**Department for Health and Social Care Consultation**

**Learning Disability and Autism Training for**

**Health and Care Staff**

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**Response from Learning Disability England**

**April 2019**

**About Learning Disability England**

Learning Disability England is a charity and membership organisation working to make life better for people with learning disabilities and their families.

Membership is open to any person, organisation or group that supports Learning Disability England’s aims and wants to be part of making them happen.

The aims are:

1. What is important to people with learning disabilities is heard and understood:

We work to influence policy makers, providers and commissioners to understand and act on what really matters to people with learning disabilities and their families (not only in health and social care). We help people with learning disabilities speak for themselves raising their profile in society, in general, showing people as citizens living ordinary lives.

2. There is a change in behavior in service design and delivery that builds on rights

We help policy makers, providers and commissioners of services work in ways that people with Learning disabilities say are the best or most important.

3. Demonstrate coproduction and real collaborative working making a difference

We are working to show how the 3 groups in the membership can work together to solve long standing problems or make a difference together. We support people with learning disabilities being in positions where they can speak truth to power or are decision makers themselves.

4. Live our values and model the change we want

We try to build trust through strong networks and to share power and influence through all parts of LDE. We will help other people and organisations change how they work by being open and honest about how LDE works, the problems and the successes so others can see what is possible or ask us what we are learning.

**Who we heard from**

We asked our members for feedback on the consultation. We heard from lots of different people and groups. This included people with a learning disability, families, allies and organisational members.

We co-wrote a letter with CHANGE about experts by experience being employed to co-design and co-leading the training.

Feedback was gathered from the National Self-Advocacy Convention in Blackpool in February 2019.

Members have continuously offered feedback on this consultation and wider issues like the Mental Capacity Act Review.

We heard from members and the wider community during the initial consultations on the NHS Long Term Plan and their feedback once it was published.

**Response Summary**

Learning Disability England supports the proposal for mandatory training around learning disability and autism.

We think all staff should receive face-to-face training which has been designed and delivered primarily by people with learning disabilities and/or autism.

We think people with learning disabilities should be employed to design, deliver and evaluate the training. This means they should be paid the living wage and have a proper contract. They should be paid the same amount as any non-disabled co-trainers.

There are many programmes that already work using this model and it should be considered best practice, informing and providing the basis for the mandatory training.

**In Detail**

1. **Content of mandatory training**

The priorities for the trainings content from all members were:

* Addressing assumptions or attitudes health & social care staff might have that are incorrect
* The Mental Capacity Act
* Communication (including with families)
* Rights based on citizenship
* Tools or practical examples of what makes a difference

Many professionals hold outdated opinions of people with learning disabilities and/or autism. Much of this is based on stereotypes and myths. We want the training to challenge these oppressive attitudes. The training being led by people with learning disabilities is a great way to do this as it challenges attitudes while showing people what people with learning disabilities can do.

A rights-based approach to properly implementing the Mental Capacity Act was a priority for training content for all our members. We hear stories of unbalanced, ill-informed decision making having adverse effects on people’s health care. This can be through people’s decisions not being respected or an assumption made that professionals decisions are informed when they were not.

We know there are lots of good resources available, but many professionals don’t know how or don’t have time to use them properly. Using these tools can improve people’s experiences significantly.

Our members did not tell us that detailed information on diagnosis or syndromes was a priority for inclusion in the training.

Self-advocates particularly would like to see the training talk about the social model of disability, focusing on rights and personal stories. They would like to see the training be a positive experience for people, despite gaining knowledge of the failures, inequalities, abuse and death. They would like professionals to leave feeling like they know how to tackle some of these problems and use best practice techniques and resources.

Our members shared different views on if training for autism and learning disability should be one or separate training sessions. The majority thought it should be separate but acknowledged a third of people with autism also have a learning disability, so there is cross over. They felt that some training could include both but there should also be separate sessions.

