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Raising awareness of the issues affecting those with learning disabilities and/or autism doesn’t just affect those receiving the training – it also empowers those delivering the training.

Israel, the lead trainer for the project, said the following about his experience:

“It all started when I decided to openly share my diagnosis of Autism during the job interview. I felt that the Treat Me Right! Project was a perfect fit because the main purpose was to tackle inequality for people with Learning Disabilities and/or Autism. Being accepted as openly autistic and having the chance to talk to people directly about my life experiences has not only provided me with means for personal development but has also allowed me to empower other people as well. Being accepted and listened to then, was the best way to support me to become my best possible self.

Becoming a disability and Autism advocate has meant a massive breakthrough for my personal development. I’ve not only managed to demonstrate to people that they were wrong in assuming I could not become a professional public speaker, but I have also found out that I can inspire other people in the Spectrum and empower them too. My favourite bit of the experience comes in form of changing peoples’ beliefs around Autism. Autism is not something anyone should be ashamed off. It is rather evidence of the huge diversity of human existence. Learning that I can contribute to society and shift people’s perceptions on Autism was my biggest personal achievement.”

Israel has had to leave Certitude to return to Spain for personal reasons but hopes to return to the Treat Me Right! project.
Kiether, a new trainer, said the following:

“\textit{I felt that Treat Me Right! provided me with a friendly human environment where people with different conditions could work together towards a better future. Being reassured about potential difficulties was key for me to feel like I wanted to be part of the project. For instance, it was really important to be given as much information available with plenty of time in advance to organise my journeys to deliver training. As result of the above, I felt empowered and full of motivation to go out and speak to people about Autism and Learning Disabilities in a positive way.}

Providing training to organisations like Mind or the NHS means a real boost to my self-esteem. I feel now that what I do matters to society. Working as trainer has not only provided me with opportunities to get paid employment for the first time in my life but has also allowed me to share some of my passions with other people. In doing so, I realised that now I’ve got stronger arguments to pursue a future career, whilst also got plenty of new interesting stories to share with family and friends”

Kiether is still working for the Treat Me Right! Project as a trainer.
It can also be a rewarding experience for managers...

Helen, who managed the project, said the following:

"Managing the project and managing an autistic project lead was a rewarding professional experience for me. As a manager, it’s my job to help staff have faith in their own abilities and convince them that they can do the job. With Israel, I had to demonstrate his ability to him. We worked together to find a structure that we were both comfortable with that would mean that he went from never having delivered training before, to being a confident, knowledgeable and talented trainer.

First, we created the resources together. This meant that Israel had ownership of the material and was comfortable with the message he was delivering. He then observed me co-deliver for one week. After that, he was my co-trainer for a week, then I was his co-trainer for a week. We then added in a co-trainer for a week whilst I observed, then he felt confident to deliver by himself. The structure really helped both of us to know where we were – it also helped me let go when the time came!

There were several little things that helped us to develop. Regular meetings were important. We met once a week for reflection and to look at feedback. It gave us both a chance to discuss issues before they became worries. Looking at feedback also gave us something concrete to base performance analysis on, rather than personal feeling or experience which can be difficult for some autistic people to articulate. I soon learned the best way to set up the room so we could both be comfortable, and it
helped both of us that sensory input was minimised as much as possible.

Managing Israel and this project has been one of the most rewarding experiences of my professional career. I can’t wait to use what I’ve learned to encourage more neurodivergent staff to push their boundaries.”

Helen continues to manage the Treat Me Right! Project.
1. Introduction

Certitude’s Treat Me Right! Team are based in West London. Treat Me Right! was formed in 2008 by individuals with a learning disability, carers, commissioners and Certitude in response to the treatment people with learning disabilities (LD) received in hospital highlighted in Mencap’s Death by Indifference report (2007). The project started by working both with individuals to ensure they knew their rights, but soon carved out a niche in delivering high quality learning disability and autism training, all of which is co-designed and co-delivered with people with lived experience of learning disabilities, autism or both. This gives those with lived experience a paid job with Certitude and a chance to get their voice, and that of their peers, heard.

This project was commissioned by Health Education England as part of the establishment of the London Learning Disability and Autism Community of Practice, set up to replicate the successes of the Kent, Surrey and Sussex Community of Practice. This community aims to eradicate health and social inequalities faced by those with learning disabilities and/or autism by working together, sharing good practice and raising awareness.

1.1 Rationale

Having worked extensively in medical establishments, in both primary and secondary healthcare and with several social care organisations, it became clear to us that by the time people reached these services, they were often there as a last resort. There had likely been several chances for intervention from community and advice services who were possibly unaware of people’s rights and best practice with regards medical treatment, capacity and reasonable adjustments.

