

Dimensions' response to the consultation on mandatory learning disability and autism training for health and social care professionals

About Dimensions

Dimensions is a not-for-profit social care provider for adults with learning disabilities and autism. We support around 4,000 adults across England and Wales.

Dimensions Group employs around 7,000 people, most of whom are involved in the day to day support of people with learning disability and autism. All of Dimensions employees will receive training in learning disability and autism awareness, as well as training to develop the skills and knowledge to support the individuals they work with.

Since 2018, Dimensions has led the #MyGPandMe campaign to tackle health inequality for people with learning disability and autism. This has included the delivery of training to GP surgeries across the country.

This submission draws on interviews with people we support, families, support staff, health care professionals and Dimensions Learning and Development team.

Introduction

This consultation was launched in response to the LeDeR review and campaigns from individuals such as Paula McGowan, raising the issue of early mortality for people with learning disability and autism.

We believe that changing attitudes and shifting approaches to patient care for people with a learning disability and/or autism is essential to improving outcomes.

Those in both the social care and health care workforce should receive training that develops a positive attitude and approach to working with people with learning disabilities and autism. This should be the foundation of any skill development in these sectors.

We recommend that all health and social care professionals receive face to face training from someone with lived experience, to challenge stereotypes and foster positive attitudes.

Beyond this the needs of the health care and the social care workforce are, at points, different and nuanced. Mandatory training should not be one size fits all. Individual employers should be able to tailor further training and skill development for health and care professionals to the role they perform and the level of contact they will have with someone with a learning disability and/or autism.

With this in mind, Dimensions' submission sets out our experience of good practice in both health care and social care respectively, and makes recommendation for how we think training should be delivered. In both instances, we believe people with lived experience must be meaningfully involved in training and remunerated for their contribution. The submission proceeds as follows:

- 1: What does good patient care look like for people with learning disability and autism (Question 11)
- 2: Meaningfully involving people with learning disability and autism (Questions 15 & 16)

- 3: Supporting and employing people with a learning disability and autism to deliver training (Questions 14 & 17)
- 4: Issues relating to health and social care (Questions 4, 5, 6 & 7)
- 5: What does good health care training look like? (Questions 1, 2 & 3)
- 6: What does good social care training look like? (Questions 1, 8 & 21)

1. What does good patient care look like for people with learning disability and autism?

People with learning disability and autism face profound inequalities in health services. In recent years, successive pieces of research have underlined the stark mortality gap that exists between people with a learning disability and the general population, including Death by Indifference; the Confidential Inquiry into Premature Deaths of People with Learning Disability (CIPOLD); the Mazar's Report; and the Learning Disability Mortality Review (LeDeR).

The most recent NHS Digital figures set the mortality gap at 18 years for women with a learning disability and 14 years for men.¹

People with learning disability and autism deserve high quality healthcare. Premature and preventable deaths, resulting from barriers to access, underline an injustice that cannot be tolerated. Equality and fairness demand that people with learning disability and autism have adjustments to meet their needs and that they are treated with care, concern, dignity and respect.

Case Study – Thinking about the patient, Paul's story

Paul has never liked being in unfamiliar surroundings with unfamiliar people. This can cause Paul great anxiety which can result in some very challenging behaviour. But it's important that Paul gets used to going to his local surgery for his appointments and health checks.

Every Friday morning staff book a taxi for 11am to the surgery and book another for 11.20am from the surgery to Copper Beach, a local pub! Paul's support staff prepare a flask of tea, a couple of biscuits and Paul's favourite mug.

At first, the staff at the surgery arranged things so as soon as Paul walked in, there was a chair straight in front of him next to the water cooler. Paul would sit down and have his tea and biscuits

Then after 6 weeks of visits this changed to the support staff guiding Paul straight through the waiting room and into the consultation room to have his tea, making sure that Paul can see his flask as he goes.

Once in the room Paul has his tea and biscuits - his support staff and the surgery staff chat to Paul and make sure that he is relaxed and comfortable.

