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Improving mental health support for autistic people

The UK government published the Adult Autism Strategy: statutory guidance in March 2015. The guidance sets out various obligations for health and social care providers, including recommendations on staff training in autism awareness and making reasonable adjustments for autistic service users.

In this article we present the experience of Tees Esk and Wear Valleys (TEWV) Foundation Trust in implementing these recommendations, and hope that other professionals find it helpful for application in their own organisations.

TEWV Foundation Trust is one of the largest mental health trusts in the country, covering a large geographic area. Mental health problems are common in autistic people - over half of all autistic adults have a diagnosable mental health disorder (Buck et al., 2014) (Mattila et al., 2010) and suicide rates are seven times higher than the general population (Hirvikoski et al., 2016). Therefore it can be argued that there is a particular onus on mental health trusts to improve their offer to autistic patients. In early 2017, TEWV launched a trust-wide autism project to do just this.

The spark for the project came from the statutory guidance, but the real impetus came from the recognition within the trust that it was the right thing to do for our patients and their families. We had received feedback (including complaints and serious incidents) that autistic patients sometimes felt they weren't properly understood and that reasonable adjustments weren't being consistently made. Staff too, had told us that they didn't have enough knowledge about autism and sometimes felt ‘stuck’ when trying to support autistic patients with major

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mental health problems. A staff survey at the start of the project showed that only 42% of TEWV staff were confident that they could make reasonable adjustments for autistic patients.

Note - the term ‘expert by experience’ in this article refers to either an autistic person or their family member/carer.

Assemble the team

Crucial to the success of the project was strong support from the Trust’s senior leadership:

- The Chief Operating Officer was Project Sponsor
- The executive team released a sum of money (roughly £400,000 of non-recurrent funding, over two years)
- An autism strategy manager (Jacqui Dyson) and trust-wide autism clinical lead (Conor Davidson) were appointed
- An expert by experience (autistic service user), autism nurse consultant (Anne Cahill) and an administrator were recruited to the team.

In the first half of 2017 we held a series of consultation events with staff, service users and carers to identify the key issues and agree our overall strategic and clinical approach for autistic people. At this point, the focus of the project was on adult mental health services, as we perceived this to be the area of greatest need.

Some consistent themes emerged from the consultation:

- The high rates of mental distress and mental illness experienced by autistic people
- The difficulty accessing mainstream mental health services
- The lack of staff training and understanding of autism
- The long waiting times for assessment
- The lack of post-diagnostic support.

Another key theme was the importance of involving autistic people and families in the project in a meaningful way. This became one of our guiding principles: we are proud that every single element of the project has had input and active
involvement from experts by experience, including the planning and delivery of training, membership of the trust autism steering group, and indeed this very article you are reading.

The TEWV autism framework

Following the consultation stage the TEWV autism framework was produced, setting out our aims and objectives and the means by which we will achieve it. Our overall ambition is:

Autistic people should have equal access to mental health and learning disability services, and be treated by autism-aware staff who are able to make reasonable adjustments when required. Our ambition is to be the most autism-friendly NHS organisation in the North of England.

The key strands of work outlined in the framework are as follows:

1. Ensure there is a clear pathway to autism assessment in every TEWV location. Where TEWV provides autism assessment, to ensure it is of uniformly high quality and to work to reduce waiting lists as far as possible.
2. Put in place staff training in autism awareness and treatment of autistic patients with co-occurring mental health issues.
3. Ensure that reasonable adjustments for autistic patients identified and implemented at every stage of the care pathway.
4. Provide consistent, high quality transitions from children and young people services to adult services.

As well as these specific aims, we also have a more overarching goal - to win hearts and minds. For too long, general adult mental health services have regarded autism as 'not our business'. We have even heard anecdotal reports of autistic people having trouble accessing mental health treatment because clinicians tell them 'we don't deal with autism'. By the end of the project, we hope that all TEWV staff appreciate that autism is their business.
Staff training

Our first action regarding training was to survey a sample of TEWV staff and clinical team managers about whether or not they had previously had training in autism, and their confidence in supporting autistic patients. This survey revealed significant gaps in training.

Secondly, we consulted with staff and experts by experience to map what mental health professionals should know about autism. Ideally staff would receive several days of autism training but there also needs to be a compromise between desirability and feasibility, given the large amount of statutory and mandatory training professionals have to complete, not to mention their demanding and increasingly busy day job.