The project aimed to give those organisations and families the tools to correctly signpost to the right services. Also, with the change of eligibility criteria for support and the restrictions in funding for some specialist organisations, we saw evidence that community, carers and advice organisations had more enquiries from those with mild to moderate learning disabilities or autism without a learning disability and didn’t always feel equipped to deal with them. There was an opportunity to train these community organisations to improve the health and wellbeing of those with learning disabilities and/or autism more broadly than we had been able to in the past.
1.2 Project Aims

The aim of the project was to provide training to the staff and volunteers of Citizen’s Advice Bureaux (CAB), Carers Centres, Patient Advice and Liaison Services (PALS) and BAME Information & Advice services to improve knowledge supporting the health needs of people with learning disabilities and/or autism. We also offered training to families of people with learning disabilities and/or autism who receive support, advice and information from these services. The training aimed to enable staff, volunteers and family members to become LD Health Champions and better understand and advocate for the rights of people with learning disabilities and/or autism.

Project Outputs

The programme took place across London from August 2018 to July 2019 with the target of offering training to:

- 150 staff and volunteers in CABs across 32 London Boroughs.
- 100 staff and volunteers across London’s 17 Carers Centres.
- 100 staff across 15 PALS teams across London.
- 100 staff and volunteers across 15 London BAME Information & Advice services.
- 60 family members across London.
- Delivering 2 Practice Development Network Events.

The practice development events would be used as an opportunity for those trained to share good practice, discuss challenges that they’d had implementing the training and share experiences with other professionals.

| Health inequalities and the Confidential Enquiry | • Become aware of learning disability health inequalities and what these are  
| Reasonable Adjustments legislation and case studies | • How they are preventable  
| DoLS, the MCA and how these relate to healthcare | • How to recognise early signs  
| | • How to support people to access appropriate health services to receive timely and effective treatment  
| | • Understand health services’ responsibilities under the Equality Act 2010  
| | • What reasonable adjustments are  
| | • How to implement them within their own services  
| | • How to encourage health service providers they interact with to implement reasonable adjustments  
| | • What DoLS are and their relation to the MCA  
| | • How to recognise when these are being used in health service  
| | • The legal process for obtaining them is  
| | • How to challenge the use of DoLS when needed |
| Health Action Plans and passports (HAPs) | - What HAPs are  
- How to ensure people receive high-quality HAPs  
- How to challenge the use of HAPs or poor delivery |
<table>
<thead>
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<tbody>
<tr>
<td>Our Health Trainers’ experience of receiving hospital care</td>
<td>- Staff and volunteers gain insight into people with LD and autism’s experiences in hospital and the impact reasonable adjustments can have on individual experiences</td>
</tr>
</tbody>
</table>
| Learning disability and autism awareness (basic and in-depth) | - How to recognise ASD symptoms  
- How autism can affect people and their communication and sensory needs  
- What adjustments can be made to better support people with LD and/or autism  
- How autism overlaps with and differs from LDs |
| Becoming effective advocates | - Importance of sharing learning with colleagues, wider organisation and external partners  
- How to ensure everyday practice is embedded across the organisation |

Anne C., TMR! trainer.
2. Project Approach

All training sessions were co-delivered by Treat Me Right! trainers, at least one of which has lived experience of autism and/or learning disabilities. Treat Me Right! believes that co-delivery and co-production are fundamental to the success of our training and those working with us should be paid a proper wage for their time and insight as experts. The real-life stories of those with lived experience offer insights that simple information sharing could not; a unique knowledge and insight into the healthcare system. The trainers received training and support around their presentation skills. This project provided paid employment with and development opportunities for them, as an organisation Certitude is committed to creating opportunities for education, training and employment for all, and this is one example of how we do it. Also, where possible, we recruited trainers with lived experience who had a personal experience of each area’s services, which extended the reach of our recruitment beyond those supported by Certitude.

To reach as many PALS teams as possible, we contacted Learning Disability Liaison Nurses we had worked with previously, and asked them to promote the training at their pan-London meeting. This enabled us to establish key contacts who understood the value of our training in every NHS Trust.

During the initial stages of the project we encountered difficulties in making contacts at Citizens Advice. It was difficult to speak to the correct person because we had no way of contacting them beyond what was open to any member of the public and the services were very busy. Those we were able to reach often had difficulties releasing staff from services for training. We decided to use a different approach and called, emailed and wrote to them to try to reach them, but despite our perseverance it still proved to be a difficult task. It was at this point that we approached Health Education England to request broadening the scope of the project to general advice services, which proved successful.

To map as many community and carers organisations as possible, we looked at each London borough individually and listed all the community organisations that operated in them. We did this by using the community mapping resources that already existed – either through councils, Healthwatch or volunteer centres – where guides to local resources are published and contacted them. We have maintained this mapping tool as a resource and have shared it both within and outside our organisation.
We approached over 1000 organisations by email and telephone and once the message had got out we very quickly started taking bookings for sessions.