The staff at the surgery have Paul's communication plan – they understand that as Paul is registered deaf, he takes most of his communication from facial expressions and body language. The staff know to over exaggerate their facial expressions when they are smiling and welcoming Paul.

¹ [Health and Care of People with Learning Disabilities. Experimental Statistics: 2017 to 2018. NHS Digital. January 2019](#)

Question 11: What best practice are you aware of in delivering training on learning disability or autism?

Dimensions has developed a training package for GP surgeries alongside Books Beyond Words that focusses on communication and reasonable adjustments.

The training sessions are co-led with someone who has lived experience, which is a crucial element of the training. We detail this approach further in the submission below.

Dimensions' approach is informed by our experience of involving people with lived experience in training of our own workforce. Essential though it is, there is only so much professional expertise can give; it is a person's ability to demonstrate lessons and suggestions from their own lived experience of services that adds the authenticity and details that provide the firmest of evidence for a colleague or organisation to change or act. Their expertise is based on their own individual experiences and this unique position helps in connecting to others with similar experiences and also adds a very real dimension to us as a collective.

Evaluation of the #MyGPandMe training has underlined positive impact, with participants reporting high rates of confidence in key areas working with people with learning disability and autism after the training:

- **94%** of participants said they were either confident or very confident understanding what having a learning disability or autism might mean for a patient accessing services, and
- **94%** of participants said they were either confident or very confident making reasonable adjustments, and
- **89%** of participants said they were either confident or very confident communicating with patients²

2. Meaningfully involving people with learning disability and autism

Involving people with learning disability and autism can have a significant impact on practitioners' attitudes towards patients. Empowering people with learning disability and autism, who are very often seen as vulnerable and who may only be seen by health services when they are unwell, directly challenges stereotypes.

Meaningful involvement means co-trainers will be empowered in sessions. For example, being given opportunities to make visible choices and exercise control over a session; having the space express what matters to them and share their experiences. The pace of the sessions will be led by them, the ground rules for the session might be decided and explained by them, or designed around them and anyone training alongside them will typically be facilitating, rather than leading, the session.

Meaningful involvement can take many forms and can be made to work even for people with profound learning disability, where co-trainers think creatively about how to involve the person they are working alongside.

This form of involvement is demanding and trainers with learning disability and autism will need support to develop the expertise and skills needed to be an effective trainer.

Many people with learning disability and autism will have valuable lived experience and it is important that professionals are able to hear this. The format for sharing this experience should not be

² #MyGPandMe: Little things make a big difference (an interim report on training for GP practices in learning disability and autism), Dimensions, 2019

tokenistic and people with lived experience should be involved further than simply sharing a story about healthcare they have received.

If people with learning disability and autism are not given an authoritative role in training, it is unlikely that attitudes and unconscious bias will be challenged sufficiently.

Case Study – Meaningful Involvement in Training

Tom and Dan deliver training to professionals. The training covers a timeline of learning disability policy since the 1800s. The aim of the session is to make professionals think about prejudice and stigma against people with learning disabilities.

Tom's strengths are engaging directly with trainees, sharing his experience and bringing humour to the session. Tom finds it difficult to remember the details from the timeline and to read from the slides.

Tom and Dan carved roles in the training, so Tom doesn't need to know the details of the history on the timeline. Dan introduces the different dates and events, and then Tom asks the group to think about how this would have made people think and feel at the time, then he puts questions to the trainees. After they have discussed in groups, Tom leads the feedback session. Tom decides who feeds back first, when to draw the discussion to an end and what Dan should write up on the board as the group feedback.

Question 15: What support or advice might be needed for people on how to best involve people with a learning disability or autistic people in developing training?

Involving people with learning disability and autism effectively will require guidance and clear standards.

