

A Framework for improving the experience of autistic adults using TEWV Services.

MARCH 2018

making a

difference

together

Why does TEWV need an autism framework?

Autism is more common than a lot of us think. It affects around one in every hundred people. It is estimated that there are approximately 20,000 autistic people living within the TEWV catchment area.



Key facts about autism

- Autism affects one in every hundred people
- Autism is not just a childhood condition – it persists into adulthood and old age.
- At least half of all adults with autism will experience mental health problems at some stage.

At least half of all adults with autism will experience mental health problems at some stage of their life. This includes common mental health disorders like anxiety and depression, but also disorders like psychosis, schizophrenia and bipolar disorder.

Because of this, many patients treated by TEWV for mental health problems will also have autism. So it is important that all TEWV staff are aware of autism, understand how autism affects people, and are able to effectively work with patients with autism.

A lot of people who think they might have autism find it hard to get a diagnostic assessment, or have to wait too long for an assessment. Some people are misdiagnosed with other psychiatric conditions when in fact they have autism. So we need to make sure there are clear pathways to diagnostic assessment in all TEWV localities, and keep waiting times as low as possible.

The government launched a national autism strategy, *Fulfilling and Rewarding Lives*, in 2010, and an updated version, *Think Autism*, in 2014. These have influenced the TEWV autism framework. The Government's vision is:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”.

The TEWV autism ambition

TEWV's mission is to improve people's lives by minimising the impact of mental ill health or a learning disability. We do that by being a recognised centre of excellence with high quality staff providing high quality services that exceed people's expectations.

We have consulted with service users, carers, staff and partner organisations to work out how best to apply the trust values and mission to working with autistic people. Our starting point is that diversity of all kinds adds value and meaning to society, and we therefore commit to listening to autistic people and the insights and expertise they bring. We recognise that everyone has the potential to lead a life meaningful to them irrespective of their symptoms or diagnosis. It is important that all TEWV services and staff recognise that autism is their business. People who require an autism diagnostic assessment should be able to access such an assessment in a straightforward way. Autism should not be a barrier to accessing mainstream TEWV mental health services and learning disability when needed. When someone with autism is being treated by TEWV services, staff should take their autism into account and make appropriate adjustments to the treatment if required.

Our ultimate ambition is for TEWV to be seen as the most autism-friendly NHS organisation in the North of England.

Our autism ambition is summed up below :

TEWV's autism ambition

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.

1.0 Our approach

In collaboration with autistic people, carers, staff and partner organisations, we have identified the following key themes:

1. There should be a clear pathway to autism diagnostic assessment in all TEWV localities.
2. Where TEWV provides specialist autism diagnostic services, they should be of a high standard.
3. All TEWV staff should be trained in autism awareness, and relevant clinical staff trained to a higher level of autism expertise.

4. TEWV staff should understand the impact of autism on mental health, and be able to make reasonable adjustments where necessary.
5. There should be a consistent, high quality transition plan for young people with autism when they move from child into adult services.

Despite the extremely tight funding in the NHS currently, the TEWV Board thinks that autism is important and has prioritised this piece of work. To support this money has been allocated to enable us to work through a range of initiatives to make our services more autism-friendly. However, the resources available are relatively small, and because of this we are taking a phased approach. This means that we are focusing initially on our front-facing adult mental health teams. These include access teams, crisis teams, community mental health teams, liaison teams and street triage teams. We have picked these teams because they are the 'front door' of the trust, that the majority of patients have first contact with. Also, we have identified adult mental health as the directorate where autism awareness training is most needed.

The ultimate goal of all TEWV treatment packages is to help the patient make as full a recovery as possible from their mental health problems. We recognise that it is not possible to 'cure' autism, as autism is a neurodevelopmental condition and not an illness. However, it is possible to successfully treat mental health problems associated with autism, and help autistic people achieve the same level of wellbeing and recovery from mental health problems as we would expect for all our patients.

