

# Lived Experience of Restraint, Seclusion & Segregation (RSS)

Stories & recommendations for safer care



“**Advonet**

Providing Independent Advocacy”



**CHANGE**

# Contents

|  |           |
|--|-----------|
| <b>Our project- giving a voice to people with lived experience .....</b>                                     | <b>3</b>  |
| <b>About us .....</b>  | <b>4</b>  |
| <b>What did the project aim to achieve? .....</b>  | <b>4</b>  |
| <b>How did we gather people’s stories of restraint, seclusion and segregation?.....</b>                      | <b>5</b>  |
| <b>Who did we speak to? .....</b>  | <b>6</b>  |
| <b>What did people with lived experience tell us about restraint, seclusion and segregation (RSS)? .....</b> | <b>9</b>  |
| <b>RSS- a difficult subject.....</b>   | <b>9</b>  |
| <b>Attitude and empathy among staff .....</b>  | <b>10</b> |
| <b>Staffing levels .....</b>   | <b>12</b> |
| <b>Training.....</b>   | <b>13</b> |
| <b>Institutional culture .....</b>   | <b>14</b> |
| <b>Impact on frontline care staff.....</b>   | <b>15</b> |
| <b>Care planning.....</b>  | <b>15</b> |
| <b>Safe and effective RSS.....</b>   | <b>17</b> |
| <b>When RSS hurts .....</b>  | <b>17</b> |
| <b>Ask, listen, do .....</b>   | <b>18</b> |
| <b>Recommendations for change .....</b>  | <b>20</b> |
| <b>Acknowledgements .....</b>  | <b>23</b> |

## Our project- giving a voice to people with lived experience

**Advonet** and **CHANGE** were asked by the **Care Quality Commission (CQC)** to listen to people with real life **experience of restraint, seclusion and segregation (RSS)** in care settings.

We reached out and, with support from other organisations, we heard many stories of RSS. We reached out to people with varying needs, diagnoses, gender, background, ages, ethnicity and experience, from all across the country.

We were moved and humbled by the bravery and honesty of all the people who chose to participate. **This report is by, for and about you**, and we thank you wholeheartedly for telling us your stories.

This report has one overall aim: to put the authentic voices of these people with lived experience at the heart of the conversation about safe and effective care. It is important that decision-makers hear these people, learn from them, recognize their contribution, and take their views and recommendations forward into action.

***“I understand the importance of restraint and the protective element, but protection should feel safe and secure, not sudden, aggressive and violent. I think all staff who use restraint should see this feedback.” - Natalie***

## About us

**Advonet** provides independent advocacy services to people in Leeds. Along with our partners, we aim to offer advocacy to anyone who has a need. We help our clients to speak up and have their voices heard on issues that are important to them.

**CHANGE** is a human rights organization led by disabled people, working to build an inclusive society where people with learning disabilities are treated equally. Their work is informed by the expertise of people with learning disabilities, which focusing on delivering real change in areas that matter to people with learning disabilities.

**CHANGE** became an **Advonet** enterprise in September 2019.

## What did the project aim to achieve?

Advonet and CHANGE have worked together to deliver the project, speaking to many people with lived experience across England, and collecting their stories of restraint, seclusion and segregation.

From the very beginning, we had very clear aims- to give people with lived experience, who chose to participate, the space, time and tools they needed to:

- **lead the project,**
- **control their own involvement,**
- and **feel heard and safe** at all times.

We wanted to ensure that project participants told **the stories they wanted to tell**, and that they told us **the stories they felt needed to be told**.

## How did we gather people's stories of restraint, seclusion and segregation?

We held a planning event in Leeds in July 2019, to ask for feedback on how the project should be planned, and how to hear people's stories in a safe and inclusive way. The key aspect was **to let participants lead their involvement and retain control of their stories and experiences.**

Everyone who took part gave their consent for their stories to be included in the project, and all participants were assured that their personal information would not be included in the report. All identifying information, such as names and locations, have been replaced or removed. All participants were given the option to contribute in greater depth if they wished, and we encouraged them to seek advice or support before agreeing to discuss experiences which, in most cases, were very distressing for them to talk about.