The “word of mouth” element to the training was powerful, resulting in the number of sessions picking up significantly in the final months of the project. For example, one session was arranged in a community centre for people from several organisations, who then booked sessions for their teams.

We also used Twitter to get in contact with organisations. We followed the types of groups that we wanted to engage with, then tweeted them asking who the best person in the organisation to talk to about training was. This approach often got us a name of someone to contact which, in many cases, led to training being booked.

Due to the nature of the organisations we were approaching, and their varying needs we offered a modular training approach, where they could select the modules that were relevant to them and design their bespoke session.
3. Project Delivery

Between August 2018 and July 2019, we delivered:

95 training sessions to 60 organisations and teams and to 802 people

Of the 802 people, 36 were from voluntary action groups, 15 were from Healthwatch, 72 were from BAME community groups, 27 were from Citizens Advice, 153 were from carer’s centres and groups, 178 were from PALS teams and 321 were for general community advice.

Having expanded our delivery from BAME community groups to generalised community advice, we delivered to the following groups as well as Citizens Advice, PALS teams, Carers and Carers centre staff:

- The Equality and Human Rights Commission
- The Samaritans
- Mind City, Hackney and Waltham Forest
- Staywell Home Enablement service
- Jobcentre Plus job coaches
- Hyde Housing tenancy support team
- Blackfen Community Library
- Solace Women’s Aid
- Hackney Community Choir
- Family Court Support Team
- Healthwatch
- OneYou
- Community Police
- Spectra Sexual Health charity

“[I have learned] that people with autism do not look different but they may feel different. I will use [this] skill and knowledge to approach clients with Autism so I can fully understand them. Not to expect them to fit any pre-conceived notions of being autistic”

Attendee, East End CAB
We delivered in 27 London boroughs. The areas in which we delivered in are highlighted below:
4. Impact and Achievements

The training was very well received by all organisations that undertook it. Community organisations recognised a need to improve their knowledge and understanding of the needs of people with learning disabilities and/or autism so they would be able to fully access their service. They welcomed the chance to talk about their own experience, either from their family, personal lives or work related, as they had not had a space to do so previously. Families and carers that were trained told us that they valued the chance to talk to an autistic adult, something that didn’t happen often within their networks. Families also said that they weren’t told about the Mental Capacity Act until their children were older and didn’t understand their role in it. They often felt that this left them unprepared and feeling shut out during medical decisions. We also found that often, where English wasn’t the first language of the family, they didn’t understand the diagnosis, so it was important for them to discuss the meanings of different conditions.

Several said they would like to introduce our trainers to their children.

“I wanted to say a massive thank you again for your talk last night. We all found it fascinating and insightful and your knowledge and passion for the subject really came through. We’ll be able to use what we learned not just in supporting callers but in everyday life.”

- The Sutton and Croydon branch of Samaritans

The lead trainer has lived experience of autism and the co-trainers have a mixture of lived experience with autism spectrum conditions, learning disabilities and difficulties and sensory impairments. The sharing of this experience was key to the success of the training. People were able to see examples of what was being talked about which reinforced the lessons, and were able to hear real life stories about what had worked and what had presented challenges.

By far the most common feedback was that participants better understood terminology, especially highlighting the difference between a learning disability and a learning difficulty. The people we trained often felt nervous about using the wrong terminology in an ever-changing world. There was also significantly raised awareness of the sensory issues autistic people may face when accessing advice and information services. There was a general awareness with most groups that communication, social functioning and changes to routine would present difficulties for autistic people, however most were unaware of the impact of sensory issues and how these may be a barrier to a person receiving good advice and support. The training encouraged participants to develop actions which they could implement straight away. For example, after delivering training to two different parts of the same Trust, the PALS teams in both the Princess Royal Hospital in Orpington and Kings College Hospital, we were pleased to discover that after training the managers of these teams were able to implement what they had learned and were giving autistic people more time to process information. They also felt able to have a conversation about reasonable adjustments with that person and then implement the adjustments.

Participants took the opportunity to ask questions, some about service delivery, and others about life experience. This facilitated discussions about how to improve the experience of people with learning disabilities and ensure equal access to their service for all who wish to use it. Family members trained found it useful to talk to disabled adults, as their experience often centred around children and they didn’t have a lot of information about adults.
Horn of Africa Youth Association

We were introduced to this organisation when a contact asked me if we could go and speak at their disability support day. We were still scoping organisations at this point so we jumped at the chance! Their open day was a lovely experience and they asked for three sessions in consecutive weeks. We had to be flexible because it became clear that they needed much more basic information than we thought. It turned out that they were confused, and this was for several reasons. Firstly, their language didn’t differentiate between autism, learning disability, physical disability, mental ill health and dementia, so they were unclear as to what their children’s diagnosis meant. The local Autism support organisation didn’t offer any translation service so many had paid for information that they couldn’t access, leaving them hesitant about approaching others. We also didn’t have translators but we asked the centre if anyone could volunteer and they were pleased to offer that to us, saying that they would have offered it to the local service if they had asked, but didn’t feel that they could offer it first.

