

# Involving experts by experience in Learning Disability Awareness Training

A summary of findings from interviews with self-advocates, family carers and NHS practitioners

August 2022

## Introduction

The National Development Team for Inclusion (NDTi) was commissioned in 2019 by the South Regional Health Education England Intellectual Disabilities programme to find and share best practice in training people who work in NHS Trusts to support people with learning disabilities. The aim is to support staff development to help them achieve better outcomes when they are working with people with learning disabilities. Further information about the project can be found [here](#).

Early findings from the different strands of this project (surveys, hospital interviews and evidence reviews) highlighted the important role of experts by experience - self-advocates and family carers - in the design and delivery of learning disability training. People who had attended training told us that the involvement of experts by experience made it more memorable and impactful for them.

This small research study was undertaken to explore the enablers and barriers to involving experts by experience and to produce this evidence-based guidance on how self-advocates and family carers can be involved well in the design and delivery of learning disability awareness training.

## What did we do?

We explored the perspectives of three groups of people - Self-advocates, Family Carers and NHS practitioners - with experience of being involved or involving experts by experience in learning disability training. We used our networks to identify and approach people with this experience and asked them to take part in an online interview or a focus group. The three groups of interviewees were asked different questions.

One NDTi researcher and one expert by experience (living with learning disability and/or autism) worked on this project together - designing the questions, conducting the interviews, and analysing the data together. The expert by experience was paid at researcher rates for their work.

We spoke to a total of 10 people for this research between May-July 2021. Seven were interviewed individually online and one focus group of three people was conducted, also online.

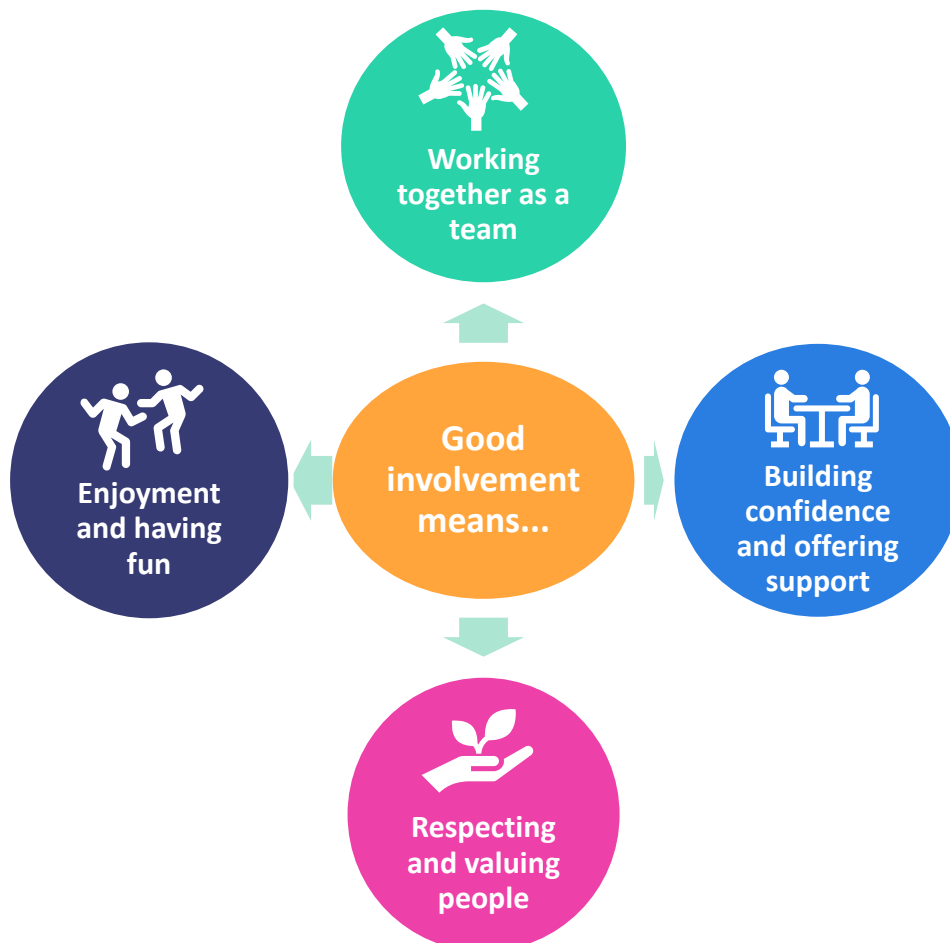
## Who did we speak to?