Some participants completed questionnaires, some were interviewed (face-to-face, via video messaging, or over the phone) and others took part in focus group sessions. We aimed to reach out directly to people with lived experience of RSS, and initially we planned to set up a steering group, with people with lived experience meeting to discuss the stories we had gathered and co-produce the final report.

Some of the key feedback we received was that information about the project should be as accessible as possible, so we circulated an easy-read information leaflet and produced questionnaires for experts by experience (individuals and their families/carers), to help start the conversation about restraint, seclusion and segregation. These were circulated widely amongst health, care, advocacy, and third sector organisations, and we encouraged people to contact the project directly by email or via social media.

We were active on social media where we discovered many people with lived experience of RSS had previously given feedback. Some felt they not seen much change or response and therefore did not wish to engage with further consultation. Anecdotally, this seems to have been exacerbated by the events at Whorlton Hall, which re-energised debate about the progress of Building The Right Support (this policy launched in 2015 as part of Transforming Care, which was the policy agenda set up to get people out of inpatient hospitals in response to the events at Winterbourne View). Families and parents, in particular, expressed anger and frustration at the missed Government target to move between 35% - 50% of people

with a learning disability and/or autism out of institutions and into community-based support by the end of March 2019.

People also found it very hard to revisit their experiences, especially if they had been involved in similar projects in the past. Some people who contacted the project cited fear of reprisals from staff and care providers, or were mistrustful of the CQC and/or the Government, so did not feel confident in their anonymity or safe to tell their stories to us.

We adapted our approach to overcome these issues, and reached out to other organisations who work with people with learning disabilities, mental health problems or autism, to ask for their support to reach out to people who may want to contribute to the current review but needed support to feel safe and protected in doing so.

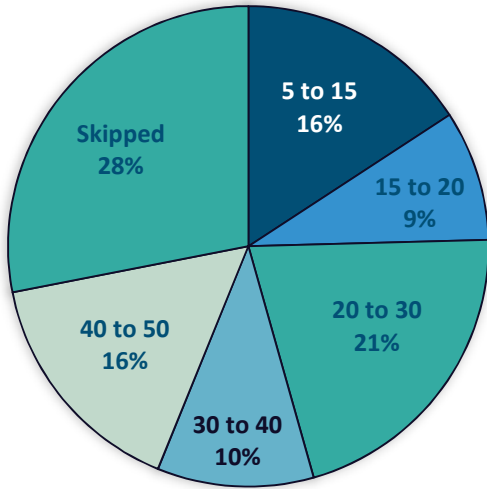
In December 2019, we held some very successful events where people with lived experience, as well as some health and care professionals, came together to talk about RSS, and identify the main themes and recommendations to take forward in this report. These were slightly different to the steering group plan we had originally envisaged, and these provided us with the opportunity to spend a lot of time with individual people's stories. The analysis from these events provided the framework for this report.

## **Who did we speak to?**

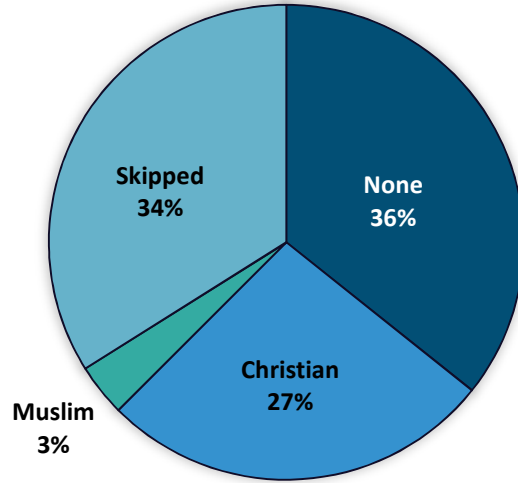
We collected stories from 30 people with direct lived experience of RSS. We also heard from 25 carers and family members. We reached out across all demographics, aiming to capture stories from people of varying needs, diagnoses, gender, background, ages, ethnicity and experience. As far as possible, we wanted a proportional representation of both children/young people and adults who have autism, learning disability, or mental health issues. Some people chose not to provide information about their additional needs. The breakdown is shown below; only categories that had entries have been included. This data represents only those 55 people who contributed their stories (carers/family members provided information about the person with direct experience of RSS).