Our three sessions with them consisted firstly of questions and answers about the differences between different disabilities. For the following sessions, they asked if they could meet someone with autism and someone with Down’s Syndrome. They told us that they really valued the opportunity to hear about their experiences. Our first two sessions had been during Ramadan, so we really enjoyed sharing food with them at our last session.

Equality and Human Rights Commission

We were approached by the commission about the training. They had heard about us through one of our mailouts and wanted to know more. We very quickly agreed to it even though it was technically out of scope at the time. We all felt very nervous about it as we saw it as our chance to really make a difference. When we got there, the staff were interested and engaged and we left feeling like we may have put an idea into the head of the people who can make real change at a national level.

"I have been paid to attend many courses and awareness sessions through work as a DEA and this is hands down the best course I have been on. This is huge within my field because most of the training is by professionals that don’t have these conditions. I have learned so much."
- Employment adviser, via Blacken Community Library

Jobcentre Plus

We were approached by the job centre after a contact from a working group asked for disability training for her branch. She was a disability advisor and found that although there was lots of general understanding about reasonable adjustments for people with physical disabilities, the other job coaches she worked with tended not to have as much understanding around learning disabilities and/or autism.

We delivered an initial session at Acton Jobcentre plus, then further sessions at Shepherds Bush, Stockwell and two sessions in Fulham.
At the sessions we found out that lots more people with learning disabilities and/or autism were being found “fit for work” by assessors under new benefit rules so there were more individuals being referred to them for job coaching and extra support to get into work, but they had received no training on how to do this. They found it particularly useful to learn how people with autism may find job interviews difficult, as these aren’t always representative of the role. For example, people may be asked why they want the job, and have to be more imaginative than talking about the functions of work.

**Hackney Community Choir**

We were approached by this group when someone we trained at another organisation spoke to a friend about the training.

The community choir were increasingly becoming an organisation that were socially prescribed to, and they wanted to make sure that they were doing as much as they could to be inclusive to any neurodivergent individuals that were coming to them. Some members of the choir also told us that they had family members who had autism or learning disabilities that they wanted to understand better.

The session was really well received and positive.

**“I really wish you could meet my child”**

This was something our trainers with lived experience heard often. It was clear through delivering the training that people who had children with disabilities often found it difficult to imagine their children as adults. Others were surprised to learn that learning disabilities and autism carried on into adulthood, or that it wasn’t something that only affected young boys. This made us realise how important it is for people with learning disabilities and autism to be visible!

**“We don’t have disabled people here”**

Some organisations said that disabled people didn’t use their service, or it wasn’t for people with disabilities. We spent time explaining to those places that people did use their services, they just weren’t aware. Not everyone is comfortable sharing their neurodiversity and we hope our training went some way to changing that, by providing role models and a vision of how diversity can be a gift for raising awareness.

“I wanted to get in touch just to reiterate our thanks for having you attend our office on Tuesday as a means of providing us training, your approach was absolutely spot on, standalone and has really got people talking at Hyde and sharing stories as to where Hyde’s response particularly with regard to reasonable adjustments can be improved.

Take some time have a read through some of the comments outlined on our intranet yesterday which is accessed by over 1300 members of staff. We would absolutely love to consider further opportunities to work with you and would happily take suggestions as to how we can keep up the momentum and awareness.”

- Hyde Housing
Lessons from co-delivery

The Treat Me Right! project believes wholeheartedly in co-delivery and it is fundamental to everything that we do. We made this clear in all of our materials and when we approached organisations. We have found the following is very important when co-delivering:

- Everyone is different – what makes a session work for one expert by experience will make it difficult for another. What is important is having a relationship of trust and mutual respect.
- Training isn’t necessarily about speaking. Some people may choose to make their contribution by being present, being in a video or showing slides.
- Even the best trainer will find it difficult to make reading from slides interesting! What trainees value more is dialogue, it is much easier for people to engage in. We find that having a conversation gets better results.
- People get really nervous when you use the word “Role play” so don’t use it! Conversations, questions and scenarios work much better.
- Debriefing is so important. People are often sharing information and experiences that may be uncomfortable or upsetting. Make sure you both know that you don’t have to share anything you don’t want to, and spend some time afterwards talking about how sharing made you feel and decide if that’s something you would like to share again.
- Expect the unexpected! The best learning always comes from unexpected places. Your lesson plan may rely on you giving over specific information, but you can make sure most of that is on the handouts. Questions, interruptions and unexpected moments make the session much more memorable!

