

Case Study 1:

Grapevine's Learning Disability Awareness & Health Inequalities Training

August 2022

Context

Grapevine, Coventry and Warwickshire, is an independent charity that helps and empowers people experiencing isolation, poverty and disadvantage. The organisation strengthens individuals, sparks community action, and shifts power across systems and services. At Grapevine, The Health Team are part of the Help and Connect project commissioned by Coventry City Council. They are experts by experience and believe:

Every person with a learning disability should be able to live a happy, healthy, and safe life. We should all be treated with respect and have the same access to good health care. Our lives matter too!

They deliver a range of work to empower their peers and enable better access to healthcare services for people with learning disabilities to improve health outcomes. One aspect of this is their Learning Disability Awareness and Health Inequalities training, entitled 'Disable the Label'. This 2.5-hour training session is designed and delivered by the Health Team members and two project leads.

Aims

The purpose of this workshop is that it will have a positive impact on personal perceptions and working practice and that people will be able to:

- recognise what a learning disability is (and is not) and the types and causes of learning disability
- understand the health needs of people with learning disabilities and barriers to health care that impact on their health outcomes
- understand and implement 'reasonable adjustments'
- share best practice in the delivery of positive patient experience
- challenge perceptions of learning disabilities and the impact of labels.

Who is it for?

The training is aimed at health and social care, students, and professionals, and The Health Team has been delivering this workshop on a monthly basis to staff across all departments for over 10 years. Following on from regular participation in the Enhanced Care Programme for hospital staff, at University Hospitals Coventry & Warwickshire NHS Trust (UHCW), the full workshop was commissioned by the Associate Director of Nursing, Quality & Patient Safety. The training was requested as the Trust recognised a need for learning disability training following concerns around the quality of health care for people with learning disabilities raised by Oliver McGowan's avoidable death and the wider LeDeR work. The organisation has made specific efforts to flag the training to departments where they identify the need but it is available to anyone working in the Trust:

It is for anybody and everybody. We all meet people with learning disabilities and healthcare should be inclusive for all.

This workshop is suitable for people working in a range of roles and settings and it has been delivered to healthcare professionals, social prescribers, students and nursery nurses. The Health Team ensure the training is kept up-to-date and amended based on national and local changes as well as feedback and session evaluations. Grapevine are also able to design and deliver a more bespoke workshop if that is needed.

How does it involve people with learning disabilities or their family carers?

Members of the Health Team with lived experience have been central to the design of this workshop and are also part of the delivery team. It is their voice that is most important in the workshop. Family carers are not involved in delivering the training, but they have been consulted about what topics it is important to cover. For example, they flagged concerns about the lack of use of hospital passports and stressed the benefits of these. The workshop has a strong message about the importance of involving families/carers/supporters when someone with learning disabilities is in hospital.

The Workshop – what happens?

Although the focus of the workshop is health, they want to give a broad insight into the lives of people with learning disabilities. Therefore, they talk about the social and family sides of people's lives as well. People with learning disabilities are vulnerable in the community and so they discuss hate crime:

We want people to understand about their lives, not just their health.

The team believe giving a more rounded picture is important for helping to change perceptions and attitudes – it helps people with learning disabilities to be seen as people first and foremost.

The session starts with introductions and immediately getting the participants involved by asking them questions about health statistics.

They are shocked by some of the statistics.



The workshop is designed to be interactive and there are lots of different activities they use to get everyone involved. These include:

Scaredy Pants Plus:

In this exercise all participants are given a piece of paper in the shape of a pair of pants and asked to write what their fears or worries about working with patients with a learning disability are. These are then pegged out on a washing line and they are discussed as a group. Some of the worries people have shared are about:

- patronising people
- not being able to understand someone
- fear of being attacked
- upsetting the patient

This opportunity to “air their dirty laundry” gives a chance for participants to acknowledge their own fears and think about how that might be impacting on any interactions with patients with a learning disability. Grapevine find the same worries and concerns are often shared and it can be reassuring for people to know they are not alone in their worries. The trainers take care to never dismiss any fears and concerns but instead to address them and ask the group to think about what could be done to help.



They have adapted the exercise to make sure it works for those who did not have any concerns. If this is the case, they ask people to share previous fears and what they have done to overcome them. This is an opportunity to share best practice.