Many more people with lived experience attended events, gave feedback on other people's experiences, made recommendations, and gave their support- in all, approximately 150 people contributed to the project.

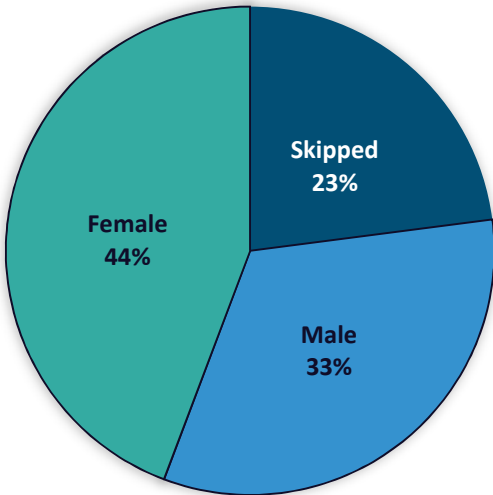
### AGE



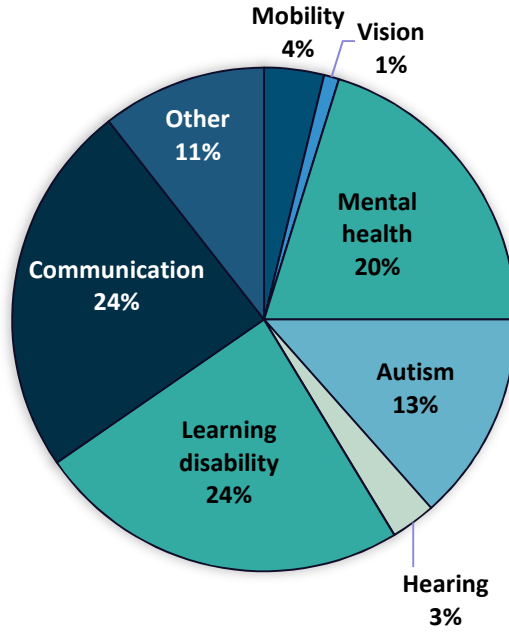
### RELIGION



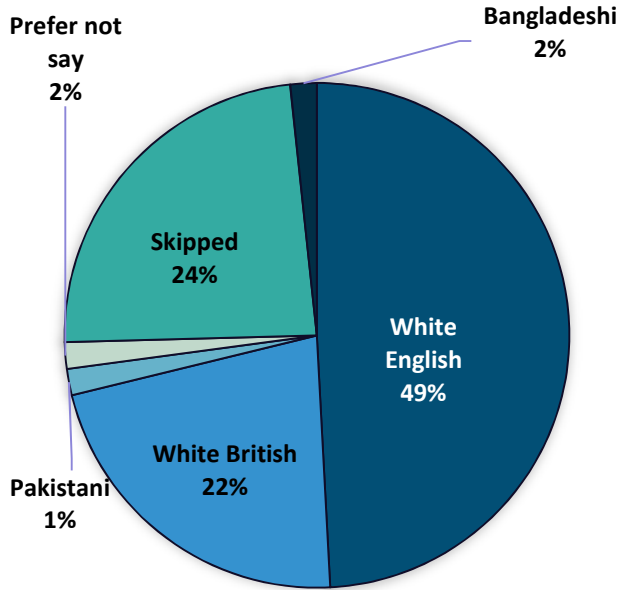
### GENDER



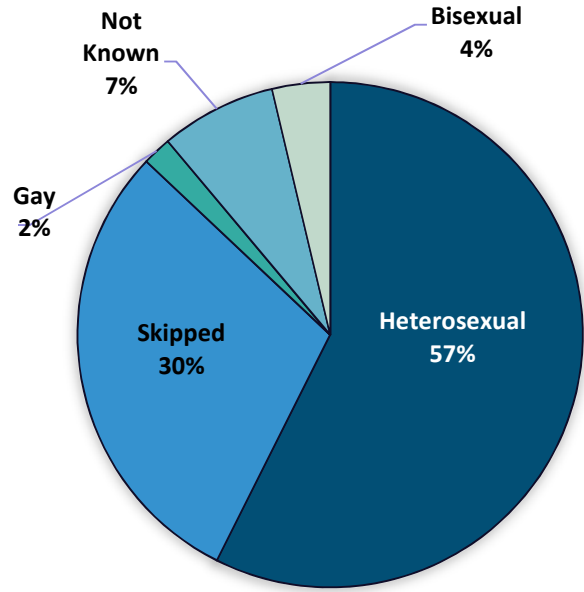
### ADDITIONAL NEEDS



## ETHNICITY



## SEXUALITY





## What did people with lived experience tell us about restraint, seclusion and segregation (RSS)?

### RSS- a difficult subject

Before, during and after experiencing RSS, people experience very strong feelings. This graphic shows some of the feelings that were mentioned most often.



The biggest words above- **afraid, scared, angry, upset**- were the feelings that were talked about by almost every one of our participants.

They talked about their feelings before the incidence of RSS, and their behaviour as well. Many people with lived experience felt that they sometimes had difficulties with their strong feelings and it could be challenging for them to regulate these.

Almost all our participants found it difficult to talk about their experiences of restraint, seclusion and segregation. They offered a lot of insight into how these bad practices had come about, and the same problems came up again and again. It was felt that these problems create an environment in which negative feelings and behaviour from staff and care providers can take hold; this makes it difficult to provide safe and person-centred care, and puts people at risk of being subjected to avoidable restraint, seclusion and segregation.

**“[I felt] angry, upset, confused because I didn’t understand them.”**

**“I was distressed, upset and agitated.”**

**“...I was scared I didn’t know what do. I shouted and staff said I was being angry.”**

## **Attitude and empathy among staff**

People with lived experience talked about staff in healthcare settings, and often they told us that staff lacked empathy and were not person-centred. People felt their needs were ignored if they required a considered and compassionate approach, or were causing an inconvenience for the staff. Our participants noticed a lot about attitudes, environments and culture and they had strong views about how this impacted on RSS.