- Three self-advocates (people with a learning disability); all had experience of being involved in learning disability training (all in paid roles).
- Three family carers; all had experience of being involved in learning disability training (in paid and voluntary roles)
- Four NHS practitioners; all had experience of involving people with a learning disability in training in a variety of ways (all paid staff).

## What did we learn about involving experts by experience in learning disability awareness training?

Our interviewees had been involved in different ways and had delivered different types of learning disability awareness training. We looked for issues and themes arising within each group and then looked across different groups (self-advocates, family carers and NHS practitioners). Four key elements emerged as important for good involvement of experts by experience in learning disability awareness training.





## Working together as a team

Experts by experience described what it felt like to be part of a team, how things worked well and when things went wrong. Feeling connected to, understood and valued by other team members was important. We were told that teamwork means being involved from the start, seen as equals with something to contribute.

*Family carers are included from the start as equal partners...it helps to be part of the solution not the problem.*  
(Family carer)

Interviewees said that good teams understand each individuals' abilities and challenges and give choices about getting involved. They said involvement worked well when people felt supported and able to be themselves. Changing how things are done, for example using plain language and having longer flexible meetings, all helped with teamwork. NHS practitioners described the benefits of working with an established team who already know and trust each other.

*Trust and a safe space is very important...somebody who supports and facilitates the group before during and afterwards.* (NHS practitioner)

Participants said that people in a team shouldn't feel under pressure or on their own. Some experts by experience had a mentor or 'buddy'; some worked together with NHS practitioners as co-trainers. Family carers said flexibility was important when arrangements had to change due to their caring responsibilities. Self-advocates told us that being in touch with the team regularly was important, especially during COVID-19 when they were working from home.

*I've never had to do it on my own...they are always there for me.* (Self-advocate)

NHS practitioners were aware of the power imbalance involved in working with experts by experience, and said that whilst good involvement practices help, they do not remove it. Participants agreed that the experience of people with higher needs should be included and said that family carers and using video can help bring them into the conversation.



## Building Confidence and offering Support

Self-advocates and family carers described how their confidence in their training role developed over time. They said that nervousness about training was natural and got better with practice, feedback and ongoing support. Co-training meant that people could learn from and support each other in real time. Buddying and mentoring also provided good support and helped confidence.

*I had no confidence when I started ...having support has really helped. (Self-advocate)*

*Working with my buddy has really helped my confidence...we help each other. (Self-advocate)*

Participants agreed it was important not to make assumptions about individuals and what they needed – the focus should be on getting to know people, building on their strengths and making individual adjustments. Some self-advocates said they appreciated having technical support for presentations, or help getting online during COVID-19. Others said that preparation time and being able to rehearse with somebody beforehand helped their confidence.

*I got lots of chances to practice before the course. (Self-advocate)*

All participants agreed that relaxed and informal training took the pressure off and worked as well as formal presentations. Not feeling rushed and allowing enough time for delivery was important for the confidence of self-advocates and family carers. NHS practitioners said they supported less confident experts by experience to share their experiences by having a structured interview format, Question & Answer sessions or a pre-recorded video clip. Participants agreed this support was important to avoid potential over-sharing.

NHS Practitioners commented on the time and resources needed to support people properly and said that their organisations needed to resource involvement work with additional time and money. They highlighted the benefits to organisations of having a skilled and confident pool of people to draw on for training. Experts by experience agreed and said that their skills need regular use.

*Confidence and skills can disappear quickly...you need to keep on refreshing or you lose it. (Self-advocate)*

Feedback was important to experts by experience – helping people improve and feel more confident. But feedback needs to be sensitively handled. One expert by experience told us she did not appreciate having her outfit commented on!

