Making sure people who work in NHS trusts have the training they need to support people with learning disabilities

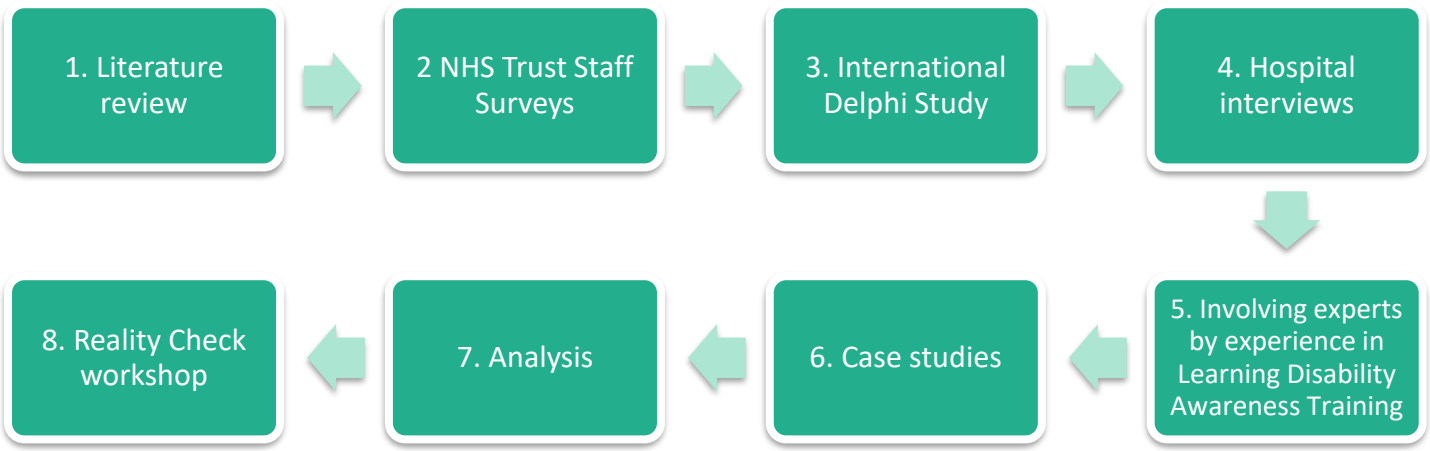
November 2022

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 was to support staff development to help them achieve better outcomes when they are working with people with learning disabilities and their families/supporters. The focus of the project was on learning disability training, rather than on a broader approach that includes autism, although the principles extend beyond learning disability. Further information about the project can be found here.

This paper provides an overview of the various elements of the project and a summary of the key findings from the different stages of the work. Fieldwork had been planned to begin in hospitals in March 2020 and therefore the approach had to change, and this allowed some additional stages of work to be undertaken.

What did we do?



1. Literature review

The first stage of our project was a review of published and unpublished literature to summarise the existing evidence base about the most effective and sustainable approaches in relation to training for NHS Trust staff.

The key research question for this literature review was:

What is the current evidence on the effectiveness of learning disability training programmes directed at staff working in NHS Trusts?

We searched for relevant evidence in a range of databases. Our primary search aimed to identify papers that related to learning disability training in healthcare settings, but we also undertook further searches to allow us to benefit from transferable learning in related areas.

We identified fourteen articles about learning disability training delivered in a health care setting. There were several quality issues and limitations in relation to methodology and content.

In summary, our review of the literature demonstrated that learning disability training can lead to positive outcomes in terms of increased knowledge, confidence, and attitudes. There was some evidence to suggest that training leads to change in practice; several studies provided some examples of this but very few conducted follow up research to measure changes in practice over a longer period. There was also some evidence on the positive impact of training on the people with learning disabilities involved in developing or delivering the training courses.

We wrote three reports about what we found in the literature review:

- A main report discussing the findings of the studies reviewed. This contains full details of the search strategy and the references of the articles found and cited, along with an evidence grid summarising the articles reviewed.
- An easy-read summary.
- A summary of our literature review report.

This literature review was then used to inform the next stages of our project.

2. NHS Trust Staff Surveys

The second stage of our project was conducting surveys with hospital staff in the South of England region to find out more about the content, format and experiences of learning disability training for the non-specialist workforce.

We developed two surveys which were shared with staff working in NHS Trusts in the South region:

Survey 1 was for staff involved in delivering the learning disability awareness training and aimed to find out more about the content and format of the training.

Survey 2 was open to all staff working in the Trusts and explored their experiences and views on learning disability awareness training.