Ultimately we settled on:

- Level 1 ‘autism awareness’ training for all staff (including non-clinical staff), comprising of a 10 minute video
- Level 2 ‘understanding autism’ training for clinical staff.

Both level 1 and level 2 training materials were co-produced with service users. All of the face-to-face training is co-delivered with experts by experience. To create the level 1 video we filmed one staff member and one expert by experience, and then embedded the film in the Trust’s Equality and Diversity e-learning package. This training is mandatory every 3 years meaning every staff member will eventually see it. The video can be watched here.

The level 2 face to face training has been delivered 45 times at the time of writing (October 2018). It is always jointly delivered by an expert staff member and an expert by experience in a variety of locations in the region. We are fortunate that TEWV has a number of staff with autism expertise who have taken time out from their day jobs to help deliver some of the training sessions.

Although the level 2 training is not mandatory, we have been heartened by staff response. Nearly all of the sessions have been oversubscribed and feedback has been highly positive - 90% rate the training as relevant to their role. In particular the contributions from experts by experience have been highly praised in the feedback.

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As of October 2018, 635 staff have received Level 1 training and 700 staff have received Level 2 training including external professionals such as GPs and police officers. The aim is to have trained 80% of clinical staff by March 2020.

Reasonable Adjustments

Preliminary audit and survey results showed that reasonable adjustments were being applied in inconsistent, idiosyncratic ways. The challenge was to establish a mechanism to prompt clinicians to consider and implement reasonable adjustments as a routine part of their practice.

Through consultation, a select group of staff, service users and carers were invited to produce a ‘Clinical Link Pathway’ (CLiP). A CLiP is a series of resources that are complementary to the existing TEWV standardised care pathways.

The aim of the autism CLiP is to support clinicians in collaboratively discussing, identifying, implementing and reviewing reasonable adjustments in their practice. The CLiP resources developed so far include:

- A new questionnaire for patients and carers regarding needs specific to autism
- Guidance on considering the sensory environment
- General hints and tips about communication
- Advice on healthcare/hospital passports
- Guidance around the clinical considerations for assessing and treating mental illness in autistic people.

The Trust has also agreed to allocate a specific activity code in our electronic records system which enables clinicians to clearly document both reasonable adjustments made and the discussion with patients and carers. This allows easy access to this information for any clinician involved in the individual's care. The CLiP is currently in pilot form with a plan to roll it out across all Trust localities throughout 2019.
Children and young peoples’ services

The initial focus of the project was on general adult services but similar problems existed in children and young people’s services (CYPS), in particular long waiting times for children’s autism assessments. In May 2018, additional funding was secured to expand the scope of the project to include children and young people’s services, and a CYPS trust-wide professional lead and assistant were appointed.

Currently we are mapping the provision for autism assessment within children’s services across the Trust in order to produce a gap analysis (including capacity and demand variations). Our ultimate aim is to streamline the autism assessment pathway for children, including how we achieve greater consistency across the trust in assessment processes such as use of clinical tools and paperwork.

Another priority is transitions for young autistic people (from 17.3 years) from CYPS to adult mental health/LD services, ensuring the transition protocols and procedures explicitly consider autism.

We are also carrying out a review of therapeutic interventions in CYPS across the Trust, identifying good practice in relation to working with autistic children. The autism CLiP, which currently only applies to adult patients, will be adjusted for children’s services shortly and piloted within CYPS with a view to rolling it out across the Trust.

We will also establish a baseline of autism training in CYPS across the Trust with the aim of developing a comprehensive training plan. CYPS staff are now being encouraged to attend the Level 2 training that is already well established in adult services.

Autistic adult’s view

Richie

When I was working with the team it was awesome. I am 100% in support of everything the team are doing. Positive and negative feedback is meaningful as it demonstrates that people are listening.
The mental health component of the work is particularly relevant to my own personal experience of accessing mental health services in the past which was not good. Through the work that the team are doing I am hopeful that if my children for example were to access mental health services in the future their experience would be much improved as a result of the training.

The work needs to continue so that more autism awareness training is given that helps staff see autistic people as individuals and make reasonable adjustments to meet the needs of the individual.

