



**The Oliver McGowan Mandatory Training on Learning Disability and Autism Evaluation: Learning about involvement of experts by experience in design and delivery of training.**

Project Report  
NDTi December 2022



## Background



Oliver McGowan was a young man who had a learning disability and autism.



Sadly, Oliver died because he was given anti-psychotic medication when he was in hospital.



Oliver and his family told the doctors that he did not want or need the medication, but he was still given it.



After Oliver died, his mum, Paula McGowan led a campaign for more training for health and social care staff.



In 2019, the government said there should be training for staff who work with people with a learning disability and or autism.



This training must be given to health and social care staff.

This is called mandatory training.



The training is named after Oliver and is called The Oliver McGowan Mandatory Training on Learning Disability and Autism.



This training had to be written by people with a learning disability, autistic people and their families.



In June 2020, 4 organisations were chosen to deliver and test this training.



The National Development Team for Inclusion (NDTi) in partnership with Bemix and My Life My Choice were chosen to check the training.



To read more about what we found out you can read our final evaluation report [here](#).



Nearly everyone we asked said having people with lived experience involved in the training worked well for them.



Experts by experience include people with a learning disability, autistic people who have a learning disability, autistic people, and their families.



The involvement of experts by experience will be an important part of the training as it is delivered to more people.



In this report we will tell you what we learnt about what worked well and what could be better in how experts by experience are involved in both the design and the delivery of the training.



This report is mostly based on what we heard in focus groups from trainers with and without lived experience and what evaluation team members with lived experience saw.



**We hope the learning will be used to make sure future training is the best it can be.**

# The design process



Being fully involved in co-production was very important to trainers with lived experience.



Making changes so the right people could be involved at the right time helped people be fully involved. This is called making **reasonable adjustments**.

## 1. The process of co-design



### What helps?

- Making sure the training materials are made easier to understand if people need this.
- Working in small groups.
- Breakout rooms and small numbers of people when working online.



### What makes things harder?

When there are lots of complicated training materials to review and understand.

## 2. Decisions and who has final say



Many people did not know who had final say on the design of the training.



Sometimes people worked hard on parts of the training that got changed after quality checking.



Many people found this discouraging.



**It is important to be clear about how decisions will be made and who will have final say from the beginning.**

## 3. Getting the right mix of people



Having the right mix of people involved matters.



Experts with learning disabilities and autistic experts said having lots of views was important.



This meant having people expert at different things such as health or training or being a family member.





Some people with learning disabilities and some who need more help to understand found it harder to be heard at times.



**It is important to make sure people who need support to be involved get support that is right for them.**

#### **4. Being involved with the right thing at the right time**



Everyone valued being part of designing the training.



Some people said they didn't need to be involved in designing every part of the training.



Others said being involved in everything made them feel more confident to share their own lived experience.



The most important thing was being involved at the right time.



One person with lived experience who was involved in co-producing part of the training said:

“By the time I got involved the house was built and we could only choose the wallpaper.”

# What we found out about training delivery



All the trial partners involved experts by experience in the delivery of the training.

All trainers said these things were important:



Good support before, during and after the training.



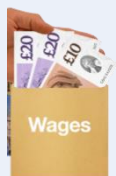
Learning and developing skills in doing training.



Practising doing the training.



Treating all trainers as professionals.



Paying trainers.

	Monday	Tuesday	Wednesd
MORNING	Training		
AFTERNOON	Training		

Some experts were involved in part of a session, others did a whole day session.



Experts with lived experience involved in designing the training did not always deliver the training they designed.





People who received the training told us in interviews and surveys that they valued the training being delivered by people with lived experience.



The words in the cloud are the ones they used the most when speaking about the involvement of trainers with lived experience in the training.



There was a lot of agreement between trainers with lived experience and trainers with professional experience in the following areas.

## Supporting Trainers

Three things that made the training session go well and the training experience a good one were:



Preparation before the training.



Trainers supporting each other during the training session.



Debriefing (talking about how the training session went, afterwards).



When these three things aren't done properly this also affects people being trained.

## How trainers prepared.



Getting to know how each other liked to work.



Deciding who was going to talk about which bits.



Working out what personal stories to tell and when to tell them.



Agreeing if one person would lead the whole session.



Agreeing how to share out different sections.



Some less experienced trainers needed support to practise their script.



Others liked to write things out in their own words



How well trainers with and without lived experience prepared influenced the delivery of the training.



Some people found it hard when they only met their co-trainer minutes before the training began.



Observers said some people with lived experience read a script or a list of bullet points and did not seem to know the training materials well.



Sometimes trainers jumped into each other's presentations, or interrupted one another, or shared stories which seemed unsuitable.



Good support happened when there was a good relationship between trainers.



Some trainers without lived experience did not know what to do if their co-trainer became upset during the training.



Having a debrief after the training was very important because:



- The training could be changed to work better.
- People could be supported if sharing their story brought back difficult memories or they were asked an upsetting question.



People who attended the training also said it was important that trainers with lived experience got the right support.



Peer support between trainers helped some people manage difficult experiences.



Sometimes there was less awareness of the need for support for autistic experts by experience.



**We think preparation and debriefs with trainers who are working together needs to be built into the training.**



## Developing training skills

This training always planned for people with lived experience to be trainers or co-trainers, not just come in and tell their personal story.



In our focus groups we asked trainers with lived experience:

- Had they had any training in training skills before these trials?
- What training experience had they had?
- Were they taught to be a trainer for the trials?



## We spoke to **22** experts by experience



- **18** had experience of doing training or presentations.
- **6** had been trained to be a trainer before the trials.
- **12** said they learned to deliver this training as part of the trials.