"Can I feedback to you and the project that it was the best Autism and learning disability awareness training I have done. I have worked with people on the Autistic spectrum for about 15 years and taken part in a lot of training over the years, the content and yours and Kiether presenting style was really interactive and benefited my own learning style, so thank you I learnt a lot in your training."

- Wandsworth Carer Centre

Practice development day

We set up two practice development days towards the end of the project. We delivered these sessions at the Calthorpe community centre in Central London. This social enterprise was discovered by two of our trainers after they delivered a session at Guys dental hospital. We offered one session as an open session to those who were not part of teams and were interested as individuals, or those who could not make it to their team session. We delivered our in depth learning disability and autism awareness session.

This was followed by a celebration lunch with several of our trainers and those attending the morning and afternoon sessions who could make it. We shared a lovely lunch together and reflected on the project and what we had achieved. We also had a chance to discuss any issues

[I have learned] how societal views/comments negatively impact disabled people; how to help autistic people manage their sensory needs and other tips on being disability ally!

- Attendee, Ending Harmful Practice Women’s Service
the attendees were having around provision for people with learning disabilities and/or autism.

Later in the afternoon, we had a session with speakers. We were joined by Leo Anderade who told us the story of her son who spent several years in Assessment and Treatment Units following a breakdown in his education placement. Feedback showed that her powerful story, and her work with the Seven Days of Action programme had a huge impact on the people attending, and it was useful for them to hear what life could be like for those for whom autism has an impact on their behaviour and their ability to live safely in the community.

“Thank you for delivering the LD Awareness session today in Park Royal Centre for Mental Health. The staff and students gained so much out of your session. It was certainly an eye opener for me, and I wish I have this knowledge years ago enabling me to provide better service to patients with learning disability/difficulty.”

- Ward Manager at the West London Mental Health trust
5. Challenges

The first challenge we came across was contacting Citizens Advice as outlined. We had limited success and although were able to deliver to some offices it was not enough to meet the target. But we had discovered a significant interest from general advice organisations and following discussions with funders we gained agreement to extend the scope of project to them.

It was also difficult to contact PALS teams, as their lines were often used busy or only answered at certain times. We managed to spread the word by contacting hospital learning disability liaison staff and asking them to impress the importance of the training. Teams then had some accountability and someone within the trust ensuring that they undertook the sessions. This was very successful, and we have delivered to trusts such as Bart’s Healthcare and the Royal Free.

In order to target as many BAME and community advice organisations as possible, we attended networking events and scoped out organisation’s borough by borough, as well as contacting London-wide organisations. By far the biggest challenge with these organisations was speaking to the correct person who had authority to book training with us. We were often faced with reception staff who felt that the training was inappropriate or that their organisation wasn’t for disabled people, so they didn’t need the training. We frequently needed to explain that learning disabilities and autism were often invisible disabilities.

The organisations we approached were largely staffed by volunteers and we recognised that we needed a flexible approach to project delivery, often delivering at evenings and weekends. In order to meet the learning needs of each organisation, we delivered a modular approach to training, breaking the subjects down into short, 30-minute sessions so each provider could pick sessions to meet their needs. A copy of our training menu is at Appendix 1.

The change in criteria for statutory learning disability services to only include those with a severe or profound need resulted in a significant number of individuals with mild or moderate learning disabilities and/or autism without a learning disability or enduring mental health issue, relying on community services and groups for ad-hoc support. These organisations were doing their best and relying on their own experiences and instincts to provide services which showed the need for training. Family and carer groups were generally more informed, but those who didn’t have English as a first language were often left unsure of what their child’s diagnosis meant, as the equivalent didn’t exist in their language. Some believed that the conditions only affected children so valued the chance to meet an adult with the same condition.
6. Post training feedback

We sent out a questionnaire post training to ask attendees how much more confident they felt and how confident they were that their organisation supported those with learning disabilities and/or autism well. We also asked for specific examples of how the training impacted the service they had given. The data is below.

- **Do you feel more confident supporting those with learning disabilities and/or autism in your role?**
  - I feel much more confident: 33
  - I feel somewhat more confident: 13
  - I feel a bit more confident: 12
  - I feel the same: 0
  - Less confident: 0

- **Do you feel more confident that your organisation provides a good service for those with learning disabilities and/or autism?**
  - Much more confident: 21
  - I feel somewhat more confident: 26
  - I feel a bit more confident: 10
  - I feel the same: 0
  - Less confident: 0
Can you give some examples of how the training has impacted the service you have given?

Having training delivered from lived-experience perspective is without a doubt, the most impactful method of delivering training. The sometimes very personal but also comprehensive style of delivering training was very much appreciated."

“For example, I would be more mindful of the verbal expressions I use, as I understand that some of them could be taken literally, when that was not the intent. In addition, I now realise that some of the physical changes may be because of the feeling of being overwhelmed/over-excited”

“Having a better understanding of the challenges a person with Autism faces. Not being afraid to ask suitable/ appropriate questions to gain a better understanding of their condition in order to see if we can make the environment more suitable.”