- Those who work with people as facilitators will need to understand the co-trainers communication and style of presenting.
- Guidance should encourage facilitators to think creatively about how to meaningfully involve people, including the use of different media, opportunities to use technology, and role carving within a session.
- Guidance should set out standards for making all sessions accessible e.g. easy read agendas, traffic light cards, setting ground rules and no jargon. Implementing these rules in a room that does not have a majority of people with a learning disability sends a strong message about inclusion.
- Guidance should support the design of accessible train-the-trainer sessions. Having expertise through lived experience doesn't necessarily mean a person has the confidence to impart this to others. Whether a one-off session or part of a wider programme to facilitate people's development, it is important to design an open and engaging environment that makes it easy for people to get involved and is inclusive of all abilities. This will mean learning through fun exercises, the use of imagery and props and a safe space for people to communicate their own feelings and thoughts.

Question 16: What support might be needed for people with a learning disability or autistic people to ensure they have the right skills to participate in training?

Co trainers with a learning disability or autism will need:

- Specific training to help develop skills and confidence. The outcome of training should be the ability to lead a session and have authority over how training proceeds.
- Time to develop a relationship and rapport with a facilitator, so the facilitator can understand the co-trainers strengths and abilities.
- Support in their role to deal with any difficulties that might arise from training for example, being asked challenging or difficult questions; sharing a personal and upsetting experience; being exposed to difficult and upsetting stories and statistics about health inequality.
- People should be encouraged to find and tell their own story and to have pride in it. We have found that story-telling by people with lived experience is one of the most powerful and effective ways for others to learn. This is strengthened by highlighting the relevant lessons and learning-points as the story unfolds. It makes things both tangible and emotional which are ingredients that very much help behavioural change.
- Time to prepare with the right support and to reflect after each session on what worked for them. Trainer development should be treated as an ongoing learning process for the person with lived experience and the facilitator.

It should be noted that most trainers will benefit from:

- A clear format for training with defined responsibilities, tasks and actions within the training.
- Working with facilitators that they know and with whom they have a good relationship (particularly around different ways of communicating).
- Options for adapting training content to best suit their strengths and abilities – for example, playing a video that they have developed to share their story if they find it difficult presenting in person.

Organisations such as Change, Books Beyond Words and Certitude have been co-training healthcare professionals alongside trainers with learning disabilities for many years and could provide in depth advice and support in involving trainers with learning disabilities.

3. Supporting and employing people with learning disability and autism to deliver training

#MyGPandMe training sessions were co-delivered by someone with a learning disability and/or autism and a facilitator. Two of the #MyGPandMe trainers are employed by Dimensions at a strategic level to develop campaigns and policy. The other trainers were people supported by Dimensions who had an interest in health and put themselves forward to deliver sessions locally.

Feedback on the training was positive overall, but it is notable that the two trainers who are employed by Dimensions received more positive feedback and were singled out in evaluation forms as the 'best' part of the training. Having the authority of employment challenges attitudes (and runs counter to the norm for people with learning disability and autism), automatically shifting the power balance in sessions and making professionals think differently.

We believe people with learning disability and autism must be employed to deliver training. Employment recognises the level of skill and expertise an individual will bring to the role as well as formalising the professional support and development opportunities that trainers will need.

Health services should employ people with learning disability and autism to deliver face-to-face training to professionals. Trainers might be employed by hospital trusts and clinical commissioning groups to cover training engagements across a particular area.

Trainers will be supported to develop skills and design their input to a training framework, allowing for personalisation whilst also ensuring trainees receive the right information to develop relevant knowledge and awareness around learning disability and autism.

CCGs and Trusts may consider employing people in training roles to also provide quality reviewing services across a local area. This would create opportunities for trainers with learning disability and autism to identify gaps in services and keep training relevant and targeted.

This dual role of trainer and quality reviewer would also boost the amount of work available to an employee with a learning disability and/or autism and facilitate the creation of a viable role within the Trust or CCG. Dimensions works to this model to train our workforce and review the quality of service delivery, allowing the organisation to employ almost 50 people with lived experience in these roles.

We recognise that in some cases it may make sense for the Trust or CCG to outsource these services and work with local networks and organisations to find trainers. In these instances, the group should be commissioned to deliver these services, including hourly rates for trainers' involvement that acknowledge their skill and expertise, and sufficient funding to meet costs of supporting trainers in their role.

Question 14: What are the barriers to involving people with a learning disability or autistic people in delivering training as proposed?