I have learnt such a lot about myself through working as an expert in the team and I am using new skills to establish my own business. Working with the team gave me the confidence to be the “real Richie”.

Carers’ views

Hazel

I am a carer for my son who has a diagnosis of autism and catatonia. I first met Jacqui, my local Mental Health Trust Autism Strategy Manager, when she came to present at a council of governors development day. It was clear early on that she understood how important it was to improve the experiences of autistic people accessing mainstream mental health services, and that she wanted autistic people and their carers to be working together on this project right from the beginning and learn together to bring meaningful changes. Carers get a gut feeling when a professional is genuine about co-producing and co-delivering and not just making a tokenistic gesture.

So, I joined the steering group and we consulted with autistic people and their families, and the professionals working with them. We all worked together on producing and delivering the elements of the project, including the autism framework document, the training videos, the face to face training, and the autism CLiP.

I am finding the whole experience of working together on this project meaningful. I feel valued and actively involved: in fact, I think the team got more than they bargained for, as I am not known for going with the crowd and can be very vocal on what should be happening!
In particular, nationally there needs to be some clarity around what is meant by “abnormally aggressive and seriously irresponsible behaviour” in autistic people. I would like to see a change in language - the current terminology locates the problem within the individual/their behaviour, rather than seeing distressed behaviour as a means of communication about what is distressing them.

The team recognise we have still a long way to go locally and nationally, and welcome the NHS ten year plan making autism a priority and the Autism Act refresh next year, not forgetting the current independent Mental Health Act review. All are opportunities to change hearts and minds and bring real change and make genuine improvements for autistic people accessing mainstream mental health services.

David

Prior to 2016 there was no evidence that the staff of Tees Esk and Wear Valleys NHS Foundation Trust were receiving the autism awareness training required by the Autism Act statutory guidance. The Trust was also clearly failing to make the most basic of reasonable adjustments for autistic people.

Over a number of years I had been complaining to the Trust about an absence of any real leadership on autism. That situation changed when, in 2016, the senior team at the Trust realised that delivering on its duties and responsibilities under both the Autism Act and Equality Act was ‘The right thing to do’.

I was initially surprised and then delighted to be asked to be a ‘critical friend’ to the Trust as it developed its Autism Strategy. I’ve also appreciated being a member of the team that has shaped and developed the training programme and reasonably adjusted pathways and documentation. My comments, feedback and ideas have all been treated with respect and properly considered. To be part of a wider team that has genuinely involved service users, carers, managers and members of staff has been a breath of fresh air.

NHS staff are often not confident in their ability to make reasonable adjustments for autistic people – it is seen as being all too difficult. The training programme and support materials developed by the Trust have, I believe, demonstrated that making adjustments for autistic people is not as complex as many staff think.
I look forward to the Trust being recognised as the most autism-friendly NHS organisation in the North of England.

The future

At the time of writing, the autism project is only funded until March 2019. However, our experiences so far have crystallised the perception that autism, perhaps more than any other condition, cuts across everything we do as a trust. All staff will come across autistic patients. It therefore makes sense to expand the scope of the training and CLiP beyond adult mental health clinicians, and include other directorates such as learning disability, forensics, older age as well as children and young people.

As such, we are hopeful that the lifespan of the project will be extended to March 2020, which should allow time to complete level 2 training, roll out the autism CLiP and the work on transitions and children's assessments. It is important that we evidence that the project has resulted in clinically meaningful improvements. We are collecting a variety of outcome measures, including:

- Training analysis of numbers trained, in which teams
- Staff surveys of autism knowledge and confidence in applying reasonable adjustments
- Case note audit of reasonable adjustments for autistic patients
- Qualitative feedback from staff on their experiences of using the autism CLiP
- Patient feedback including complaints and serious incidents.

In September 2018 we consulted on what the Trust's autism strategy should look like beyond the lifespan of the project. It was acknowledged that there is a need for ongoing staff training, and given the new national 12 week target for autism assessment waiting times, the Trust also needs to ensure our specialist autism teams are adequately resourced. In addition, there is a need for specialist autism expertise/consultancy to work into general mental health teams for complex and high risk cases.

All of this will require consistent levels of additional funding, but we are hopeful that the prioritisation of autism in the NHS ten year plan will allow mental
health trusts like ours to invest more into autism services. Autistic people and their families deserve no less.

References