The surveys were designed by the project team (which included people with lived experience) and informed by the literature review. The questions covered:

- the format and content of the training
- involvement of people with lived experience[1]
- the impact of the training
- any changes in practice and what supported these

A total of 20 individuals who were involved in, or who had knowledge of, the delivery of Tier 1 and Tier 2 learning disability training in different training departments across the South regional HEE Intellectual Disabilities area completed Survey 1. A total of 171 respondents working in Tier 1 or Tier 2 roles completed Survey 2 about the learning disability training available in their trusts from across the South regional HEE Intellectual Disabilities area. Of these respondents only 54 had received learning disability training and 117 had not. Those who had not completed any training were asked if they would like this training and about their reasons for their answer.

We wrote three reports about what we found from the hospital staff surveys:

- A main report discussing the findings of the interviews This contains full details of data from the staff surveys.
- An easy-read summary of the staff surveys
- A summary of our report of the staff surveys

[1] In this report, we use the term 'expert by experience' or 'people with lived experience' to refer to both people with a learning disability, as well as their family carers.

3. International Delphi Study

The third stage of our project was a modified International Delphi survey which was undertaken to identify, and reach consensus on: the aims, design and content, and ways to maximise the impact, of learning disability training programmes for NHS Trust staff in England.

This Delphi survey was considered 'international' due to the international makeup of panel members and 'modified' as the items for the survey were obtained from the existing literature and informed by the staff surveys in stage 2, up, rather than being determined by an initial open-ended question to the panel.

The international panel consisted of 57 professional experts from mainstream primary healthcare and acute hospital settings and learning disability health professionals. The panel included experts from Australia, Canada, Japan, New Zealand, Netherlands, Norway, South Africa, Sweden and the four countries of the UK (England, Scotland, Northern Ireland, and Wales).

Delphi Round 1

Panel members were asked to rate the importance of each item using a five-point Likert scale (1 = Unimportant, 2 = Little importance, 3 = Unsure, 4 = Important, 5 = Very Important). Experts were also asked to make additional comments/suggestions to several open-ended questions after each section. These responses were used to devise additional items which were presented in Round 2.

Delphi Round 2

In this round those items that did not reach the 70% consensus target were represented to the panel for review along with the group rating for that item. Panel members then had the opportunity to return the same rating as in Round 1 or change their rating.

We wrote three reports about what we found from the Delphi Study:

- Delphi Study Discussion Paper - how learning disability awareness training for NHS Trust staff can have the maximum impact
- An easy read version of the Delphi Study Discussion Paper
- A summary of the Delphi Study Discussion Paper

4. Hospital interviews

The fourth stage of our project focused on interviews with hospital staff across the South regional HEE Intellectual Disabilities area. We had initially planned hospital visits to interview a range of staff, to collect information and to identify examples of good training. These face-to-face interviews were delayed, then cancelled due to COVID-19. Instead, hospital staff were offered online interviews via Zoom or Teams.

The research team for this project included NDTi researchers and experts by experience (living with learning disability and/or autism). They were involved in designing the questions, conducting and analysing the interviews. All online interviews were conducted jointly by an NDTi staff member and an expert by experience trainee researcher.

Hospital staff who ran training and who were willing to be interviewed were identified via our survey. We identified staff who had attended training via the Trainers and contacted those who gave their permission. Different questions were asked of the two groups of interviewees.

We wrote two reports about our findings from the interviews with hospital staff:

- Findings from hospital interviews
- An easy-read version of the hospital interviews

Stages 1-4 were described in our initial bid. However, due to COVID-19 we were unable to undertake the planned hospital visits and the number of online interviews we did with staff was limited. Therefore, the project devised some additional stages of work to build on the findings from the different strands of this project. The evidence reviews, surveys, Delphi Study and hospital interviews had highlighted the important role of experts by experience (self advocates and family carers) in the design and delivery of learning disability training. We felt it was important to explore how this could be done well.

5. Involving experts by experience in Learning Disability Awareness Training

This small research study was undertaken to explore the enablers and barriers to involving experts by experience. Using interviews and focus groups 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.

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.

We used the data to produce evidence-based guidance on how self advocates and family carers can be involved well in the design and delivery of learning disability awareness training.

Available resources:

- Involving experts by experience in Learning Disability Awareness Training. A summary of findings from interviews with self-advocates, family carers and NHS practitioners.
- Easy Read summary of involving experts by experience in learning disability awareness training
- Training toolkit - What to do and not to do (before, during & after the training)?

6. Case studies

We wanted to look at good examples of learning disability awareness training. We looked at responses to our information request in stage 1 of the project and the project team identified some examples of work they considered to be good practice. The two examples selected were:

- Grapevine's learning disability awareness training course which helps people understand more about learning disabilities and they also hear about the experiences of people with a learning disability in health care and other services.
- The Oxfordshire Family Support Network's 'Working with Families' workshop. The purpose of the workshop is to improve relationships between families and those professionals working in Adult Social Care.