Some people with a learning disability and/or autism may feel limited in how much they can work as they are in receipt of income related benefits. We are aware that some people limit the hours they work to avoid a decrease in their payments. This is particularly the case for people who might be able to work a bit over the work allowance before income support tapers

, but not much above, essentially meaning that they are left worse off as they move to a higher level of employment.

The Department of Health and Social Care should work with the Department of Work and Pensions to ensure that people with learning disability and autism are not prevented from taking on training roles, responding to the likelihood that people with a learning disability and/or autism might be unlikely to take on increasingly higher hours at work or to progress up a pay scale in the way that is envisaged by the current income support system.

Question 17: How should people with a learning disability or autistic people be remunerated for participation in training to health and social care staff?

It is important that people are properly remunerated for their time and their expenses when delivering training. This is not only essential to ensure that people with learning disability and autism are treated with fairness and valued for their contribution to improving health services, it also sends a clear message to those who are being trained by them that the person with a learning disability and/or autism is respected and valued.

As attitudinal change is an essential part of improving patient care and consequently health outcomes for people with a learning disability and/or autism, properly employing trainers and bestowing on them worth and authority in their role is a crucial element of delivering mandatory training.

We believe this is an opportunity to join up policy to close the disability employment gap and support more people with a learning disability and/or autism into work.

4. Issues relating to both health and social care

There are some issues that span health and social care, including the principle of meaningfully involving people with lived experience in training and ensuring that professionals' attitudes towards people with learning disabilities and autism are developed alongside skills and knowledge.

Question 4: Do you agree that the different levels of training should reflect the Learning Disability Core Skills Education and Training Framework (and in due course, the Autism Framework)?

The Learning Disability Core Skills Education and Training Framework and Autism Framework are comprehensive and we support the use of these frameworks to benchmark knowledge and skills for health care professionals and for social care professionals.

It remains that all people who might have contact with someone with a learning disability or impact on their experience in a health service should be trained to understand the barriers experienced by people and to reflect on how they might improve outcomes for people and respond to them with dignity and respect. This will require all members of the workforce to receive a basic level of training that focuses on challenging bias. Beyond this, different professionals should undertake training that enhances relevant skills and knowledge, in line with the tiered system.

Question 5: We propose that individual employers should assess which level of training staff need and ensure that they get it. Do you agree?

It is important that people with a learning disability and/or autism can expect certain standards in their health and social care services. Foundational training should be sufficient to ensure that people are treated with dignity and respect by professionals and that the whole service is attuned to their needs.

Individual employers should be able to exercise some discretion over the level of knowledge and skill needed by staff members, but this should be additional to a basic level of training that is designed to influence the workforce's attitude towards someone with a learning disability and/or autism.

Developing an understanding of what an individual learner actually needs seems to be a more person-centred and evidence-based approach.

Refresher training should be completed regularly, but this should acknowledge that such training can take different forms, and shouldn't necessarily just consist of making someone work through the same e-learning module multiple times. We would recommend the focus, if this was the case, was on learning outcomes and behavioural change.

Q6: What support might employers need in determining the appropriate level of training for a member of staff – e.g. a more detailed tool for assessment?

An assessment tool could be of some practical value, provided it was relatively simple and not cumbersome to use. In our organisation and probably many others, the people most likely to be conducting any assessments would be managers, and they are already incredibly busy. We recognise our own responsibility in also ensuring that those responsible for assessing are suitably trained with good assessment skills.

Question 7: We do not propose that all staff should have face to face training; just those with roles which mean they will be in regular contact with people with a learning disability or autistic people in Tiers 2 and 3. Do you agree?

We do not agree with this approach. We believe all health care and social care professionals will benefit from contact with someone with a learning disability and/or autism in face to face training. Whilst we recognise that this is a more resource intensive approach to training, it is also more likely to embed a whole service culture of meeting the needs of patients with a learning disability and/or autism. Hearing from lived experience is vital.

In many of the responses to our research, patients and their families underlined how problems and errors in one part of the service impacted on other parts of the service, leading overall to poor outcomes.