Our role as a mental health trust is to help autistic people with additional mental health needs. More general autism support is the responsibility of local authorities. So we need to work in partnership with colleagues in local authorities - and also other organisations (for example, the National Autistic Society) - to ensure that there is adequate support in the community for our patients with autism.

1.1 Diagnosis

It is important to acknowledge that TEWV does not provide specialist autism services in all our localities. There is a specialist autism team based in Stockton, which provides diagnostic assessments to adults in Teesside, Durham and Darlington. Learning disabilities teams in some areas provide diagnostic assessments for adults with learning disability and suspected autism. In York and North Yorkshire, TEWV does not have any specialist autism services for adults without an intellectual impairment. In these areas, autism assessments are provided by the Tuke Centre based at the York Retreat.

Because of the current funding situation in the NHS, autism diagnostic services (for both children and adults) typically have long waiting lists. This is the case all over the country, not just in areas covered by TEWV. TEWV is committed to work with our partner organisations (such as clinical commissioning groups, CCGs) to try and make sure that autism services are properly funded.

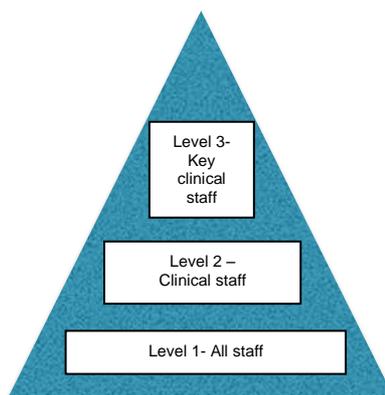
Our goals regarding diagnosis are:

- That there is a clear pathway to diagnostic assessment for each locality
- Where TEWV provide autism diagnostic services, to ensure that they are of a high standard (for instance, meet NICE guidelines).
- To ensure that TEWV autism diagnostic services provide a consistent standard of care.
- Where TEWV provide autism diagnostic services, to work with commissioners to ensure they are adequately funded to meet national standards on waiting times and NICE guidelines.

1.2 Training

We have a three level approach to autism training. Level one is basic autism awareness training, which we require all staff to complete. Level two training is for clinical staff who are likely to encounter patients with autism. Level three training is more in depth training for people who are responsible for making decisions with or about the service for autistic people.

Figure: training matrix



Goals:

- That all TEWV staff are trained in basic autism awareness, delivered via an e-learning training package.
- That relevant clinical teams (starting with front-facing adult mental health teams) receive face-to-face training. This training should cover: recognising autism, key features of autism, effective communication with autistic people, and treating mental health problems.
- Autism experts should have higher level training, which is evidence based and appropriate to their role.
- Autistic people, carers and staff should be involved at all stages of producing and delivering training.

1.3 Reasonable adjustments

Reasonable adjustments is a term used in the Equality Act 2010. Reasonable adjustments are changes that make NHS services more accessible and effective for patients with disabilities, including autism. Reasonable adjustments should be personalised – what works for one autistic person might not work for everybody with autism. Some examples of possible reasonable adjustments are given below .

Examples of reasonable adjustments (please note these are only a few examples – every person with autism is different so in practice reasonable adjustments will be personalised).

- Taking into account your communication differences – for instance many autistic people find it hard to talk on the telephone.
- Using clear and straightforward language.
- Offering written or visual information.
- Offering the first appointment of the day so you do not have to wait in a busy, noisy waiting room.
- Provide an autism alert card or hospital passport so it is easier for healthcare professionals to understand your needs.

Goals:

- To record the diagnosis of autism on our computer system so involved staff are alerted to the presence of autism.
- To ensure that clinical staff are trained in making reasonable adjustments.
- That reasonable adjustments are considered in the patient's care plan where necessary.
- That all TEWV new buildings are designed to be autism-friendly.