**“Staff laughed at me because I was crying and asked me to put radio on but I wanted someone to stay and talk to me...”**

**“...the staff had made her angry because they kept saying ‘she’s dead, calm down’ and that was upsetting her so much that she got angry instead. If you take time to listen to her, she can tell you things like this, but it takes time and she has to trust you.”**

**“Staff were shouting all the time, no-one was being calm so I wasn’t calm either.”**

**“Staff intimidated people, they knew their triggers and used them against them. Culture of fear.”**

Parents, who had often spent a long time observing how their child was being cared for, made similar observations:

**“Every action is seen as aggression, so they went straight in with restraint – not least restrictive.”**

**“No analysis of behaviours, to understand and adapt their own behaviour.”**

**“Every report/incident is written up as “my child did this”, no mention of ward environment, possible illness, etc.”**

Where staff showed empathy, and were attentive and responsive to individuals and their needs, people always noticed it- they reported far better outcomes and felt happier with their care.

**“A lady support worker looked in my care plan and she knew I liked hot chocolate and Penguin biscuits, so she brought me some and let me sit in the lounge on my own.”**

**“I wrote my own care plan and once they knew how much I need my DVDs, they let me use my money to buy a tablet and headphones instead and I watch it wherever I am, if I need to.”**

**“Staff do talk to you afterwards. It’s a debrief, we talk about how it could go differently and I get some input, makes sense and it does help to talk.”**

**“Where I am now, they do talk to me. They support me and take time to communicate with me. Staff at the old home didn’t want to be bothered because of my deafness.”**

## **Staffing levels**

At a systemic level, our participants mentioned the same issues again and again, with a lack of adequate staffing in care settings being a common factor.