“I am more aware of the very individual needs that someone with autism may have and would be more sensitive to these needs and therefore helping me understand my client and deliver a better service.”

“I understand a little more about being over stimulated and how this is expressed by someone with autism”

“give people time to say what they need to”

“The training has allowed me to be more cognisant of people’s disabilities that may not be apparent at first sight. Therefore, I have been more observant of our service users and look out for any signs of their disabilities and be more of a good listener. In supporting Clients, I feel I am now better able to support persons with disabilities using our service”

“I would consider learning impairment as one of aspect which I would provide more resources to accommodate the needs for communication.”

“Confidence booster to client who seems to be on autistic spectrum but never got diagnosed. He is now more confident to speak to potential employers more openly about what he can do.”

“I have noticed several times when people with autism have been distressed, I have changed how I assess the areas around for potential triggers such as noise or bright lights. This has made me more intelligent in how I deal with our young people and I have avoided situations that could have escalated quickly.”
**Anything else?**

“Great positive attitude of the trainers and relaxed way of answering questions allowed for a more relaxed atmosphere so that clinicians feel comfortable opening up about their own experiences. Highly effective”

“The personal experiences of our trainer were an excellent frame of reference, his anecdotes really helped us to lodge our new knowledge of how autism works and affects family life.”

“The training session was very informative, and it was good to hear the real-life experiences of the Trainers.”

“valued this informative training and led by trainers with a lived experience, this is so essential. I have shared and recommended this training with others within my organisation”

“I would be also be more confident in knowing that I have tried to communicate better with someone who is using my service, to ensure equalities in its delivery”.

“More training is needed to bring the perspectives and stories of people with learning disabilities and living with Autism. How best to interact, what would be appropriate and useful.”

“I like what you do, I think it’s very important in terms of our education system, but also in our wider society in general.”

“The sessions were very informative and at times heart-warming. The delivery of the session by individuals who have LD or Autism is much more beneficial as you can see how it feels from the aspect of the client.”

“The person who delivered our training was fantastic. Learned a lot in 1 hour that will stay with me for a lifetime.”
7. Next steps

We delivered sessions in Job Centres which were well received, particularly due to the introduction of the Employment Support Allowance which puts the emphasis on readying people on benefits for work. We found that people working in Job Centres didn’t necessarily have the confidence around supporting those with learning disabilities and/or autism and reported that they wanted to do better for those referred to them. We have further sessions booked with Job Centres and hope to expand this work which will become increasingly important as Universal Credit is rolled out.

Our experience of employing someone with autism as the lead trainer and working with people with lived experience of learning disabilities as co-trainers, has shown that we need to further improve our own practice standards when recruiting, interviewing and developing a diverse workforce that reflects the people we support. To this end we aim to develop a practice guide for employers that will give employers confidence in their employment practices and encourage them to employ more people with learning disabilities and/or autism.

We are currently working with funding received from The Economist to expand our awareness training to retail and banking outlets, to further support people to access their community.
8. Recommendations

We believe that anyone in a public facing role should have awareness of learning disabilities and autism so they can give the best support to people using their services. The information should focus on the less well-known facets of these conditions, such as sensory differences and autistic people who don’t generally fit into common conceptions, including autistic women, autistic adults without learning disabilities and autistic people of colour.

This reliance on community organisations is set to continue with people being referred to the community groups through Social Prescribing and we are meeting with projects providing connections to community groups to see how/if we can work together.

Our work has shown us a need to raise awareness among hospital and medical interpreting staff, who may be asked to interpret information about different disabilities where the terminology doesn’t exist in the mother tongue.

Report written by:
Helen Cairns
November 2019
Learning Disability and Autism Awareness – Training Menu

All of these sessions are co-delivered with someone with lived experience of autism and/or learning disabilities. The sessions are at a time and place convenient to you and will contain real life experiences and examples of what works.

**Basic Learning Disability and Autism Awareness**

**Health Action Plans and Passports**

**Mental Capacity Act and DoLS in Healthcare**

**In depth Learning Disability and Autism Awareness**

**Reasonable Adjustments, Legislation and Case Studies**

**Health Inequality and the Confidential Enquiry**

**Effective Health Advocacy**

Contact: Helen Cairns (Project Manager) 077 34 300 697 HCairns@certitude.london

Israel Bernal (Lead Trainer) 075 48 162 135 IBernal@certitude.london
Health Action Plans and Passports

This module looks at the tools and plans you can use to help people with learning disabilities and autism stay healthy and improve their access to health services.

This module is ideal if you and your group or team would like to give practical support and advice to individuals to reduce health inequality, improve their access to health services, and help them stay healthy and improve their health awareness.