*Good feedback really helps and gives you an extra confidence boost. (Self-advocate)*



## Respecting and Valuing people

Participants agreed that good involvement happened when people felt valued and respected for their contribution. Being part of a team, treated as equals, understanding their role and what to expect were all part of this. Knowing what they are getting from involvement in terms of support, training and payment was also important. Participants agreed that although payment was not the most important factor, it was a part of feeling valued.

*Being paid is essential.  
(Self-advocate)*

*I am paid a proper wage.  
(Self-advocate)*

*Experts by experience like having a job. They are paid good money and this helps them feel valued.  
(NHS practitioner)*

All the self-advocates we spoke to were paid for their work, but some of the family carers were volunteers. Some participants pointed out that volunteers can also feel valued and that volunteering can lead to paid roles. Other ways of rewarding and valuing people such as vouchers, payment in kind such as references and meals out were mentioned. Tea and cake and a nice lunch were seen as part of treating people well. Letting people know what happened as a result of training was also highlighted as an important part of respecting people's input.

*Let them know what happens. People want to make a difference – tell them what impact the course has made so they feel useful and valued. (Family carer)*

All interviewees were motivated by making a difference, and for some there was also an element of challenging themselves or progressing their role or career. Interviewees agreed it was important to get to know people, to nurture their skills and future aspirations. This involved giving choices and playing to people's individual strengths and interests, rather than throwing them in at the deep end or involving everybody in everything.

*Choose the right expert by experience for the job, some are not ready for it and it is not right to put them on the spot. (Family carer)*

Respecting people and their personal story was important to interviewees – some self-advocates and family carers were happy to talk about their personal experiences in detail, others were more cautious. Participants said that supporting people to share only what they were comfortable with was a key part of respecting/valuing people. They suggested different ways to ensure people did not share more than they wanted to, including having a question and answer format (practiced beforehand), compiling vignettes or case studies, recording or filming personal stories in advance.

*I had a rough childhood, I don't want to talk about the rough bit...I made up a story, I changed it and nobody knew it was my story.*  
(Self-advocate)

Several interviewees mentioned wellbeing and the emotional impact of this work on individuals. NHS practitioners said they got to know people well by working together and become aware of when people were upset or what else was going on in their lives. They said it was important that individuals knew their own care would not be affected by their involvement in this training work.

Participants said that worry and confusion around being paid when on benefits needed to be addressed from the start. We were told that whatever payment options are in place they must be clear, and the systems must work well. It helps if organisations are committed to the involvement process and see this through.



### Enjoyment and having fun

The self-advocates and family carers we spoke to all said they enjoyed taking part in learning disability training. All interviewees were enthusiastic and committed to raising awareness but said it is

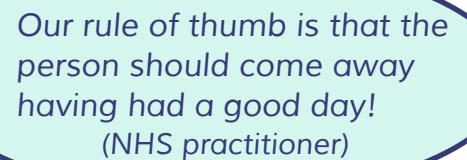
important to have an enjoyable training experience.

*I feel so good after training...I am passionate about making a difference.* (Self-advocate)

*We all really enjoy it...we come out with a spring in our step.* (Family carer)

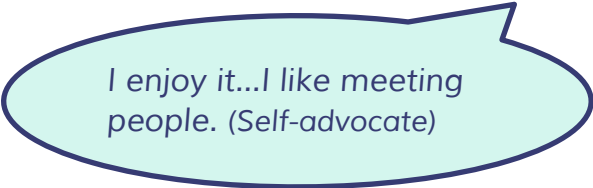
*It's the best job.*  
(Self-advocate)

NHS practitioners said they enjoyed working with experts by experience and that they had learned a lot from them about bringing fun and laughter into their training. They said they worked hard to make involvement in training as relaxed and unstressful as possible.