LDE member Dimensions are currently offering training to whole GP practices. They have completed around 23 out of 50 planned training sessions, reaching around 250 professionals. They have shared their interim report assessing the impact of their My GP and Me training.

They have identified 4 key areas for training.

1. Meaningfully involving people with learning disability and autism.

2. Training professionals with different roles together.

3. Focussing on reasonable adjustments and person-centred thinking in services.

4. Introducing communication tools designed to empower health professionals.

There is a link to the full report in appendix 4.

1. **Staff roles and Training**

Members think that all staff should receive good quality face to face training. This allows the training to be interactive and dynamic. It allows people to ask questions that they can’t ask their patients. We know this makes training more impactful.

Several members expressed concern that online training will not address the issues of discrimination people experience because of negative attitudes or culture.

We disagree with the proposal in question 7. We think it’s important all staff get face to face training. We think professionals should train with a mix of other job roles. This allows the professionals to understand a person’s journey through the service/system and the barriers along the way. It can help them understand how reasonable adjustments can be used at different points in the journey and how all staff are involved. For example, supporting patients to reduce anxiety when they are being admitted or signed in can allow an appointment to be more efficient as the patient is more relaxed.

Relationships and communication between different staff during the process effects peoples experience. A family member shared a story with us about reception staff being very reluctant to turn off the radio in the waiting room and their failure to recognise this as a reasonable adjustment. After asking several times they did but did not understand how that could have affected the entire appointment for that person.

We like the idea of a training passport as discussed in question 8. We think it is important that employers know how much training their staff have had and can make sure it’s up to date.

1. **Delivering Training**

We agree that there needs to continuing professional development and training for new entrants. We would like to see this as part of inductions to new roles, within the first year. We think this training needs to be prioritised by employers.

We would like there to be a standard for training, to ensure across the country training is good quality. However, we also want training to be adaptable, flexible and innovative. We want training to develop as we learn more about best practice and new ideas come to light. We know that meeting the needs of a group is important, we want training to meet the needs of professionals to ensure it is valuable to them as well as us.

We suggest that the Department for Health and Social Care also needs to work with disability rights organisations and self-advocacy groups as partners for developing the common curriculum. Going beyond working only with professional bodies and large charities.

Best Practice

There is growing evidence of the impact of co-delivery of training, delivered by experts by experience. This builds on work of people like Baroness Hollins who, in her role at St. George’s Medical School, employed people with learning disabilities since 80s & 90s. You can read about her experience in Appendix 2. This approach demonstrates the power of the partnership of expertise of professional & person with lived experience.

This work has been published in 5 medical journals as an example of best practice. We believe for this approach to work in educational settings teaching on this subject must be examined. Failure to examine results in it not being taken seriously as a subject.

LDE member Certitudes feedback on their ‘Treat me right’ training reinforces the point on co delivery having the potential to have greater impact than e-training or training delivered by professionals alone. Evidence can be found in appendix 3.

E- Learning

We are concerned about the possibility of e-learning. Evidence given to us by our members suggests face to face training would be vastly superior to independent online training. We think face to face learning has a more significant impact on individuals’ attitudes and approaches to people with learning disabilities and autistic people. Although face to face training is more expensive we think it is more cost effective in terms of its level of impact.

For example, we know there are many resources currently available to help health and social care professionals, such as health passport, which should improve the experiences of disabled people of services. However, they are often not used correctly, used at all, or known about, despite having been around for a long time. Current online training has ad little impact on this.

1. **Involving people with a learning disability and autistic people**

In partnership with CHANGE, Learning Disability England created a letter regarding how people with a learning disability and autistic people should be involved in this training. You can read the full letter in appendix 1. We have had more than 100 organisations and individuals sign the letter in support.

We know that people with learning disabilities face many barriers to good quality health care and employment. Most of the work they do is unpaid. However, people with learning disabilities and autistic people have lots of experience and expertise about their own lives and about what it means to be a disabled person.They are best placed to lead on designing, delivering and evaluating this training.