Part of our evaluation involved observing some training sessions.

The observers who carried out observations were all skilled and trained trainers, as well as all having lived experience.

The training observers looked for how trainers:



- explained the agenda and training content
- joined up experience and content to learning aims
- made the training work for people who learned in different ways

Observers did not like when they saw:



- people reading out lists of points
- people not knowing when to share their story
- people not knowing how to link their story to the aims of the training



One person who came to the training said they did not learn much. They said neither trainer with lived experience had the skills to speak to people or explain things clearly.



**We learned from the focus group that sessions on how to train would have been useful.**

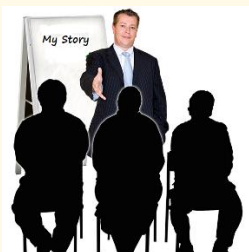
## Sharing Stories



Trainers with lived experience often share their experiences by telling stories.



This is a very good way of getting across the messages needed in this training.



Sharing the right story, in the right way, at the right time, takes lots of skill.





One trainer without lived experience talked about having to jump in to stop someone sharing too much in public in case they felt bad about it afterwards.

## Professionalism



**Trainers with lived experience need support to know they should not share their own views or give personal advice when training.**

## Knowing about learning disabilities and autism



Trainers with lived experience need to understand about the experiences of others.



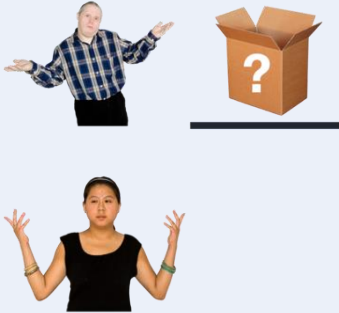
Observers noticed trainers on an autism course calling people with learning disabilities 'special needs people'.



In a focus group someone with a learning disability talked about 'autism and challenging behaviour' as if they were linked.



When the training about autism and learning disability was done in two separate courses there was a gap in learning about people who are autistic and have a learning disability.



Trainers with and without lived experience talked about not knowing what was being taught in the other course.



Learn

Some trainers said they wanted to learn about the other training.



**Trainers all need to learn about the experience they don't have and what words people with different experiences use to talk about themselves.**

### What works in developing skills?



- Peer support.
- The same training teams working together.
- Train the trainer courses.



**When autism and training courses are not run together trainers should go to the other training course to learn what is being taught.**

## **The working relationships between co-trainers**



Trainers said the training got better the more they got to know their co-trainer.



Trainers talked about learning how to support each other and having fun during the training.



People watching noticed that training was good when the relationship between co-trainers was good.



People who took part in their training said they learned a lot from how the trainers treated each other.



Some said seeing good co-production was one of the best things about the training for them.



If the relationship between the co-trainers did not seem equal this was bad for the training.



One observer did not like it when a trainer without lived experience called a trainer with lived experience 'sweetheart'.



Good relationships between co-trainers made the training better.



Those good relationships were also good for the trainers.



Becoming a trainer provides work and helps people make more connections.



Having the right mix of trainers with the right experience is important.



Trainers also that said having more trainers with different backgrounds is important



**The opportunity for people with lived experience to always train with the same person or in small mixed groups could be very good for the trainers as well as for people on the course.**

## Co-ordinating training teams



Trainers with and without lived experience and training leads said there was a lot of work involved in organising the training for big groups of people.



As well as having to book rooms or set up Zoom calls, the people coming to the training needed to be supported and organised.



We need to think carefully who will do this work when the training is given to move people.

## Being Paid



Paying people who are on benefits has been an issue for a long time.



If people are paid in way that is not allowed, they could lose their benefits including their housing benefit.



Some of the trainers with lived experience were already working as trainers and were not affected.





Many of the trainers with lived experience did experience these issues.



**These issues will need to be thought about when planning future training.**

## Being involved in different ways



Experts by experience we spoke to in focus groups wanted to be involved in the training in different ways.



Some wanted to join in for a short time and just tell their story, others wanted to be involved for the whole training session.



**There needs to be room for experts to be involved in the training in different ways.**

## Equal and fair payment



Being paid fairly was raised as an issue





Some experts by experience said they only got paid for the time they did the training not for all the planning they had to do.



Trainers brought many experiences from their work and home lives. The big message was do not assume that because someone brings lived experience they should get paid less.



**All trainers must be paid for planning time, doing the training and debriefing. They must be paid for any extra things like travel costs.**

## Summary



Based on what we have learned here are some ideas that we think will help the training be the best it can be.



Lots of trainers with lived experience need to be recruited and trained round the country.

Training should include:

- presentation skills
- dealing with difficult questions
- how to help keep everyone to time

Trainers with and without lived experience need to be supported well.



This should include:

- having a manager
- being paid for their preparation, delivery and debrief.
- time to plan
- time to practise doing the training
- time for co-trainers to build a relationship



All trainers without lived experience need the skills to be able to work with, and support, a co-trainer with lived experience.



All trainers need to know about all the training about learning disability and autism that is being delivered.



Experts should only use a script of what to say when it has been adapted to their experiences and is in their words.



Reasonable adjustments should be made for all expert by experience trainers to make sure they get the right information and support.



A co-ordinator job should be made so someone is in charge of organising the training sessions.



Work should be done to make sure trainers are from a mix of backgrounds.



Health and social care could think about working together to make sure the quality of the training and the skills of the trainers are always good.



Experts by experience need to be involved when the training is reviewed and have enough time to think and make suggestions.