

The Oliver McGowan Mandatory Training Evaluation: Learning about involvement of experts by experience in design and delivery of training

NDTi

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Executive summary

[NDTi's evaluation](#) of The Oliver McGowan Mandatory Training on Learning Disability and Autism clearly showed the importance of including people with lived experience in the training. Across all the training packages, at least 95 per cent of survey respondents agreed that input from experts by experience worked well for them. Experts by experience include those with lived experience of being autistic, having a learning disability, experiencing both, or being a family member of someone with either experience.

In this report we focus on what has been learnt across all the trial partners about what worked well and what could be better in relation to the involvement of experts by experience in both the design and the delivery of the training. This learning can be used to inform future delivery and ensure best practice going forwards.

This report draws primarily on the focus groups conducted with trainers from across the different trial partners (both with lived experience and without) and observations of the training carried out by evaluation team members with lived experience, as well as some insights from surveys and interviews with participants who received the training.

Findings about the design process

Trainers with lived experience involved in the design of the training reflected that they valued being fully involved in co-production. There was learning about the optimal way to do this:

- **The process of co-design** – people needed the right support to be able to contribute positively and fully, including the provision of materials in easier-to-understand formats.
- **Decision-making and sign-off** – the timing and responsibility for these need to be made clear from the start. People found it disheartening when there were changes made to the training during the quality assurance process.
- **The mix of people involved in the design process** – as well as those with personal expertise of a learning disability or autism, clinical experts, training experts and family members were highly valued and considered essential.
- **The right involvement at the right time** – being involved at a late stage hindered people's engagement.

Findings about the delivery

Trainers with and without lived experience shared the importance of good support before, during and after the training. The following issues were raised for consideration:

- **Supporting trainers** – there is a clear need for consistent preparation and debriefs with trainers who are working together, which will need to be incorporated into wider delivery of the training.
- **Developing training skills** – the experts by experience should be co-delivering the training and not simply sharing their personal experiences. Therefore, they need to be taught the skills to deliver high-quality training. This would include learning about presentation skills, dealing with difficult questions, encouraging participation from attendees and keeping to time.
- **Sharing stories** – sharing the right story in the right way, at the right time, and linking it back to the learning aims it relates to, is a skilled activity and experts by experience need to be appropriately supported with this.
- **Professionalism** – there is a need for support for experts by experience around appropriate sharing of their personal views and providing advice.
- **Shared knowledge of learning disability and autism** – all trainers need to be familiar with all the training (about learning disability and autism) and be able to cross-reference and refer to it all accurately.
- **The working relationships between co-trainers** – Seeing true co-production, good support, respect and positive interactions between the trainers was a highlight for many participants and something they were able to learn from. All trainers without lived experience need the skills to be able to work with and support a co-trainer with lived experience.
- **Co-ordinating training teams** – there is a clear role for someone/a team to co-ordinate the training sessions, for example booking dates, running webinars, co-ordinating availability and ensuring cover if someone is off sick.
- **Being paid** – remuneration of people who receive welfare benefits has long been an issue, with different rules for the various benefits about how much can be earned before benefits are affected.
- **Capacity for varied involvement** – some experts by experience said that they enjoyed joining for a short while to share their own experiences, and others expressed a preference in playing a full and equal co-trainer role along with trainers with professional or clinical experience.
- **Equal and fair payment** – it is important to ensure equal and fair payment for experts by experience. All trainers (with and without lived experience) must be and paid for their preparation, delivery and debrief.



Background

Oliver McGowan was an autistic teenager who was admitted to hospital with focal partial seizures. Despite Oliver not having a mental illness or psychosis, he was administered antipsychotic medication against his and his family's wishes. Oliver was known to be intolerant to all forms of antipsychotic medication. This led to Oliver's brain swelling, resulting in his death. An independent Learning Disability Mortality Review found that Oliver's death was potentially avoidable.

Following Oliver's death, his mum, Paula McGowan, led a [campaign](#) for more training for health and social care staff to provide them with the confidence and skills to understand the needs of people with a learning disability and/or autistic people in their care. In 2019 the government¹ announced funding to develop and test a learning disability and autism training package that could be deployed. This is the Oliver McGowan Mandatory Training on Learning Disability and Autism.

Trial and evaluation partners were appointed to co-produce, co-deliver and co-evaluate the training. Every stage, including consultation, planning and procurement, and delivery, has included the direct involvement of autistic people, people with a learning disability and their families, and people with professional expertise.