We think it is essential that people with learning disabilities are employed with proper contacts and paid salaries which are above the living wage to do this work. Using zero-hour contacts or paying them less than co-trainers is not acceptable. It reinforces oppressive ideas about people with learning disabilities and suggests their contributions aren’t valuable.

An inherent part of this training is challenging attitudes. By modelling the change we want to see across society in this training we are challenging attitudes about disabled people’s ability to work and speak up for themselves and their experiences. We are also showing how they can take on leadership positions.

We would like to see people with learning disabilities in a chairing or co-chairing roles. For them to be present and active in designing and running sessions. Online training or training that is not designed or lead by people with learning disabilities will not be as valuable or impactful. We feel it will be tokenistic and a tick box exercise.

Self-advocates have told us they think this work should be completed by local rights based and self-advocacy organisations. These organisations are at the heart of getting the voices of disabled people heard. Many already participate in projects around training for disability awareness and quality checking health and social care services. They have active and capable people with learning disabilities as members and support structures already in place. Supporting these organisations to lead on training will make training more impactful for health and social care whilst also supporting their work more generally, strengthening the rights of people with learning disabilities.

We also know that some of our organisational members who are providers have done great work around training like this and employing people with learning disabilities as equal colleagues. Learning Disability England aims to support self-advocacy and rights organisations to work with providers to make sure we are all working together to achieve more and share resources.

There are currently lots of people with a learning disability who run training programmes, it would be ideal to recruit them to also run train the trainer courses for other people with learning disabilities. We would like to see a pot of money set aside to fund this to ensure trainers get good quality training, ensuring the have the skills and knowledge to make this training as beneficial as it can be.

Training the trainer programmes need to be well funded and accessible. The course needs to be designed with people with learning disabilities and/or autism in mind. The opportunity for co-trainers or support in other ways should be funded, for example if people need support to travel. Providing this support to the people who need it will enable their inclusion.

We also know that many families are passionate about their loved one’s experiences in health and social care services and would be interested in being part of designing and delivering training. Involving families and allies in this will add another important perspective. Many families find that they are often ignored or not listened to when they are trying to advocate for their family member within these services. Families can be an invaluable resource to ensuring good outcomes are achieved.

1. **Mandating Training**

We support training being mandatory for all health and social care staff.

We think inclusion in the NHS contract should be used to ensure all providers of NHS funded services are required to provide the appropriate levels & methods of training.

We think self-employed staff/lone practitioners/partners should be required to complete the mandatory training. We think this is particularly important as lone working puts people at a greater risk of making a mistake or not having support to check in with. It is important that all staff have this training.

We think the training should be linked to a professional’s registration to practice or to terms of their employment contact. As we think all staff should receive training it is necessary for other methods to exist as not all staff will be linked to professional bodies. For example, receptionists.

1. **Monitoring and evaluating impact**

We think people with learning disabilities should be in paid roles, leading inspections and evaluations of training. Many of the self-advocacy organisations that are our members run quality checking projects locally which access health and social care services. We think getting feedback from people with learning disabilities and their families is very important. We want to make sure people are receiving quality training not giving as many people as possible an online course with no or limited impact.

We are concerned about CQC and Ofsted alone leading on verifying the implementation and quality assurance. We feel they are currently stretched and under resourced. We want to know how they would access the training impact or quality records and what the consequences would be for services that fail to comply.

We think training needs to be happening for at least 2 years before it is externally reviewed for consideration of change. This is so we can access the difference it makes in how staff work and treat people. We want to know what impact it has on their behaviour within the service. We want to know if it improved the experiences of people with a learning disability in health and social care services.

1. **Cost and Benefits**

We think the importance and purpose of this training goes beyond any possible economic benefits. It is a human rights issue. The LeDeR programmes findings around preventable deaths and health inequalities show this to be a matter of oppression and discrimination. The fact people with a learning disability die on average 20 years younger than their non-disabled peers from preventable deaths is a disgrace. The lives this training could save can and should not be quantified in terms of economic benefit.

