **Consultation response from a sample of people with lived experience**

**December 2020**

ARC NI facilitates the Telling It Like It Is (TILII) project which consists of groups of adults with a learning disability who are keen to have their voice heard. TILII groups operate across the following Trusts namely Belfast, South Eastern and Western. The meeting of TILII members occurs within both local communities and a hospital setting.

ARC NI is committed to increasing the capacity of people with a learning disability to have a say in issues that affect their lives. One of the ways ARC NI does this is by supporting their contributions to public consultation processes.

The Department of Health is completing a review of the use of restrictive interventions within health and social care settings and local governance arrangements, including restraint and seclusion. The DoH approached ARC NI, amongst others, for support to gather the views of a range of people with a learning disability, who may have been in a situation where they have experienced or witnessed any restrictive interventions. ARC NI agreed to support TILII to be empowered to give their suggestions and opinions enabling them to work together in partnership to develop and expand HSC services, be partners in the care that they receive and improve quality of care delivery, promoting quality of life.

The DoH will use the information gained through consultation to develop a framework that will focus on what individuals and/or groups of people believe can and should be done to minimize and/or prevent the use of these types of interventions.

### **Methodology**

Due to the sensitive nature of the consultation topic alongside the recognition of the potential to cause distress to individuals who have experienced any restrictive practices, each participant was interviewed on a one-to-one basis.

They were supported to share their first-hand experience of restrictive practices and the impact of these interventions on people, followed by an exploration of their suggested options for improvements.

22 adults with a learning disability took part, of which:

- 11 people were from hospital setting
- 3 people were from a residential setting who have had lived experience of hospital settings
- 6 people were from supported living, who have had lived experience of hospital settings
- 1 person who lives with family but has lived experience of hospital settings and supported living.
- 1 person who lived with parents and now lives alone with support from a sibling.

Where the report describes community settings, this includes family homes and community services.

## Feedback

### Restrictive Interventions (in general)

All twenty-two individuals spoken with had actual lived experience of restrictive interventions.

#### Key themes:

#### 1. For those living in hospital

People currently living in a hospital setting had varied views dependent on the type of restrictive practice in place.

For example, those individuals' who are detained under the secure component of care experience additional levels of security, such as locked doors, procedural security, such as control of various items coming into the ward, and restrictions on use of their own property for example their personal mobile phones.

Five people who are currently detained felt the restrictions on their use of mobile phone was justified. They understood that recording applications such as photo and video could be used to intrude into the lives of other patients. They were able to give examples of the use of cameras and video to take images of service users and staff which could compromise the dignity and privacy of said individuals. They also understood that sensitive personal data about an individual's mental or physical health can be utilised in a harassing or abusive way, and that images or personal data could be transmitted anywhere and to large numbers of people within moments and without the consent of the individual. This level of understanding was described by those who had capacity. For those who have reduced capacity there was a lesser degree of understanding the restrictions placed on personal mobile phones.

However, a further two people were very unhappy with the restrictions describing them as "... too extreme". A specific individual who also suffers from multiple mental health conditions explained that they have normal sexual needs however the restriction of his phone at night was felt to be detrimental to his health. He explained that he was unable to access pornography channels which helped him to relieve his sexual urges. In turn this helped his mental health which had a direct positive effect on his behaviour. He said he had not committed any sexual offences, so watching pornography should not be a restriction so long as he does it in his own time in his bedroom. The second person who is on the autistic spectrum struggled to understand why his phone was restricted and described this as causing him to feel anxious and upset as his phone was very important to him.

More generally, seven of the eleven people currently residing in a hospital setting questioned the locking of the kitchen and felt aggrieved at having to ask for example, to make a coffee or access snacks. They felt this was inappropriate and stated the kitchen should be open at all times, removing the need for patients to request access. One patient acknowledged that safety may be influencing this free access and suggested if so, measures could be put in place such as limiting numbers in at any given time and staff available to support and monitor the kitchen activity.

All patients across all wards felt that the locking of doors was acceptable though in the conversations, all made reference to this measure affecting visits in and out of the hospital and the impact this had on their mental well-being.

For those that had capacity, they appeared to understand that staffing shortages can have a huge effect on visits and the recent pandemic has further contributed to this. However, one patient described the impact of this stating "... cannot handle it if I miss an outing due to shortage of staff/sickness and I get very distressed even though I know afterwards this was not the correct way to behave".

Three patients felt that staff shortages or sickness should not affect them being able to live their life nor should it restrict their movements. They fed back this was against their human rights and even though some of them are detained due to criminal offences, they were still allowed out to some degree. Their suggestion of improvement was that the right levels of staff should always be available to ensure the upholding of their rights.

## **2. For those living in community**

Of the remaining eleven people interviewed from community settings, ten referred to direct experience of restrictive practice when they were living in a hospital setting. Six felt that there should be better communication between staff and patient, explaining what is happening. They fed back in their experience that situations often got out of control because people are not told what is happening and why. Four individuals were unable to offer any ideas for improvement as thinking back to these times proved distressful.

The final participant had always lived in the community but as described by himself, had experienced a very restricted life, enforced by his parents. Experiences he described included not being allowed to make friends, go out when he wanted or even spend his own money on things he wanted. There was an expectation that said individual undertook a carer role as his parents aged and until their passing, the individual describes his life up until that point as "... never been allowed to live a life of my own choice". The individual confirmed it was a loving home and no physical harm ever came to him, but acknowledged if more interventions from professionals had been offered at an early stage as support to his parents, this may have enabled him to have more freedom.

## **3. Coercion and control**

There were a few examples provided by individuals across both settings where incidents involving staff and/or family members involved coercive and/or controlling behaviour. They described these in the context of restrictive practice.