In June 2020, four trial partners were appointed to co-produce and co-deliver the training packages in a trial across the health and social care sector. Each trial partner was a consortium of organisations. The National Development Team for Inclusion (NDTi) was appointed through HEE's procurement processes as the independent evaluation partner, in partnership with [bemix](#) and [My Life My Choice](#). Further details of the data collection and the findings of the analysis can be found in the final [evaluation report](#).

A consistent message across data sources (post-training survey, follow-up survey, interviews with training participants and observations) was the importance of including people with lived experience in The Oliver McGowan Mandatory Training. Across all the training packages, at least 95 per cent of survey respondents agreed that input from experts by experience worked well for them. Experts by experience include those with lived experience of being autistic, having a learning disability, experiencing both, or being a family member of someone with either experience.

Given the commitment from the outset to involve experts by experience and the strong positive response from those participating in the training, it is clear that involvement of experts by experience will be a fundamental element of the training as it is delivered more widely. In this report we focus on what has been learnt across all the trial partners about what worked well and what could be better in relation to the involvement of experts by

¹ [Right to be heard](#)

experience in both the design and the delivery of the training. This learning can be used to inform future delivery and ensure best practice going forwards.

This report draws primarily on the focus groups conducted with trainers from across the different trial partners (both with lived experience and without) and observations of the training carried out by evaluation team members with lived experience, as well as some insights from surveys and interviews with participants who received the training.



Findings about the design process



Trainers with lived experience involved in the design of the training reflected that they valued being fully involved in co-production. This was supported by trial partners making reasonable adjustments to ensure the right people could be involved at the right times.

All the trial partners involved experts by experience in the design of the training. Those who had been directly involved in designing the training eventually delivered by each of the trial partners shared a range of experiences related to the following areas:

The process of co-design

Getting the process of co-design right was key to people being able to contribute positively and fully. In some cases, experts by experience found that the amount and complexity of materials they had to review and understand was overwhelming. For those who needed materials to be prepared in easier-to-understand formats, it was essential that they had the support for this to be done.

Due to COVID-19, the co-design process took place online, which people eventually found could work well for them. Some people found the co-design process easier when working in smaller groups and so the use of breakout rooms is recommended, as is limiting the number of people involved.

Decision-making and sign-off

Many people described how the process for decision-making and the sign-off of final products was unclear. They often put energy and effort into designing certain parts of the training only to have it changed during the quality assurance process, which many found disheartening. In any co-design process, the timing and responsibility for decision-making about what will make the final cut need to be made clear from the start.

The mix of people involved in the design process

Having the right mix of people involved in the design process matters. As well as those with personal expertise of a learning disability or autism, clinical experts, training experts and family members were highly valued and considered essential. As one autistic trainer shared:

“Having clinicians and family as well as people with learning disabilities or autistic people was good – we needed lots of views.”

(Focus group, trainer with lived experience)

Some people, for instance those with a learning disability or greater support needs in processing complex information, found it harder to be heard at times during the process of co-designing the training. To ensure every voice and experience was equally valued and included, it was important to tailor support to those who needed it.

The right involvement at the right time

Not everyone reported that it was necessary to be involved in designing all aspects of the training, although for some this was helpful:

“I helped to co-produce all the materials with a team... It has made me more confident to share my personal experience to empower people.”

(Focus group, trainer with lived experience)

Some shared how powerful it was to contribute to film script design, or just to share their own experiences of healthcare to inform what went into the training. Some people valued being heard and influencing the training without wanting to get into the detailed design of The Oliver McGowan Mandatory Training content and materials. However, being involved at the right time in the process really mattered. Being involved at a late stage hindered people’s engagement:

“By the time I got involved the house was built and we could only choose the wallpaper.” (Focus group, trainer with lived experience)



Findings about the delivery



Trainers with and without lived experience shared the importance of good support before, during and after the training. They highlighted the need to practise, learn and develop skills in delivering training, and the need to recognise professionalism through roles and remuneration of trainers.

All the trial partners involved experts by experience in the delivery of the training. This ranged from being involved in part of a session to the delivery of a whole day session. The experts with lived experience who were involved in the design of the different forms of training were not necessarily the same people who then delivered the training.

The data in our final evaluation report, from the interviews and surveys, showed how much respondents valued the training being delivered by people with lived experience:

“...a really insightful way of delivering those messages. You want to hear the perspective of the person whose life experience it was. It was brilliant.”

(Quote from an interview)

“Hearing the experience from an autistic person and how he communicates and experiences life gave me a different perspective on how it is like to live as an autistic person.” (Quote from a survey)

Figure 1 presents the words that were most used by respondents when speaking about the trainers with lived experience and their input into the training.