**“I was already nervous about the staff as there was always a shortage and many should not have been looking after vulnerable people.”**

**“The hospital are short staffed, untrained support workers, heavy reliance on agency staff...high turnover of staff due to long unsupported shifts.”**

**“Seclusion is used to cover staff breaks.”**

## Training

Training for staff was a strong theme; people with lived experience of RSS painted a picture of very varied attitudes to training, with good and bad experiences.

In some cases, parents talked about a supportive culture with well-trained staff, where individual needs were being met and safe and none-restrictive care was the norm:

**“It [residential facility] cares for 6 people with LD/autism and severe and challenging behaviour. The provider is a specialist in challenging behaviour and complex needs, so all the staff are Positive Behaviour Support trained and support is very good.”**

**“Staff are also all ‘Team Teach’ trained, so are able to apply graded restraint as a last resort if needed to keep everyone safe- however, as they meet needs effectively, restraint is very rare.”**

Where training was inadequate or seemingly absent entirely, participants were of the view that this contributed to a lack of understanding between staff and the people in their care, with poor outcomes for both. Many people felt that poor training makes unnecessary incidents of RSS more likely.

**“Not meeting patient’s needs whatsoever, over stimulus by other patients in distress, alarms. Not engaged in meaningful activities consistently, too many blanket rules and restrictions. All causing meltdown, which leads to restraint. Cold emotionless staff offering no support or comfort.”**

**“Staff not trained and supported to understand the reasons for the behaviour and just react to the behaviour itself.”**

**“Seems to me that they don’t have enough staff, never mind trained people, so they sometimes go straight in there for a restraint because it brings it to a swift end and they are overworked as it is. De-escalation takes time and training and I don’t think there’s enough of either.”**

## **Institutional culture**

Almost all our participants noted issues with the overall culture of the facility where they experience restraint, seclusion or segregation. People described a lack of management oversight; many felt that staff were not supported in their roles, and that this contributed to inappropriate attitudes and behaviours from staff. It was also felt that care providers did not address issues when it was clear that quality of care was suffering.

**“...assaulted by a member of staff, restrained inappropriately causing extreme pain. Two other staff members shouting at him to get off but being ignored. Staff was suspended for a short time and then reinstated. Same staff member has been suspended previously for exactly the same assault on another patient. He continues to work there with very vulnerable patients.”**

**“I had no trust in any of the staff who closed ranks and became aggressive towards me and became unhelpful.”**

**“Poor leadership, staff not trained. Delayed discharge due to operational and delivery costs- use Mental Health Act to keep people in closed culture.”**

**“Culture of not listening to families, reliance on agency staff, not really having the right support and understanding especially therapeutic supports.”**

**“Bad apples, especially the manager. They have their own agenda, to keep people in ATU for profit.”**

**“There are those who are attracted to the power dynamic and bully other staff too.”**

## **Impact on frontline care staff**

People with lived experience were able to tell us that they saw the impact that poor resourcing, lack of training, and unsupportive cultures had on the staff who were at the frontline of their care.

**“Staff are bored (not trained, no activities) so when buzzer goes off, they are running off adrenaline.”**

**“Staff become institutionalized and traumatized by what they have to do.”**

**“Anyone who stepped out of line was challenged, some really nice people worked there but they left or became indoctrinated.”**

**“At other times he [staff member who was regularly involved with restraint] talked about how unhappy he was in the job. I thought it could be stress related.”**

## **Care planning**

Our participants consistently saw the value of good care planning, particularly in relation to avoiding unnecessary incidents of RSS.

**“There aren’t any unplanned restraints here, everyone has a plan and strategies to, like, de-escalate, so that’s really good and it seems to work ok.”**

**“They kept with me, seeing if I was alright. Staff speak to you here (residential home). Sometimes I go to my room with staff close by.”**

**“They need to learn how to support people positively in a crisis, no force first, talk to people, make a care plan. Restraint is a last resort. Any member of staff can and should read your Positive Behaviour Support plan and use it. Advocates and family should support people to co-produce their own Positive Behaviour Support plans.”**

**“The paediatric nurse is nice; she talks to me about it [planned restraint to take nutrition/fluids] and if she’s there beforehand I feel less scared.”**

There were also reports of information in care plans being misused or ignored.