One NDTi researcher and one expert by experience interviewed those responsible for designing and delivering the training and collaboratively wrote case studies.

Available resources:

- Case Study 1: Grapevine's Learning Disability Awareness & Health Inequalities Training
- An easy-read summary of Case Study 1
- Case Study 2: Oxfordshire Family Support Network - Working with Families workshop
- An easy-read summary of Case Study 2

7. Analysis

Once stages 1-6 were complete, the project team, which included experts by experience, academics and Learning Disability specialists, met to review the findings from all stages of the work and draw some overall conclusions. Additional sessions were run with the self-advocate experts by experience in advance to allow extra time for this reflection.

There were some consistent messages, summarised below, from all the different stages of the work about what is best practice in training people who work in NHS

Trusts to support people with learning disabilities.

The discussions amongst the project team in the analysis sessions reflected the importance of thinking beyond the content and style of the training and of considering the settings in which staff are working. As the training is only effective if it leads to improved care and support for people with learning disabilities, it is crucial to address any barriers preventing new learning being put into practice. The project team generated some recommendations about what can be done within Trusts to help staff to put their training into practice. We decided that a useful additional stage of work would be a Reality Check workshop with NHS staff to further explore the wider work needed to support the implementation of learning disability awareness training.

8. Reality Check workshop

We ran a workshop with a range of people from NHS Trusts and other partners, including Specialist Nurses, Human Resources and training specialists. It was led by an NDTi team that included an expert by experience and a family carer. The aim of the workshop was to explore what needs to happen at different levels (Team/departmental; Trust; National) of the system to ensure that mandatory training on learning disability is making a genuine difference.

The workshop confirmed there was a consensus among the people we spoke to that training, in itself, is not enough to achieve change. Staff working in Trusts may need resources to provide the right support and they need a system where change can thrive.

The Reality Check workshop identified actions that need to happen on (at least) three different levels to create a supportive environment for change. These included:

- **At the team or departmental level**, training needs to be followed up in supervision and staff meetings, while staff should be encouraged to support each other to test out their learning.
- **NHS Trusts** should ensure that leadership is in place throughout the organisation to emphasise why learning disability training matters and how it connects to other agendas. They should also be prepared to tackle system barriers that prevent staff from implementing change and to build a culture in which improving care is seen as the day job.
- **National/subregional partners** such as the HEE, NHSE, CQC and ICSs can help to support benchmarking and the sharing of learning, as well as producing national resources to support training.

We wrote two reports with further details about our findings of possible actions identified by staff at the workshop:

- Briefing paper: Ensuring that learning disability training makes a difference – what needs to happen?
- An easy-read version of the briefing paper

What did we find?

Content, style and general approach

- The training should be face-to-face and needs to be for a minimum of 1-2 hours for all staff.
- It should be delivered to small enough groups of staff to ensure that the approach can be interactive, rather than it being a lecture.
- The training needs to be long enough to allow time for discussions and questions.
- The training should include real-life stories and case studies. Some of these should be examples of good practice from the Trust where the training is being delivered. It is important to share positive stories of impact.
- There should be a practical focus to the training. Whilst it may need to cover legislation and policies, it must go beyond this and give advice about where staff can go for further information and about the resources within the hospital that they can use to support people with learning disabilities and their families/supporters.
- Consideration should be given to the local issues and staff needs within the Trust.
- The Trust should encourage staff working at all levels and roles to attend the training.
- Staff should be sent information about the training in a timely way, especially if there is any pre-reading or other preparatory work to be done in advance.
- Whilst the training should be generic enough to allow training in mixed profession groups, it should be able to be adapted for different staff groups. Alternatively, more bespoke department/role specific training should be offered in addition to general learning disability awareness.
- The content of a training programme should cover five separate areas: medical conditions, communication, pain, ethical standards (including safeguarding, rights and capacity/consent) and information and resources. Ten core topics were identified for inclusion: ‘diagnostic overshadowing’, fear and anxiety, reasons for greater health inequalities in this population, recognising and managing challenging behaviours, constipation, nutrition and hydration, epilepsy, dysphagia, postural care and respiratory problems.
- The training should be repeated every three years.

Involvement of experts by experience

The findings from stages 1-4 gave a clear and consistent message about the need to include experts by experience in the training and of the benefits their involvement has. Additionally, we identified some specific recommendations about their inclusion:

- Experts by experience should be involved in the design as well as the delivery of the training.
- The experts by experience should include people with learning disabilities and family carers.
- There should be involvement of people with higher levels of support need and people who use different forms of communication. This could be through videos or in person.
- The staff undertaking the training should have the opportunity to interact naturally with the experts by experience, for example over a coffee break or through an informal question and answer session.