Having said this, providing good quality care to people with learning disabilities reduces costs across the board.

* Getting reasonable adjustments right the first time can prevent illnesses from deteriorating or repeat admissions/appointments
* Deteriorating health costs social care more as more support is needed
* Poor quality services impact on the mental health of disabled people and their families
* Fewer complaints against services will be received
* Would not have to carry out inquests
* Would not have to pay compensation to families whose loved one had died of a preventable cause.

We disagree with 8.4 costings. We think that for people with learning disabilities to be valued and taken seriously they must hold a leading or co-led role and be paid the same amount as their co-trainer. Paying them less suggest their time or expertise is not as valuable as their co-trainers. This limits the impact in terms of changing attitudes.

**Appendices**

**Appendix 1**

Letter written by Learning Disability England and CHANGE. 108 organisations and individuals have signed it.



**Appendix 2**

Baroness Sheila Hollins taught at St. Georges Medical School during the 1980s and 1990s. The school employed people with learning disabilities as paid co-trainers and co-researchers.

She said, “*I am absolutely committed to the involvement of employed co-trainers with Learning Disabilities*”, using this approach had a significant impact on teaching and student learning.

We believe for this approach to work in educational settings teaching on this subject must be examined. Failure to examine results in it not being taken seriously as a subject.

This work has been published in 5 medical journals as an example of best practice.

HALL, I. S. and HOLLINS, S.(1996) The Strathcona Theatre Company: Changing Medical Students' Attitudes to Learning Disability (Mental Handicap). *Psychiatric Bulletin* 20, 429-430.

HOLLINS, S.(1982) The way we teach the psychiatry of mental handicap to Undergraduates. *Association of University Teachers of Psychiatry Newsletter* December 29-32.

HOLLINS, S. and BRADLEY, E. (1987) Mental Handicap in Context: Medical Undergraduate Education.  *Psychiatric Bulletin* 11, 389-391.

HOLLINS, S.  (1988)  How Mental Handicap is Taught in U.K. Medical Schools.  *Medical Teacher*.  10 (3), 289-296.

<http://www.intellectualdisability.info/how-to-guides/articles/the-contribution-of-actors-with-intellectual-disabilities-to-the-training-of-medical-students>

THACKER, A ., CRABB, N., PEREZ, W., RAJI, O. and HOLLINS, S. (2007) How (and why) to employ simulated patients with intellectual disabilities. *The Clinical Teacher* 4 15-20.  Blackwell publishing Ltd.

THACKER, A., PEREZ, W., CRABBE, N., McCLUSKEY, C., HOLLINS, S. and RAJI, O.The Contribution of Actors with Intellectual Disabilities to the Training of Medical Students: A collaboration between the Division of Mental Health, St. George’s, University of London and the Strathcona Drama Workshop, London.  Learning About Intellectual Disabilities and Health.

**Appendix 3**

Certitude shared feedback from their ‘Treat Me Right’ Autism training.Experts by experience play a central role in delivering those sessions. A central theme of the feedback was how helpful professionals found having an autistic person co-deliver the training. They found it “*very helpful”, “appreciated it”, “Inspiring and moving*”. Many felt it helped them understand in an interesting and interactive way that other training hadn’t managed.

**Appendix 4**

LDE member Dimensions have currently offering training to whole GP practices. They have completed around 23 out of 50 planned training sessions, reaching around 250 professionals. They have recently released their interim impact report. The link is below.

<https://www.dimensions-uk.org/wp-content/uploads/MyGPandMe-training-interim-report-March-2019.pdf>

Having completed the course

94% said they were either confident or very confident they understood what having a learning disability and autism might mean when someone accesses primary care.

94% said they were confident or very confident around making reasonable adjustments for patients with learning disabilities and/or autism.

89% said they were either confident or very confident communicating effectively with patients who have learning disability and autism.