We recognise that prescribing a training method is quite a rigid approach, and our preference would be to be able to exercise some flexibility on how best to develop competence. The term ‘face to face training’ typically is used to mean training delivered in a classroom, but there are innovative alternatives to ensure people in all tiers have interacted with someone who has lived experience.

We believe that training is effectively delivered in a variety of face-to-face environments, including classrooms, but also in action learning groups, observation and feedback, through side-by-side coaching and as part of team meetings. We would support the use of Train the Trainer approaches.

5. What does good healthcare training look like?

Health inequality for people with learning disability and autism arises in part from attitudes, stereotypes and myths about people with these disabilities.

Changing cultures and challenging attitudes in health services is a crucial part of improving support for people with learning disability and autism so that they are not disadvantaged when accessing health care.

This is not to single out or criticise individual professionals, often the places that get it right do so because the practice will have embedded a culture that spans all staff so that meeting the needs of patients with learning disability and autism becomes a way of working (and will likely benefit other patients too).

At its heart, training for health care professionals must seek to change attitudes. Making adjustments must be seen as a fundamental element of patient care; the tools, resources and guidance that help to support people’s health must be observed and implemented; and the patients themselves and those who support them must be listened to, respected and included in decisions.

Dimensions has experience delivering training to GP surgeries. Our model for training has 3 central themes that not only improve the knowledge and awareness of professionals, but also challenge unconscious bias they might hold towards people with learning disability and autism.

#MyGPandMe training was developed in partnership with Beyond Words. Its key aspects are:

- Meaningfully involving people with learning disability and autism
- Training different staff roles in a service together
- Focussing on reasonable adjustments and person centred thinking

#MyGPandMe training sought to embed a different approach to meeting patient needs and encourage practices to be proactive in the way they identify patient support needs.

Training different staff roles in a service together

In Dimensions' #MyGPandMe training, all staff members at the practice were encouraged to take part in the training.

Our research found that a) people experienced barriers through-out their patient journey, meaning everyone has a role to play in improving patient care and b) good patient care often entails different members of the practice and supporters working together to make a visit to the doctor as effective as possible.

For example, many patients reported the difficulties they had with reception staff, presenting practical issues for booking appointments and also making patients feel like they had not been treated with care or respect when they had difficulty communicating. Many people's feelings of anxiety about going to the doctor were located in their experience at the reception desk. Nonetheless, once anxious about attending their appointment, patients were likely to have a more difficult experience with their GP as well.

As a result, #MyGPandMe training focussed on joining up the different elements of someone's trip to the doctor across staff roles, to make sure someone with a learning disability and/or autism received the best care throughout. This approach encouraged fruitful conversations and worked towards embedding a whole practice culture where the needs of people with learning disability and/or autism are identified from the moment they ring the practice or walk through the door.

Furthermore, many of the practical tools and resources that #MyGPandMe trainers shared with practices were relevant across practice staff, for example – a health passport has vital information for a GP, but also explains communication tips to reception staff; Summary Care Records can be used by practice nurses as well as to GPs to understand someone's need for reasonable adjustments.

"I normally arrive about 30 mins before my appointment. My surgery has issued me with a red wristband, like the kind you find at the swimming pool. They have not explained to me what is supposed to happen when I wear this wristband, but as someone with ASD I have been asked to wear it.

The waiting room is always busy with lots of noise and commotion, children running around, lots of smells and noise. The ding of the announcement board when a GP is ready to see the next patient, makes me jump and keeps me on edge. I am hypervigilant and am aware of all that is going on around me.

I would like to be able to go and sit outside my doctor's door until he is ready to see me, as it is quiet in the area where the GP offices are situated. However, I feel as if I need approval for this, so when I arrive I diligently show my red wristband at reception and politely ask if I can go and sit outside the door, one time I was told of course, other times I have been told no, you have to wait in reception until you are called. There is no consistency in what you can and can't do. There is no quiet area that people can wait in, which would be useful to me, alternatively a text when the GP is ready to see me, then I could leave my car and come into the building, anything to not have to wait in the busy reception area which is overwhelming."