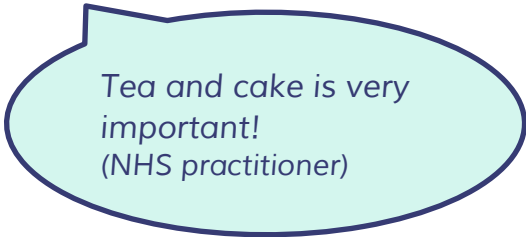


*Our rule of thumb is that the person should come away having had a good day!*  
(NHS practitioner)

Meeting people informally and socializing made training enjoyable for the self-advocates and family carers we spoke to. They particularly enjoyed talking to the other participants when training included tea breaks and/or lunch. Training that allowed time for these conversations and socializing was enjoyable and we were told that these informal/chatty sessions/can be just as effective and more fun than formal training. Experts by experience told us that if they enjoyed the experience, they were more likely to do it again.



*I enjoy it...I like meeting people.* (Self-advocate)



*Tea and cake is very important!*  
(NHS practitioner)

Participants said that online working had an impact, with several finding being online was daunting, especially at first. Although some enjoyed being online, others felt isolated working from home and missed the social interaction. Some participants added that using different methods and being creative with film and video was enjoyable, less daunting than formal presentations, and gave them extra skills.

# TOOLKIT: What to do and not to do (before, during & after the training)?



## Teamwork and Collaboration

DO's	DON'Ts
<ul style="list-style-type: none"> <li>• Create a strong team - where people feel safe and supported</li> </ul>	<ul style="list-style-type: none"> <li>• Don't rely too heavily on the same individuals</li> </ul>
<ul style="list-style-type: none"> <li>• Aim to involve different experts by experience - from the start</li> </ul>	<ul style="list-style-type: none"> <li>• Don't bring experts by experience in late</li> </ul>
<ul style="list-style-type: none"> <li>• Give choices about roles and the way people participate</li> </ul>	<ul style="list-style-type: none"> <li>• Don't decide things without experts by experience being there</li> </ul>
<ul style="list-style-type: none"> <li>• Build in extra time - longer meetings, clear paperwork, catch ups etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Don't assume everybody wants to be involved in everything</li> </ul>
<ul style="list-style-type: none"> <li>• Check in often - does everybody understand, are they happy with their role?</li> </ul>	<ul style="list-style-type: none"> <li>• Don't exclude the experiences of people with higher needs</li> </ul>
<ul style="list-style-type: none"> <li>• Consider using groups or teams who already work together, know and trust each other.</li> </ul>	<ul style="list-style-type: none"> <li>• Don't allow individuals to feel on their own or under pressure on the day</li> </ul>
<ul style="list-style-type: none"> <li>• Be clear about expectations and roles on the day</li> </ul>	<ul style="list-style-type: none"> <li>• Don't let individuals feel responsible for letting people down</li> </ul>
<ul style="list-style-type: none"> <li>• Where possible, deliver training as a team e.g. co-trainers</li> </ul>	<ul style="list-style-type: none"> <li>• Don't 'drop' people after the training course is over</li> </ul>
<ul style="list-style-type: none"> <li>• Have a Plan B if somebody has to drop out or leave early on the day</li> </ul>	
<ul style="list-style-type: none"> <li>• De-brief with team members soon after training sessions</li> </ul>	
<ul style="list-style-type: none"> <li>• Give and discuss feedback from training</li> </ul>	