Although this message was very clear, conversations with hospital staff responsible for the delivery of the training identified some challenges in including experts by experience. These included:

- Difficulties in sourcing a budget to pay for their involvement
- Problems with paying people who are on benefits
- Practical issues such as transport
- The need for sufficient training to ensure those delivering training have the necessary skills.

We know it is essential that experts by experience are included well and that their interaction with other trainers should be a positive example. If the trainer without lived experience does not role-model respectful, supportive partnership working then this undermines the messages of the training.

We felt it was important that rather than simply recommend the involvement of experts by experience, we provided some more detailed guidance on how this can be done well and some of the actions needed to ensure they are well-supported before, during and after the training.

Therefore, we undertook some additional qualitative research to explore 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. This work identified four key elements as important for good involvement of experts by experience in learning disability awareness training:

- Working together as a team
- Building confidence and offering support
- Respecting and valuing people
- Enjoyment and having fun

There are links to the available resources from this stage of the work on page 4 and these include a toolkit on what to do and what not to do.

Wider work to support the training

- **Training should signpost other sources of information that people can use.** This might include websites such as Easy Health which is an online library of accessible health information with simple words, clear pictures and films. There is a wealth of free easy read health information (leaflets and videos) about common health conditions. The hospital intranet could host a page with links to recommended resources and websites.

- **Further support should be provided following the training to help staff to put what they have learnt into practice.** One of the hospital trainers we spoke to estimated that most of her time was spent supporting hospital staff in their day-to-day activities:

> ***"On the job training is how we embed the skills"***

She described how she will always support a member of staff with their first Mental Capacity Assessment or Best Interests Meeting. This type of practical input supplements the theoretical training about such topics.

- **Peer support groups should be set-up for people to engage with after the training.** These could give an opportunity for reflective practice and further case-study discussions. People could bring real-life problems to the group to discuss and to seek advice from their colleagues.

- **The introduction of Learning Disability Champions.** It is important that staff know where to go when they need further advice. This will often be a Learning Disability Liaison nurse but not all hospitals employ people in this role and they provide a 9-5 service generally. Learning Disability Champions could be used as another source of further information. These Champions should take this on a voluntary role but there should be protected time for the work and it should be accompanied by extra training.

- **Increased visibility of people with learning disabilities.** Trusts should look for opportunities to hear from, and work with, people with lived experience. The value of their input into the design and delivery of learning disability awareness training is evident, but there are other ways of ensuring their feedback on, and thoughts about, the services a Trust provides. Volunteers play a central role in many hospitals. Consideration could be given to a targeted campaign to recruit, and provide appropriate support for, volunteers with learning disabilities.

- **Provision of training materials.** The staff surveys showed that staff valued having course materials in the training sessions that they could take away.

- **Provision of resources.** Hospital staff need access to basic equipment and technology. Tablet devices were often cited as being useful for communication and distraction. One trainer spoke about her desire to create activity boxes for each ward that could be used with people with learning disabilities. Whilst she had identified the need for this resource, she did not currently have the time to do this.

- **Regular updates.** The Delphi Study Panel reached the consensus that awareness training should be refreshed every three years. However, some members of the project team felt strongly that staff would benefit from more frequent refresher sessions, although it was acknowledged that Trusts may find it difficult to allocate additional training time for staff. There was a suggestion that the training could be supplemented with the regular sharing of e-learning updates, links to new resources and relevant, short videos. This could assist with new learning but also serve as a reminder of the main awareness training for the staff that receive updates.

- **Assessment of the impact of the training.** It is essential to explore the effect of learning disability training and this needs to go beyond asking for feedback from people on their views on the content and quality of the training immediately after the session. Assessing the impact of the training should include looking at if it is making a difference in practice. In the interviews there were several suggestions from those delivering training about how this can be through:

    - auditing of reasonable adjustments
    - monitoring of hospital data, complaints and incidents (including data from the LeDeR review) to enable the training to target recurring issues and to allow more bespoke training for departments where it is needed
    - sending factual surveys to staff to check knowledge on subjects, such as the Mental Capacity Act
    - the use of "mystery shopper" visits to wards by experts by experience who are part of a hospital user group.

Conclusion

There are well known health inequalities for people with learning disabilities and over the years there have been many calls for more, and better, training to help address these. Since this work began, the Health and Care Act 2022 introduced a requirement for service providers registered with CQC that their employees must have received training on learning disability and autism appropriate to their role. We hope that this work commissioned by the South Regional Health Education England Intellectual Disabilities programme has helped identify what constitutes good practice in relation to learning disability awareness training for NHS Trust staff. However, whilst training is a vital aspect of improving health and social care for people with learning disabilities it may not in itself reduce the inequalities they experience. Therefore, there is an urgent need to consider what system changes and wider work must accompany the training to ensure that it is leads to better care, support, experiences, and outcomes for people with learning disabilities.

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