- An autistic person

Focussing on reasonable adjustments and person centred thinking

Reasonable adjustments are a right not a privilege and can play a crucial part in improving outcomes for people with a learning disability and/or autism.

#MyGPandMe training focussed on making reasonable adjustments, as 60% of patients said they did not receive them at the GP and 74% of GPs told us that they wanted more training on how and when to make reasonable adjustments.

There are some generic adjustments that will often benefit most patients with a learning disability, e.g. longer appointment times, a quiet waiting area, and booking appointments at the beginning or end of the day. As all people are individuals, everyone will also benefit from specific and tailored adjustments that help them to access health services. For example, where someone has a fear of getting up on a hospital bed, implementing a plan to make them comfortable and be able to examine them lying on the floor.

"The dentist took the time in finding out what he needed, how best to communicate and slowly gained trust before the treatment. This was through a series of 4 short visits to the dental surgery.

He was accompanied by a support worker who he has a great relationship with and this was a big part of how he could also trust the dentist.

There has been concern for some time about brain damage because of self-harm. The dentist went out of her way to organise that he have an MRI at the same time as having dental treatment so that he only had to go under a general anaesthetic once."

- A parent of a person Dimensions supports

Training cannot let health professionals know exactly what adjustments each patient they meet will need, but it can foster a proactive approach to identifying helpful adjustments and ensuring that all members of staff are aware of them. Often, this will involve ongoing dialogue with the patient and those that support them to think creatively about how barriers can be overcome, particularly around invasive tests and supporting someone to communicate about and understand their own health.

Question 1: We have envisaged three main elements to learning disability and autism training: understanding learning disability and autism, legislation and rights, and making reasonable adjustments: do you agree? Should other elements be included?

We agree with the focus of this training and believe it will support the workforce to identify and respond to the needs of people with a learning disability and/or autism.

It should be noted that alongside these areas, best practice training that is co-led will also implicitly focus on changing attitudes and challenging stereotypes. This is an essential part of training health professionals which should not be overlooked. E-learning, which does not meaningfully involve a person with lived experience or challenge bias would be less effective, even if it did focus on the important elements proposed as the basis of training.

“My GP checks on my mental health, how my medications are going, if I need any more meds and if anything is worrying me. I feel I can talk to my doctor. I may take a list of symptoms with me, if my GP spots my list he will take it from me, reading it to make sure we have covered everything that I went in wanted to tell him about.

If he hasn't had all of his appointments filled for the afternoon session he will happily keep talking to me, I was in there for an hour one time! I have said to him in the past, 'are you sure you are ok for me to come and see you, I can see another GP if you have had enough of me', he is always very positive and genuinely comes across like he wants to help and has a real interest in me!

This is rare in primary health and even rarer in secondary health care, in my experience. I have in the past made a verbal contract with my GP, that I won't do something without talking to him first, this works for me, because I've made a deal with him and I need to honour it.”

- An autistic patient

Question 2: Do you agree that awareness of how the Mental Capacity Act impacts on the way in which support is provided needs to be a significant part of training for all staff?

We agree that the Mental Capacity Act is an important part of training to improve health outcomes and will support professionals to uphold the rights of patients whilst also carrying out care in their best interests.

We emphasise that training designed to inform and influence attitudes towards people with a learning disability and/or autism should underpin this training and that assumptions in medical practice can impact on how the Mental Capacity Act is interpreted and implemented. For example, assumptions about a person's quality of life as someone with a learning disability leading to a DNAR being placed on them, sometimes without consultation or informing the family and supporters of the person.

Training on the Mental Capacity Act should be embedded in training that encourages health care professionals to challenge the bias they might hold towards someone with a learning disability and/or autism and how that might impact on the service and care they provide.

Question 3: Are there additional elements which need to be covered by training on awareness of autism and the needs of autistic people?

The mortality gap for people with profound and multiple learning disability is even starker than that for the whole population of people with a learning disability. Joining up care, working with people who know the person best, thinking creatively about adjustments and adhering to best practice guidance will benefit all patients, but it is particularly important to improving outcomes for people with profound and multiple learning disability.