Figure 1: Word cloud describing experts by experience from qualitative data across all training packages



We will now present findings about the involvement of experts by experience in the delivery of the training. Everyone who contributed to focus groups, added written comments or had a one-to-one conversation with the evaluation team had been involved in delivery of training. While their involvement varied in terms of whether they were leading or supporting training, which tiers they delivered and in the trial partner they were working with, there was a high level of consensus between trainers with lived experience and those with professional rather than lived experience in some key areas, which are discussed below.

Supporting trainers

It was clear from the experiences shared that the preparation beforehand, the support between trainers during the event and the debrief after each session are key to successful delivery and to the positive experiences of all trainers. It also appears to have an impact on learners where this isn't done properly.

Trainers with and without lived experience described how they prepared together in a range of ways, getting to know each other's approaches, deciding who was going to cover what, working out which personal stories they wanted to share when, agreeing who would lead the whole session or how to share out leading different sections. Less experienced people talked about needing support to practise their script or write things in their own words so they were ready to deliver.

"I had meetings with colleagues who had experience in the training, and I was put in touch with the co-presenter. We met to make the script easier for me."

(Focus group, trainer with lived experience)

How well trainers with and without lived experience prepared before their delivery had an impact on the delivery of the training. Some of those who contributed to the evaluation told us about how they didn't meet their co-trainer until a few minutes before the training began and how difficult that was. Observers noted in some observations that people were just reading a script or a list of bullet points, and didn't seem familiar with the materials. They also noticed where there was or wasn't shared understanding between trainers, such as when they jumped into each other's presentations, interrupted one another, or shared stories that seemed inappropriate.

Good support during the training came about because of a strong relationship between trainers (see below). There were, however, some unresolved practical concerns about how to support someone during the training if they become upset:

"If someone gets upset in the training, do you leave the room to support them? It is not without its challenges." (Focus group, trainer without lived experience)

Having a debrief was also deemed essential by the trainers with lived experience in the focus groups, some of whom learnt this through the fact that debriefs had not taken place. A debrief provided an opportunity to reflect on how things had gone and adapt approaches for the next time. It also served an important role in providing emotional support that was sometimes needed after sharing personal experiences, some of which would have been negative.

“[The training] brought up memories of things I had forgotten or buried, things that were quite traumatic.” (Focus group, trainer with lived experience)

“I was grateful for supervision. Someone asked what I thought about autistic people not having empathy. I found that challenging and it was useful to share and get support after that.” (Focus group, trainer with lived experience)

The need for the right support for trainers with lived experience was also commented on by those attending the training. When asked in the surveys about what could have been done better in the training there were comments about the emotional support received and how this could have been better:

“The autistic gentleman supporting the training did not appear emotionally stable to be doing this – he clearly needs some support with issues from the past that are unresolved.” (Survey response)

One of the trainers without lived experience felt that “people need to be kept safe from...harmful attitudes”. A debrief provided the opportunity to deal with any potentially upsetting questions or views from training participants. Peer support between trainers was one way that worked to help people process their experiences.

It was suggested that on some occasions there was less awareness of the need for support for autistic experts by experience:

“I think there was more awareness of the need for support for experts by experience with learning disabilities. But I don't feel the organisation understood the need for this for autistic experts.” (Focus group, trainer with lived experience)

There is a clear need for consistent preparation and debriefs with trainers who are working together, which will need to be incorporated into wider delivery of the training.

Developing training skills

In our focus groups we asked people with lived experience whether they had been previously trained in training skills, what their prior experience was in training, and whether they had been taught to be a trainer as part of their involvement in these trials. The intention of The Oliver McGowan Mandatory Training was for people with lived experience to deliver or co-deliver the training and not simply to share their personal experiences. Therefore, it is important to reflect upon how they were supported to do this.

“You're not just somebody with lived experience. You're a trainer with lived experience, so how do we support you to be a trainer?”
(Quote from site lead focus group)

Out of the 22 experts by experience we spoke to:

- 18 had previously been involved in delivering some kind of training or presentations
- 6 had been trained to be a trainer prior to the trials

- 12 said they learnt to deliver this particular training as part of the trials (NB this was not general training skills provision).

As training skills are quite specific, our observation process was designed by experts by experience and those with training expertise. They were looking out for how trainers explained the session agenda and content, related experience and content to learning aims, and created interactive and reflective spaces for learners with different learning styles. The observers who carried out observations were all skilled and trained trainers, and all had lived experience.

Through their observations, as well as those of some of the training participants, we have identified a number of areas that some experts by experience (especially if new to training) may need support around in terms of skill development. It should be noted that these findings were based on only a small snapshot of training sessions, and therefore are not an overarching critique but may be useful to consider when finalising the training and support for new trainers with lived experience.