Basic Learning Disability and Autism Awareness

In this module, we offer a brief introduction to learning disabilities and autism. This will allow you and your organization or team to gain a basic understanding of these conditions and communication basics.

This module is ideal for you and your team or group if you have little or no experience of supporting people with autism and/or learning disabilities.

In depth Learning Disability and Autism Awareness

This module covers the basics in understanding learning disabilities and autism, plus more. This is an ideal module if you and/or your team or group have some understanding of the issues that face people with learning disabilities and autism, and you want to take a more in-depth look at the subject.

Effective Health Advocacy

This module covers the ways you and your organization or team can be effective advocates for people with learning disabilities and/or autism that are using health services.

This module is ideal if you and your group or team provide direct support and advice to people with learning disabilities and/or autism.
Reasonable Adjustments, Legislation and Case Studies

This module covers the legal responsibilities of healthcare providers and the legal rights of people using these services.

This module examines some case studies about how to identify and make reasonable adjustments to services to improve access for people with learning disabilities and/or autism.

This module is ideal if you and your group or team provide advice and support to members of the public, people with learning disabilities and/or autism and their families and carers in your local community.

Mental Capacity Act and DoLS in Healthcare

This module looks at the Mental Capacity act, the legal framework for assessing an individual’s ability to consent to their care and support arrangements, and the Deprivation of Liberty Safeguards (DoLS), which is the legal framework for depriving a person of their liberty in a care home or hospital (for example by stopping them from leaving if they try to or monitoring them in a way that restricts them), if it is necessary and in their best interests.

This module is ideal if you and your group or team provide advice to individuals or carers around consent, or you are working with individuals and their carers who may need advice to navigate these systems.

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The Confidential Enquiry looked at the deaths of all people with learning disabilities to examine health inequality and the areas where services failed to provide adequate support to individuals. The findings showed a large and shocking difference in the quality of treatment and life expectancy. This module covers health inequality statistics, the findings of the report and the suggestions of what services should be doing to help overcome this. This module is ideal if you or your group or service is providing advice to people with learning disabilities and/or autism and their carers in the community who are having problems accessing good healthcare, or if you are raising awareness of health issues in your local area.

Flexible Training Delivery

Each of these modules are around 30 minutes long. However, we can provide a bespoke package for you and your team or group dependent on your needs.

If you are unsure what package best suits your team or organisation, please contact us. Details are below. You can also find us on Twitter (Twitter: @TMRCertitude) and Facebook (Facebook: certitude.certitude)

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Health Inequality and the Confidential Inquiry

Flexible Training Delivery
# LD and Autism Awareness

**Learning Outcomes:**
1. Define Learning disability, autism and learning difficulty and how these might impact a person
2. Challenge own preconceptions of Learning disability and autism
3. Describe cause$es$ of learning disability
4. Understand the basics of sensory processing
5. Understand the basics of communication support

<table>
<thead>
<tr>
<th>Content / activity</th>
<th>Learning Point</th>
<th>Time</th>
<th>Who</th>
<th>Resources</th>
<th>Learning Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask about the level of experience in the room with LD. Whole group work getting</td>
<td>Level of knowledge in the room can vary Personal experience has an impact</td>
<td>5m</td>
<td></td>
<td>Slides</td>
<td>2</td>
</tr>
<tr>
<td>people to think about what comes to mind when discussing Learning disabilities/</td>
<td>People first Labelling.</td>
<td></td>
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</tr>
<tr>
<td>Autism. Use pictures to get people to challenge their own preconceptions</td>
<td></td>
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</tr>
<tr>
<td>Definitions of LD, L difficulty and Autism. Causes</td>
<td>There is no “typical” person with LD/Autism</td>
<td>5m</td>
<td></td>
<td>Slides</td>
<td>1,3</td>
</tr>
<tr>
<td>Myth busting</td>
<td>Challenge preconceptions</td>
<td>10m</td>
<td></td>
<td>Videos – Things not to say to a person with Down’s syndrome Slides</td>
<td>2</td>
</tr>
<tr>
<td>Sensory differences</td>
<td>Think about how these can impact an individual</td>
<td>5m</td>
<td></td>
<td>Video – can you make it to the end</td>
<td>4</td>
</tr>
<tr>
<td>Communication tips</td>
<td>How to get the best out of an interaction</td>
<td>5m</td>
<td></td>
<td>slides</td>
<td>5</td>
</tr>
<tr>
<td>No.</td>
<td>Content / Activity</td>
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<tr>
<td>1.3</td>
<td>There is no &quot;typical&quot; person with LD/Asperger's Syndrome.</td>
<td></td>
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<tr>
<td>2</td>
<td>Videos - Things not to say to a person with Down's Syndrome.</td>
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<tr>
<td>4</td>
<td>Video - Can you make it to the end.</td>
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<tr>
<td>5</td>
<td>Slides</td>
<td></td>
<td></td>
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<tr>
<td>6</td>
<td>Video - Things people with autism are tired of feeling.</td>
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</tr>
</tbody>
</table>

Learning Outcomes:
1. Define learning disability, autism and learning disability and how these might impact a person.
2. Challenge own preconceptions of learning disability and autism.
3. Describe causes of learning disability.
4. Understand the basics of sensory processing.
5. Understand the basics of communication.
6. Understand the basics of masking in autism.