## Confidence building and support

DO's	DON'Ts
<ul style="list-style-type: none"> <li>• Get to know the people you work with as individuals</li> </ul>	<ul style="list-style-type: none"> <li>• Don't assume what support individuals might want or need</li> </ul>
<ul style="list-style-type: none"> <li>• Build on people's strengths – what do they enjoy doing, what are they good at and what helps their confidence?</li> </ul>	<ul style="list-style-type: none"> <li>• Don't assume people are familiar with your technology and platforms</li> </ul>
<ul style="list-style-type: none"> <li>• Offer a mixture of support options e.g., peer support, 1-2-1 or in a group</li> </ul>	<ul style="list-style-type: none"> <li>• Don't assume with Zoom/online works for everyone</li> </ul>
<ul style="list-style-type: none"> <li>• Offer help with technology as needed</li> </ul>	<ul style="list-style-type: none"> <li>• Don't use jargon, unclear language or overwhelm people with paperwork</li> </ul>
<ul style="list-style-type: none"> <li>• Allow plenty of preparation time – build in time to rehearse talks and presentations</li> </ul>	<ul style="list-style-type: none"> <li>• Don't rush training</li> </ul>
<ul style="list-style-type: none"> <li>• Make sure people feel confident and supported travelling to and from the training venue</li> </ul>	<ul style="list-style-type: none"> <li>• Don't allow people to share more than they feel comfortable with</li> </ul>
<ul style="list-style-type: none"> <li>• Allow plenty of time on the day – for relaxed delivery</li> </ul>	<ul style="list-style-type: none"> <li>• Don't forget people – they may want involvement or need support at different times</li> </ul>
<ul style="list-style-type: none"> <li>• Have a co-trainer - somebody who can provide support</li> </ul>	
<ul style="list-style-type: none"> <li>• Offer an interview format or a pre-prepared Q&amp;A session</li> </ul>	
<ul style="list-style-type: none"> <li>• Give/share feedback and build on positives</li> </ul>	
<ul style="list-style-type: none"> <li>• Keep in regular contact with team members</li> </ul>	
<ul style="list-style-type: none"> <li>• Offer regular training opportunities – to keep skills fresh and confidence high</li> </ul>	



## Respect and value people

DO's	DON'Ts
<ul style="list-style-type: none"> <li>• Ensure people know what to expect eg what is their role, how long will meetings/training be, what support and training is offered.</li> </ul>	<ul style="list-style-type: none"> <li>• Don't put people in training who are not prepared</li> </ul>
<ul style="list-style-type: none"> <li>• Be clear about payment or reward options – offer choices</li> </ul>	<ul style="list-style-type: none"> <li>• Don't allow stories to be shared outside the training - unless permission is granted</li> </ul>
<ul style="list-style-type: none"> <li>• Ensure systems work and will pay/deliver fees/ vouchers etc promptly</li> </ul>	<ul style="list-style-type: none"> <li>• Don't make people wait for out-of-pocket expenses or fees</li> </ul>
<ul style="list-style-type: none"> <li>• Ensure people know that getting involved will not affect the services/care or benefits they/their relative gets</li> </ul>	<ul style="list-style-type: none"> <li>• Don't allow/create anxiety about payment and impact on benefits</li> </ul>
<ul style="list-style-type: none"> <li>• Help person clarify in advance how much of their personal experience/life individuals want to share</li> </ul>	<ul style="list-style-type: none"> <li>• Don't drop people once training is over</li> </ul>
<ul style="list-style-type: none"> <li>• Nurture individual aspirations – where do they want to be, do they want this role to lead to other things?</li> </ul>	
<ul style="list-style-type: none"> <li>• Ensure people feel listened to and respected throughout</li> </ul>	
<ul style="list-style-type: none"> <li>• Ensure people have the opportunity to stop/pause/debrief</li> </ul>	
<ul style="list-style-type: none"> <li>• Make sure the system in place pays people promptly</li> </ul>	
<ul style="list-style-type: none"> <li>• Give feedback on impact of training – including their role</li> </ul>	
<ul style="list-style-type: none"> <li>• Be aware of what is happening in people's lives – signpost to other services where appropriate</li> </ul>	



## Enjoyment & having fun

DO's	DON'Ts
<ul style="list-style-type: none"><li>• Have regular team meet ups before and after training</li></ul>	<ul style="list-style-type: none"><li>• Don't be serious all the time</li></ul>
<ul style="list-style-type: none"><li>• Offer tea and biscuits or lunch</li></ul>	<ul style="list-style-type: none"><li>• Don't rush training</li></ul>
<ul style="list-style-type: none"><li>• Allow time for socialising and chatting with course participants</li></ul>	<ul style="list-style-type: none"><li>• Don't cut out the socialising – or the snacks</li></ul>
<ul style="list-style-type: none"><li>• Informal sessions– where people share experiences are more enjoyable and less stressful</li></ul>	<ul style="list-style-type: none"><li>• Don't think training has to be perfect</li></ul>
<ul style="list-style-type: none"><li>• Have meet ups for socialising/ just for fun e.g. lunches, trips to pub</li></ul>	

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