## **Particular interventions and experiences**

### **1. Physical Restraint**

From discussions with the 22 individuals:

- 21 had experienced restraint in a hospital setting; of which
- 3 had also experienced physical restraint in a supported living setting
- 1 had no experience of restraint

Of the twenty-one individuals who had experienced physical restraint in a hospital setting, the following key themes were identified.

Individuals stated in their experience that all physical restraint took place following behavioural incidents, including:

- disagreement with other patients;
- as a result of the patient becoming upset and distressed at not being able to get something they needed or wanted;
- frustration due to feelings of being forced to attend an event or appointment;
- or just being asked to do something they did not want to do.

Five people said that the physical restraint had been appropriate and had been necessary as they know they would have hurt themselves or others had this not taken place. However, they felt that possibly things could have been dealt with differently leading up to the incidents and said that if they had been listened to and allowed to explain what they wanted and why this may have stopped them getting upset in the first place.

Eight people said that personnel or certain situations make them feel more anxious and this makes them more likely to become distressed. Examples provided included agency and/or new staff who did not know or understand them; or established staff that appeared to not care or listen to their feelings or point of view.

Four of the twenty-one people interviewed said they had been sore after being physically restrained but said this was because they had kicked and struggled so much and not because staff had hurt them. They also shared their feelings of upset after an incident as on a few occasions staff had been injured.

Four people said the intervention of physical restraint had made them angrier, but these individuals could offer no alternative solutions. They recognised they had hurt others and themselves in the past when they did reach crisis level, so if they had not been restrained, staff and other people including themselves could have been hurt.

However, five people said they were struggling to learn ways to calm down and talk about their feelings and when they were upset. These individuals during a behavioural incident could think of nothing except what was upsetting them, resulting in them feeling overwhelmed and unable to use the tools they had been taught.

One person who had been physically restrained both in hospital and in supported living said they were ashamed that this had happened and were upset for the staff as the staff were trying so hard to support them. They went on to describe that sometimes when they lost their temper, they just could not help themselves, however in recent times they have learnt to manage their behaviour and did not get angry very often. They explained they did this by going to their bedroom and listening to music.

Fourteen suggested more work could be done to help individuals feel as though they were respected and listened to and as a result this may make them feel important instead of other people taking control of their lives. They also described how important making personal choices are. This was felt important to develop an individual's ability to handle how they feel. Whilst there was recognition that some work had been done in both supported living and hospital settings it was felt that more of this consistently was required as "... normal practice".

One person discussed the importance of positive behaviour management training for everyone. This tool should be available for people with a learning disability, their families and staff as part of a learning exercise (training). They suggested specifically that for people with a learning disability this may help their own understanding of behaviour when they see real situations that show actual people at risk or in danger and how this may escalate. The individuals suggested that if consent was able to be achieved, there should be the opportunity of offering reflective practice through watching actual video footage of people being restrained. This could identify when the holds and restraint are implemented correctly, or not, and when the latter the consequence of injury and/or escalated behaviour.

## **2. Chemical restraint**

Of the twenty-two individuals spoken with, twelve people had experienced what they recognised as chemical restraint. These individuals described incidents where they were getting upset. Some had voluntarily asked staff for tablets to help them calm down, whilst others were offered medication by staff and agreed. All twelve recognised that medication can help calm their anxiety or frustration and felt overall that this was okay as it was less upsetting, allowing them to calm down quickly and resulted in less injuries to either staff, themselves or their peers.

Four of the twelve people talked about being given medication against their wishes and whilst they recognised this managed their behaviour, they described how unpleasant it was to be forced to have medication.

## **3. Mechanical restraint**

None of the twenty-two individuals initially understood the term mechanical restraint. When examples of this type of intervention was explained, all individuals confirmed they had no personal experience of this. Some however had witnessed this.

The general theme of feedback was that this type of intervention was considered suitable for the purpose of keeping the individual 'safe', for example preventing someone falling out of a wheelchair, however should not be continual daily practice. An example of an observation was described where a strap had been used to keep a patient's hands from going in their mouth as they bite their hands. The individual interviewed thought this was ok if only used when the patient's hands were bleeding.

## **4. Seclusion**

Of the twenty-two people consulted, eleven people had direct experience of seclusion. This did appear to be the most emotive part of the interview with seclusion rooms being consistently described in very negative terms.

General examples of feedback included "...cold, dark and dank"; "... smelly, dirty and made me feel sick"; "... made me more angry because I could not get out of the room"; "... made me think about what I had done which made me depressed because I had no one to talk to"; "... I was scared and lonely".

Five people said seclusion should never be used. They explained that it is not good for anyone to be forced to be alone when they are angry and upset.

Four people reflected that the way individuals arrive at the room is upsetting and embarrassing, with the adjective 'dragged' being quoted in all cases and the reference to their peers watching and the impact this had on their feelings. These individuals all said they did not understand if the seclusion room was used to punish or to manage behaviour.

Whilst three people felt the principle of a room was not a bad idea, they fed back the importance of an environment to promote calmness. They suggested the benefits of it being renovated into a sensory room, or failing that, simply a clean bright room with windows so you can look outside.

One person suggested better support for all families who have children with a learning disability from the outset was required to promote positive behaviour. This would attempt to help people with a learning disability learn how to get the things they want in a positive way from an early age rather than expecting a change in the way they may have behaved for years.

Finally, seven people said working together with staff to look at ways to improve behaviour was the most important change that could be made. They explained that being part of planning the consequences if their behaviour presents as challenging would be good, as they understand better the consequences e.g., what will happen if they do become distressed and upset.