The voice of these individuals is often overlooked and truly involving them in service design and delivery remains a challenge for many services.

We believe that if you can get an approach and a service right for someone with profound and multiple learning disability, you will be getting it right for everyone. Success demands person centred thinking, proactiveness and continual attention to detail.

We recommend that the health of people with profound and multiple learning disability is also included specifically in training, to highlight the significant barriers this group of people face and to raise awareness of the poor health outcomes that need to be improved. The PMLD Core Service Standards³ should be taken in to consideration when developing learning disability training. For people with profound and multiple learning disability, it is important that the people who know these individuals really well (families or familiar support staff) are directly consulted and involved in all aspects of their care and treatment. These people can interpret their communication or symptoms. Working in partnership with families and support staff, as advocates, will promote better outcomes for this population.

“My brother got a fabulous GP who had never met him, but was on the ball and also really listened to the support worker who was interpreting his behaviours and responses. It was also a privilege to see two very different new staff step up to such daunting emergencies. These two young women were acutely aware they barely knew my brother (and it was impossible to read his 56 year medical history!) but were courageous in asserting his needs. Such a tough thing to do.”

- A sister of a man with profound and multiple learning disabilities who is supported by Dimensions talks about her brothers recent health emergency.

Additionally, we recommend a focus on autistic people who do not have a learning disability. Most autistic people that don't have a learning disability will not have support to access primary care. They face the same issues that autistic people with learning disabilities face but often do not have someone to help or speak up for them. The training should reflect the needs and experiences of this group.

³ <http://www.pmlmlink.org.uk/resources/#pml-d-standards>

“After much searching, I have found a doctor that I like, who listens to me, has shown that he cares and is interested in what he can do to help me. He called unexpectedly once because he hadn’t heard from me and he wanted to check in. That was an example of him going over and above. He has three adult patients with ASD. He took the time to go and see the consultant psychiatrist to ask what he could do to help, how he should communicate with me.”

- An autistic patient

5. What does good social care training look like?

We need to educate social care staff on rights and how to influence. Relationships care staff have with primary care clinicians and staff is key and makes all the difference. A person we support had bladder cancer, the locality manager worked with the urologist and agreed a pathway for treatment, the cancer was caught earlier and the person recovered.

- Dimensions manager

Colleagues working in social care are drawn from a wide variety of backgrounds, and so the training we provide them with needs to recognise the diverse range of people and roles within the sector. Supporting and working with people with a learning disability or autism can be highly skilled work and, in some cases, there can be significant risks if we don’t get the training right. We therefore welcome the aims of this consultation.

From the start of someone’s employment in social care, we train them to understand social care within a broader context – that often starts by covering the history of how people with learning disabilities and autism have been treated and how we have arrived at where we are now. This focusses on notable cases of when things have gone wrong and recognising what has been learned from these failures.

We also find it important to give people we support – people who have a learning disability or autism – a clear voice within this. For many incoming staff, it might be the first time they have worked with people with a learning disability or autism. Even if not, hearing about what is important to them is an essential part of a new starter’s training.

We also focus on providing training on how to interact with families, developing the skills and confidence to engage with family members and others who are a part of the lives of the people we support.

Other training we deem essential includes key areas around safeguarding, MCA and DoLS, administration of medication and the health and well-being of the people we support. It is our view that effective training takes several forms – we use online learning to provide foundational, underpinning knowledge and information. Where confidence, behaviour and skills are required, this training is often best supported by coaching and observation of practice.

Colleagues working in our services complete the Care Certificate, which supports with that. This helps us to identify particular individual gaps and areas of need, and actively involves both the

colleague and manager in that dialogue. Once a colleague has completed the Care Certificate, they work on the relevant Apprenticeship Standard for their role.

Throughout, the training we provide to our colleagues in social care is usually determined by individual or team needs, and supported by effective practice leadership.

We are also closely involved in the work to develop specialist learning disability and autism options for health and social care Apprenticeships – a member of our team is part of the national working group on this – we strongly support and welcome this initiative.