Observers shared their distress in seeing people read out lists of points, not knowing when to share their story or how to link it to a particular learning aim. One observer noted: “I could have just been sent an email with the content as it was just read out to me; it wasn’t training.” One interviewee shared in their feedback that they hadn’t learnt much about autism even though that was the course they most wanted to learn from, as both trainers who had lived experience lacked the skills to speak to the room of people and weren’t able to explain things clearly:

“The autism day was the day I was most interested in, but I learned nothing. Both trainers were extremely lovely, but were not good at speaking to a room full of people. It was difficult to hear them. I did not feel they explained things very clearly.” (Survey response)

It was evident from the focus groups that sessions on **how** to train would have been useful:

“We need people who are highly skilled in delivery: train up a workforce!”
(Focus group, trainer with lived experience)

Sharing stories

Hearing personal stories and experiences is one of the key benefits to learners of being trained by people with lived experience and one of the most powerful ways of getting across key messages in this training. Yet sharing the right story in the right way, at the right time, and linking it back to the learning aims it relates to, is a skilled activity. One experienced trainer without lived experience talked about intervening to “stop someone over-sharing something they might later regret sharing in public”.

Professionalism

There is also a need for support for experts by experience around appropriate sharing of their personal views and providing advice. For example, in one case a trainer with lived

experience shared some derogatory views about the role of nurses. In another example a trainer without lived experience shared their concern about some clinical advice the expert by experience trainer had provided in a training session:

“I had cause for concern when one co-trainer gave clinical advice to a social worker on how to deal with a client they discussed. This was extremely worrying, they were not qualified, and the advice was not psychologically informed or appropriate... This needs to be addressed in co-trainer training.”

(Focus group, trainer without lived experience)

Shared knowledge of learning disability and autism

Conversations with trainers with and without lived experience, along with observations, made it clear that whatever personal experience one person was sharing they needed to have a good understanding of the experiences of others. Observers noticed trainers on an autism course referring to people with a learning disability as “special needs people” and “the learning disabled”, and similarly in a focus group someone with a learning disability referred to learning about “autism and challenging behaviour” in a single sentence.

Observers also noted that sometimes when training in autism and learning disability were run separately, there was little or no cross-referencing between courses, thus leaving a gap in learning about people who are autistic and also have a learning disability.

“When learning disabilities and autism training were run separately, I did the autism training and didn’t know what was on the learning disability one, which made it hard.” (Focus group, trainer with lived experience)

This finding was also noted by a trainer who had a professional background rather than lived experience and said they didn’t know what content was included on the parallel course being delivered. The trial partner leads recognised this issue and spoke in the focus group about trainers needing to have the skills to share a different person’s perspective and to be able to respond to questions about learning disability and autism.

Some of the trainers were explicit about their desire to learn more about the other training:

“Autism is new to me I want to learn about understanding autistic people better.”

(Focus group, trainer with lived experience)

As a minimum, trainers all need to learn enough about how to refer to – and communicate about – the experience that they don’t carry and the preferred language that people themselves wish to use.

In terms of what has worked around skills development, a number of points were made about what worked or could work well:

- Peer support
- Consistent training teams (see below in relationships between co-trainers)
- Train the trainer courses that teach trainers presentation and training delivery skills, and how to support and manage learners

- If autism and learning disability training courses are run separately, everyone who is a trainer in one attends the other training as a participant so they are aware of the content and can ensure consistency between courses

The working relationships between co-trainers

Trainers themselves talked about how training improved the more they got to know each other, and how they could support each other, have fun and “bounce off each other” during the training. Observers also noticed the impact on delivery when the positive relationship and seamless co-working went well.

Training participants who took part in follow-up interviews shared their experiences of being trained by people with and without lived experience. For most interviewees, the training packages modelled good practice in working with experts by experience. They spoke of how their skill, delivery and personality all combined for maximum impact and memorability. Seeing true co-production, good support, respect and positive interactions between the trainers was a highlight for many participants and something they were able to learn from.

“They obviously had a really good rapport and he clearly felt comfortable talking.” (Interview, support worker)

“It felt a bit like they were modelling how to work with people ... in front of you, and that was really nice actually.” (Quote from an interview)

Conversely, on the occasions where relationships appeared poor or unequal between trainers, it could have a negative impact on learners through negative role-modelling. One observer who has a learning disability reported witnessing a patronising and negative unequal attitude to people with a learning disability when a co-trainer referred to a trainer with a learning disability as “sweetheart”. She felt strongly this conflicted with the messages of the training.