Sketches:

The trainers perform some sketches where they illustrate real life situations that they have experienced themselves. For example, John plays a doctor who gets things wrong with his patient. Firstly, his patient comes into the room in a wheelchair and he asks her to take a seat. He then ignores her and asks her mum questions about her. Throughout the appointment he continues to talk across the patient.

Another sketch is based on someone who cannot read who then struggles to book in using a digital system and gets increasingly angry about this.

After performing the sketches, they ask the participants what went wrong and what the barriers are.

The learning points covered through the different sketches include:

- time of appointment
- waiting time
- environment
- communication and avoiding jargon
- understanding
- respect
- length of appointment
- understanding what's next

Disable Our Label:

Each participant is given a “label” to wear throughout the session and they are then called by this label. These are labels that the health trainers have been given at some point in their lives. At the end of the workshop, they talk about how it feels to be called by a label and the impact of these negative labels. The health trainers remind participants that they now have the freedom to take this label off. The health trainers share some of the positive labels they would choose to use for themselves, such as “grandad”, “actor” and “singer”. This session is a powerful reminder of the impact of being labelled in a way you would not choose.

Case Studies:

The trainers talk about what happened to Oliver McGowan and Richard Handley. These are both shocking cases but discussions about them can bring out some important learning points, such as the need to listen to what family carers say. Case studies help to convey the point that some reasonable adjustments may be small but can make a big difference to people’s experiences and outcomes. After discussing the case studies, they move straight on to thinking about reasonable adjustments and overcoming barriers. The focus is on what the solutions are and what people can do in their role to improve the care that patients with a learning disability get.

In addition to these activities the trainers do a quiz and the session in general is interactive. They try to make the training fun and informal, so it feels like a positive session even though they are talking about health inequalities and some terrible individual stories.

Obtaining feedback - what difference does it make?

At the end of the workshop, participants are asked if their perception of people with learning disabilities has changed and everybody has said yes. All the sessions are evaluated more formally and the feedback informs changes made to the workshop. The evaluation has shown that the session has made staff look at things differently and is helping staff to improve people with learning disabilities' experiences and make sure their voices are heard in relation to their health needs.

I will share what I have learnt today with my colleagues to try and ensure that we make adjustments to improve the patient experience and allow them to make informed choices. Brilliant session, all three speakers very informative.

The quiz was really informative and interactive. Many of the statistics were quite shocking. It was a session that allowed me to reflect on how to improve within my role. This was an invaluable session.

Training is fantastic. I've learnt more information about learning disabilities and feel more confident to put into practice the knowledge and share with colleagues. Very well presented and clear examples given.

We all think we are aware of what people are going through, but we are not and we need to hear from others to help us look at the situation differently. It is our job to put adaptations in place – but we need to take on board their voices to make these changes.

Jane Grantham (Safeguarding Support Nurse) feels it is an invaluable session and is confident of positive changes in clinical work. Encouragingly, the delivery of the training has had a knock-on effect and led to improvements already. These have included:

- Greater awareness of hospital passports and importance of individual patient needs
- Understanding of GP Summary records and flag system
- Improved accessible information on website
- Understanding of role of Acute Liaison Team & referral routes
- Accessible colour-coded hospital map being developed
- Request for training for specific departments, e.g., Nursery Nurses

The future

Due to the difficulties of delivering face-to-face training during the COVID-19 pandemic, Grapevine did try to offer this training online. However, this did not work for some of the experts with lived experience and it was difficult to hear people. They took a decision that they were not able to deliver the interactive workshop in the way it was designed in a virtual format and they will only do the full workshop face-to-face now. Shorter, bespoke learning disability awareness workshops are offered.

They are working to bring new members into the Health Team and train them in delivery of this session so they have a larger team of trainers. This work used to be done on a voluntary basis with expenses paid but discussions are underway to remunerate the Health Team for their expertise and time.

UHCW have commissioned Grapevine for further sessions and will review this but they are hopeful it will continue, as this is definitely a training need they have identified. Grapevine are continuing to work closely with the CCG and are looking at training for other healthcare organisations and will continue to campaign on any issues they identify when delivering the training.

With thanks to Joanne, John, Susie, Molly from Grapevine and Jane from UHCW for sharing information and photos about the training.

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To find out more about Grapevine's work, please visit their website:
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