**“I tried to say what I needed but they wanted me to do something else, but I needed someone to talk to me, not music, no-one listened, other things were in my care plan and they picked what I needed, not me. I was scared and couldn't explain.”**

**Staff said this [segregation] was ‘time out’ and part of his Behaviour Plan. I was furious and had not been aware there was a behaviour plan!”**

**“...the focus was always on F’s behaviour and they would say that de-escalation plans didn’t work because she was too unwell or whatever.**



## Safe and effective RSS

Some participants had positive experiences of RSS. They were clear that this was when it was used as part of a person-centred de-escalation strategy, with compassion, and as a last resort where safety was a concern.

**“In the residential home it’s a bit different again, they try and calm you down. Even when they are doing the restraint, sometimes there is just two of them, one each on both sides of you on the settee- it doesn’t hurt. It’s over quicker...they just want to calm you down.”**

**“Staff hold me at my current care home, to keep me safe. They support me.”**

**“Sometimes it goes better than others- it can be good and make me feel safe, but not always. I was restrained once when I tried to smash a window, which I think was probably right.”**

## When RSS hurts

Our participants provided very many examples of bad practice in implementing restraint, seclusion and segregation. People spoke of many experiences where they were physically, psychologically and emotionally harmed.

**“He has been thrown to the floor and forcibly held down by up to 4 staff members, often causing bruising. Verbal abuse and threats are also made.”**

**“Approx. six people held me face down on the bed. Five did this in a safe manner but one pulled my wrist back and I thought he was going to break it. Even in my agitated state I knew this shouldn’t be hurting me so much and asked him to stop. He wouldn’t.”**

**“He has been thrown to the floor and forcibly held down by up to 4 staff members, often causing bruising. Verbal abuse and threats are also made.”**

**“After giving me the injection, the two men left me on the floor and walked out of the room, leaving me semi-naked on the floor with my trousers around my ankles. I pulled my trousers up and got off the floor. I remember crying and hiding my face, I didn’t want to look at anyone or have anyone look at me.”**

**“I had to go to A+E once and I never realised what was going on until I was restrained without warning so the paramedics could get me out of the unit. I don’t think it had to happen that way and it was f\*cking horrible. I know I kicked off but that wasn’t any way to deal with it, I was so much worse for so much longer because of the shock.”**

## **Ask, listen, do**

Our participants consistently said that they are the experts on themselves. Everyone who contributed wanted to be heard; they told us that they got involved in the project to have a chance to speak up for themselves, their loved ones and others who might not be able to tell their story.

People with lived experience talked about their feelings and behaviour, and how this was affected by the feelings and behaviour of others. They told us about their feelings of dehumanization, and how they were not listened to.

**“It makes me feel powerless...what’s the word I want...dehumanised. I don’t feel like a real human being because people can forcibly medicate me and sit on me to make me do what they want.”**

**“I’ve always been hugely upset and angry when I’ve been restrained. It’s hard on me. I feel my human rights are breached, I’ve been in the wrong place and it’s horrible. You don’t feel like a real person when people can do that to you.”**

**“...it didn't matter anyway, if people don't listen what's the point, it's always your behaviour and not other people's that gets talked about. Why? Does no-one ever think that I try not to get so upset?”**

Parents and families spoke of their distress when they, as those who they felt were best placed to advocate for the individual and their needs, were ignored, sidelined, or treated with hostility by care providers, and locked out of decision-making processes.

**“Felt like I was begging the nursing staff to do things to help him. I felt powerless.”**

**“[finding out about a restraint on child] A member of staff told me in secret.”**

**“We felt not listened to, no one cared including safeguarding services where the school was, our local authority. If we did this we'd be arrested- if organisations do it, no one cares.”**

**“Not one word from them, no communication, all hushed up.”**

All of our participants wanted to be heard, and the families wanted to be able to represent and support their loved ones. They wanted to be known, understood, and treated as individuals, and the views, wishes and needs of the person to be at the centre of the approach to their care.