Masking
Communication Tips
Impact on Individual
Sensory Differences
Myth busting
Challenges preconceptions
Everyone is different
Challenges preconceptions
LD and Autism Awareness
**Health inequality**

**Learning Outcomes:**
1. Understand the issues facing people with learning disabilities and autism when it comes to accessing healthcare
2. Know the key findings of the confidential enquiry
3. Describe how health inequality can impact care

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<tbody>
<tr>
<td>Large group work – what are the issues that face people with LD and autism when accessing health care</td>
<td>Apply barriers to how they can be overcome</td>
<td>10m</td>
<td></td>
<td>Flip chart slides</td>
<td>1</td>
</tr>
<tr>
<td>Confidential Enquiry and LER – health inequality and recommendations</td>
<td></td>
<td>10m</td>
<td></td>
<td>Slides</td>
<td>2</td>
</tr>
<tr>
<td>Case studies – Death by indifference</td>
<td>Put the inequalities into real life situations</td>
<td>10m</td>
<td></td>
<td>slides</td>
<td>3</td>
</tr>
</tbody>
</table>

**Health advocacy**

**Learning Outcomes:**
1. Understand the issues facing people with learning disabilities and autism when it comes to accessing healthcare
2. Describe the importance of asking questions of health professionals
3. Understand how record keeping can help support health issues
4. Describe diagnostic overshadowing

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</thead>
<tbody>
<tr>
<td>Summarise how people are affected by health inequalities</td>
<td>People with LD and autism are disadvantaged with current healthcare</td>
<td>10m</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Importance of asking questions and hospital passports</td>
<td>There is a role for supporters/family in ensuring fairer access</td>
<td>10m</td>
<td></td>
<td></td>
<td>2,3</td>
</tr>
<tr>
<td>What is diagnostic overshadowing and how does this affect an individual</td>
<td>Behaviour is a marker of how people are feeling</td>
<td>10m</td>
<td></td>
<td>Slides</td>
<td>4</td>
</tr>
<tr>
<td>Learning Outcome</td>
<td>Time</td>
<td>Resources</td>
<td>Learning Point</td>
<td>Content / Activity</td>
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<tr>
<td>1.2</td>
<td>1</td>
<td>Slides</td>
<td>Tom</td>
<td>Playing, constantly reviewed.</td>
<td></td>
</tr>
<tr>
<td>2.3</td>
<td>2</td>
<td>Slides</td>
<td>Tom</td>
<td>Review of the process, safety and precautions.</td>
<td></td>
</tr>
<tr>
<td>3.4</td>
<td>3</td>
<td>Slides, flip chart</td>
<td>Tom</td>
<td>Two stage capacity test: very far examples in large group work, and can be applied to all principles of the MCA.</td>
<td></td>
</tr>
<tr>
<td>4.5</td>
<td>4</td>
<td>Slides</td>
<td>Tom</td>
<td>Can be applied to all principles of the MCA.</td>
<td></td>
</tr>
<tr>
<td>5.6</td>
<td>5</td>
<td>Slides</td>
<td>Tom</td>
<td>MCA.</td>
<td></td>
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</tbody>
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### Learning Outcomes: Passports and Tools

1. Understand different types of health records and how to obtain them.
2. Describe what a hospital passport is and how it is used.
3. Describe what an annual health check is and how it is used.
4. Describe the principles of the MCA.
5. Describe the principles of the MCA.
**Reasonable adjustments**

Learning Outcomes:
1. Understand the legal obligation to provide reasonable adjustments
2. Understand what “reasonable” means in this sense
3. Understand the role of carers in providing the best experience for the individual
4. Apply knowledge to case studies

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<th>Resources</th>
<th>Learning Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equality Act</td>
<td>Legal obligation to provide reasonable adjustments</td>
<td>10m</td>
<td></td>
<td>Slides, Video – Mencap, what is a reasonable adjustment</td>
<td>1</td>
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<tr>
<td>What is a reasonable adjustments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case studies</td>
<td>Planning is key</td>
<td>10m</td>
<td></td>
<td>Case studies Paper and pens</td>
<td>2,3,4</td>
</tr>
<tr>
<td></td>
<td>Everyone is an individual</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>What’s reasonable?</td>
<td>Must be essential</td>
<td>10m</td>
<td></td>
<td>Reasonable adjustment game</td>
<td>2,3</td>
</tr>
<tr>
<td></td>
<td>Least restrictive</td>
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