The GP was reluctant to review the medication despite his family and support team feeling that he may be over medicated. The support worker persisted with the GP and told them about how much weight gain related to the anti-psychotic medication was affecting the person. The result was that over a period of several months he was weaned off anti-psychotics and is losing weight and has more energy.

“The dedication of his support worker was so important- he has a bond with my son, is dedicated to improving his life and it is not just a job for him. He is also calm and understands my son’s behaviour.

- A mother of a person Dimensions’ supports talks about her son’s treatment for epilepsy and anxiety.

Question 1: We have envisaged three main elements to learning disability and autism training: do you agree?

These elements seem to cover the key elements we would expect to see. Below we set out how we might expect to see training on each element provided for our workforce:

Understanding learning disability and autism

Looking at the need for this training to ‘challenge implicit or unconscious attitudes, which might have led staff to fail to spot key symptoms, or to ignore key information given to the individual or their family or carer’ the focus here seems to be on learners developing their understanding (i.e. being able to explain what these principles mean); evaluating (i.e. thinking critically about different situations); and applying (i.e. actually putting this understanding into practice).

Digital learning, supported by follow-up side-by-side coaching from a line manager and interaction with people with lived experience could be a suitable approach to providing this training.

Legislation and rights

It is necessary to ensure that learners can both develop understanding and also apply their learning to real situations.

In 2016, Dimensions ran a series of webinars led by a subject matter expert about the Mental Capacity Act and Deprivation of Liberty Safeguards. We measured the impact using pre- and post-confidence evaluation surveys. This showed a marked increase in confidence. As a result, issues with knowledge of MCA/DoLS, which had featured in several CQC inspection reports, greatly reduced following the webinars.

This would suggest that providing forums such as this for colleagues to explore issues relating to legislation, and ask questions to develop their understanding, can be effective.

Q8: Should there be a standard form of documentation, to act as a training passport, portable between employers, indicating when and where training was undertaken, and documenting the specific skills developed?

This is a commendable aim and one that informed the development of the Care Certificate, but it is problematic in practice, particularly in autonomous organisations (as opposed to the NHS, where training is often commissioned off a single framework).

The principle could certainly be applied – at Dimensions, we ask for evidence that certain essential training has been completed by a new starter, within the last six months. If we are satisfied that it has (the new starter is able to produce a certificate or other such evidence), we tend to accept it and deem them ‘compliant’, but this does depend on whether we are satisfied that the training will have covered the objectives we would expect.

In this sense, the idea of a portable training passport is an appealing one. But even with the Care Certificate, there are some organisations in our sector who are willing to accept evidence that someone has completed the Care Certificate, and others who are not.

The more important consideration here is that whether through the Care Certificate or other means, a manager of a new colleague will want to satisfy themselves, often through observed practice, that the individual is able to apply their learning and skills in the best, most contextually appropriate way - even if they had arrived with a training passport.

We would be keen to work with other providers to understand the potential for us to work together on an approach to pass-porting, in a way that met the needs that our various organisations would have.

Q21: We envisage that CQC and Ofsted inspections can provide a robust means of ensuring mandatory learning disability and autism training is happening. Do you agree?

Whilst understanding the need to monitor impact, and the role that quantifying completion of essential training plays in that, we would not want this to focus unduly on counting compliance levels over and above evaluating impact more holistically.

Evidencing that training is happening should be rounded in its approach – counting how many people have completed it is arguably measuring something a little different.

We note that greater attention should be given to ensuring that health services, which may not have a particular or regular focus on the needs of people with learning disability and autism, implement training. Particularly because social care providers working with people with learning disability and autism are likely to be further ahead given their focus.

Our view is that evaluating the learning impact needs to be balanced between quantitative and qualitative measures.

“At the end of the day, it is my son’s support workers who need to speak for him at the doctors. He can’t speak for himself and the doctor can’t guess what he needs. I want his support workers to care as much as I do and ask the right questions and I want the doctor to take what my son needs seriously.”

- A parent of a person Dimensions supports