**“They are not mentally ill...they're autistic and have as much right as non-autistic people to live rather than just exist.”**

**“Community and care organisations should be user-led, people with lived experience. There should be more involvement from families and advocates at the top as well.”**

“Value and care for families and make that the culture-Ask, Listen, Do.”

## Recommendations for change

**Robust, personalised and appropriate training** for care staff was a strong theme, with the aim of avoiding RSS in favour of de-escalation:

“All staff must have Positive Behaviour Support training - they must all pass this training in order to keep their job “

“ALL staff should be fully trained in autism and the organisations involved, should ensure that it is mandatory for every member of staff to read the individual’s care plan before working with them, to familiarise themselves with their needs, challenges and the triggers for their behaviour.”

“Training. Training. Training!!! In Pathological Demand Avoidance. Autism. Sensory processing. Learning difficulties. Makaton. Mental capacity. Care act. Human rights. AND rigorous vetting of staff. Decent pay. Qualifications.”

“Mandatory training in autism awareness and restraint. People who use restraint should be more aware of how restraint feels and have their understanding reviewed.”

People with lived experience said that they want to see **accountability and action**, at all levels, including funding commitments from the government for better, community-led care models.

“Implement the concordat recommendations!”

“Enforce duty of candour. Stop funding expensive models of care, poor quality of life outcomes.”

“Make hospitals accountable for failings to patients. Allow parents to have a legal say. Do not use gagging orders, these only assist hospitals, they do not help or protect patients.”

“Restraint and seclusion are a sign that care and treatment is inappropriate and failing. Restraint should be a warning sign of this and healthcare providers should be held to account accordingly.”

“Complete root and branch reform of care system. Better paid and qualified people. Better people management from providers. Safer recruitment practices.”

Our participants also sent a strong and consistent message about their **need to be heard**, and their desire to **support safer care**. They supported a **stronger role for advocacy**, including **peer and family advocacy**, and wanted a more **co-operative and involving culture within care providers**.

“At one discharge planning meeting, one provider told us that 95% of their clients had no family involved. So, those of us who are, should be welcomed, supported and valued as people with lived experience.”

“Implement the acceptance that parents are their young person’s human rights defenders and 99% of the time, they have a solution.”

“More independent advocacy, and tighten up contracts so providers have to meet minimum standards of staffing and training.”

**“Fund peer and family advocacy, and let people with lived experience go in and talk to people. The independent advocates can work alongside and support them and the families.”**

However, most of our participants voiced the view that **restraint, seclusion and segregation should be stopped**, and **people should be cared for in their own communities with appropriate support** from properly funded services and, of course, their own families.

**“Ban prone restraint. Ban the inpatient admission of people with autism and learning disability. Build the right support in the community!”**

**“Support autistic people close to home where they have the reassurance of family.”**

**“People should live in the community, like everyone else. People with learning disabilities should have better access to safe supported living in their own communities.”**

**“Do not use inappropriate hospitals and ATU's. Provide good care in community placements. Always include family in the lives of the person needing the help, families know the person the best.”**

People with lived experience of restraint, seclusion and segregation need and deserve a care system that **works for them**. This means **listening to their experiences, acknowledging their needs, treating them as individuals, showing empathy, and giving them access to support so their voices can be heard**. Individuals and families value the support they receive, and want it to work effectively for everyone; to support this, they want to be involved, not held at arm's length.

**“They need to understand the impact that their actions have on patients. It's not always about whether they are *allowed* to do something; it's whether they *should* do it, or is there another way?”**

# Acknowledgements

Produced by, and with thanks to:

**Advonet**  
**CHANGE**

Our partners:

**My Life, My Choice**  
**Pathway Associates**  
**Bringing Us Together**

**All our people with lived experience and participants in feedback events and focus groups- thank you for your time, expertise, courage and support**

Our gratitude to **Lizzy, Katie and Ian from the CQC**, for their flexibility and support throughout the project