Not only did having a positive relationship enable pairs or groups of trainers to run the training better, it was also a real benefit of being a trainer, and something that people valued in and of itself. Becoming a trainer not only provides work and status but can also enable people to build social connections and strong bonds beyond their usual circles. The opportunity for people with lived experience to deliver continuously with other trainers or in small mixed teams is potentially significant for the trainers as well as the learners.

Focus group attendees also highlighted the importance of the right mix of trainers, who bring expertise relevant to that course – at times this means having trainers with personal experience of autism, a learning disability and family carers.

It was noted by trainers that there was not enough representation in terms of ethnicity among trainers and this could have real implications for the impact on learners, as well as people with lived experience who use health or social care services:

“The priority is to recruit people to deliver the training with lived experience of ethnic minorities...as ethnic minorities are underserved (sic) and overlooked when it comes to autism and learning disability.”

(Focus group, trainer with lived experience)

Co-ordinating training teams

Focus groups with trainers of all experiences, and with the trial partner leads who were leading the different trial partners, highlighted the immense co-ordination and administrative burden of running training courses that will be delivered to a large audience. Not only is it essential that someone is booking the Zoom meeting or the room, but the training workforce also needs to be co-ordinated, managed and supported.

The points made above have ramifications for the resourcing of wider delivery, as it is not just the trainers but also the co-ordinators and supporters who will have a key role to play.

Being paid

Remuneration of people who receive welfare benefits has long been an issue, with different rules for the various benefits about how much can be earned before benefits are affected. If people are paid in a way that is not in line with their permitted earnings, it can leave people with sanctions and potentially lead to loss of income and/or housing-related benefits.

Some of the trainers with lived experience were already professional trainers or in related health or social care roles and therefore did not face the dilemmas surrounding permitted earnings. However, many of the trainers who worked as experts by experience on these trials did face these challenges.

The discussions with trainers raised several issues which will need to be considered when planning ongoing delivery.

Capacity for varied involvement

Feedback from the focus groups emphasised that there needs to be capacity to allow for varied paid involvement from experts by experience. Some people said that they enjoyed joining for a short while to share their own experiences, and others expressed a preference in playing a full and equal co-trainer role along with trainers with professional or clinical experience. There may be a need for full training roles as well as briefer or less involved support roles for people with lived experience who do not wish to become full trainers.

Equal and fair payment

As well as the implications for welfare benefits, several issues were raised regarding how to ensure equal and fair payment for experts by experience:

- Some focus group participants shared that they only got paid for delivery, and not the additional activities in preparing for training delivery. All trainers (with and without lived experience) must be remunerated for the preparation time, the debrief

before and after the training delivery and any expenses incurred, not just for the time they deliver.

- Those in the focus groups pointed out that people often bring multiple experiences – professional and personal – and there is not always a clear-cut difference between who is an expert by experience and who is a lead co-trainer. While having a range of roles may pose a challenge for ensuring equal and fair pay, the clear message was that it must not be assumed that because someone has lived experience they may incur less cost.



Considerations

The following suggestions come from the learning outlined in this report and will enable good practice as the training is delivered more widely going forward:

- A large number of experts by experience need to be recruited and upskilled around the country, to enable them to be able to deliver consistent high-quality training, rather than simply share their personal experiences or read from pre-prepared slides. This would include learning about presentation skills, dealing with difficult questions, encouraging participation from attendees and keeping to time.
- Trainers who have lived experience (and those who don't) need to be supported well, with line management, and paid for their preparation, delivery and debrief.
- Training teams made up of trainers with and without lived experience should have time to plan, get to know one another and learn how best to work together, and they should have practised delivery of the training. Establishing a relationship and rapport between co-trainers is essential.
- 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 be familiar with all the training (about learning disability and autism) and be able to cross-reference and refer to it all accurately.
- Although the content of the training is to be standardised, experts by experience should only use a set script of what to say where this is adapted to their own words and experiences and used as a supportive reasonable adjustment.
- Reasonable adjustments should be made for all expert by experience trainers to ensure they receive appropriate information and support.
- There is a clear role for someone/a team to co-ordinate the training sessions, for example booking dates, running webinars, co-ordinating availability and ensuring cover if someone is off sick.
- Action needs to be taken to ensure that the mix of trainers recruited includes those from a range of cultural and ethnic minority backgrounds.
- Health Education England, Skills for Care and the Department of Health and Social Care may wish to consider working together to put a quality assurance process in place to ensure the trainers have the necessary skills to deliver this training and that the quality of delivery is consistent between teams and over time.
- When the content is being reviewed and changes are being made, experts by experience need to be involved in a timely way so they can make meaningful suggestions on the decisions being taken.