1.4 Transitions

Transition means moving from one service to another service. The type of transition we are focusing on is moving from children and young people's services to adult mental health services. This occurs at the age of 18. Not every young person with autism will be automatically transferred to the adult mental health team – this will always be decided on an individual basis depending on need.

Transitions can be particularly difficult for young people with autism for a variety of reasons, e.g. meeting a new psychiatric nurse and psychiatrist, going to appointments in a different building. The key to making transition less stressful is planning ahead. Strategies for ensuring a good transition are shown below.

Examples of good practice in autism transitions

- Make sure decisions regarding transition to adult services involve the service user and their family.
- Prepare the young person for the change well in advance
- Introduce the new worker well before the patient's eighteenth birthday

Goals:

- There should be a transitions policy in place, available for young people and their families to read.
- Transition should be planned well in advance and discussed with the young person and their family.
- If the young person is being connected to partnership organisations, the same principles of smooth transition should apply.

2.0 How will we make sure these goals are being met and monitor our progress?

We have a variety of ways to monitor the progress of the Autism framework. These include:

- Data collection from our computer system, PARIS
- Clinical audit
- Training records
- Staff surveys
- Analysis of incidents and complaints
- Patient feedback surveys

We will produce a feedback report at the end of the project describing the progress we have made. By that stage, we expect that TEWV will be leading the way to becoming the most autism friendly NHS organisation in the North of England.

3.0 Conclusion - by autism project sponsor Ruth Briel



TEWV's autism framework comes from our beliefs and values that the mental health and learning disabilities services we provide should be respectful and personalised to the people and communities we serve. In addition, we believe that services are best when they fully involve people that use them, their families and friends and of course people who provide services.

Autistic people have a higher incidence of mental health problems, and may require services to be delivered in a slightly different way but they may also bring new insights and ways of thinking about the way we deliver services and bring a different contribution to our service user voice.

For these reasons we believe that providing services that are autism friendly is not just the right thing to do in line with our values - it will lead to better services for everyone.

3.1 What have autistic people and people with an interest in autism said about this framework?

“...a document from TEWV so positive about autism. We are looking to improve on something good”

“...good to read that carers have been consulted on this work”

“ we need to be explicit about the role of TEWV and the role of other public sector partners”

“...involvement opportunities with TEWV is a caring positive”

“.....we want to improve things and work together to develop our skills using evidenced based practice.....”

“..... learning from the experts and carers is the best!”



4 A note on terminology

Throughout this document the term 'autism' is used to refer to all types of autism spectrum disorder, including Asperger's syndrome.

Service users and carers who have been involved in this work have asked us to refer to them as autistic people and therefore this term is used throughout this document.

5 Background to TEWV

Our mission, vision and goals

TEWV provides a range of mental health, learning disability and eating disorders services in County Durham, the Tees Valley, Scarborough, Whitby, Ryedale, Harrogate, Hambleton, Richmondshire and the Vale of York.

Our mission

To improve people's lives by minimising the impact of mental ill health or a learning disability

Our vision

To be a recognised centre of excellence with high quality staff providing high quality services that exceed people's expectations

Our strategic goals

- To provide excellent services, working with the individual users of our services and their carers to promote recovery and wellbeing
- To continuously improve the quality and value of our work
- To recruit, develop and retain a skilled, compassionate and motivated workforce

- To have effective partnerships with local, national and international organisations for the benefit of our communities

- To be recognised as an excellent and well governed foundation trust that makes best use of its resources for the benefit of our communities

6 How did we develop this framework?

Our starting point for this work is that autistic people and their families/carers, should be involved in every element. It is people with lived experience of autism who can tell us the most about the difficulties they face and what we can do to make our services better.

To develop this framework, we held a series of consultation events throughout 2017, to which autistic people, carers, TEWV staff, and partner organisations were invited. We also set up an email virtual reference group for service users and carers to directly communicate to us. Draft versions of this framework were widely circulated and we received a large amount of feedback, which has been incorporated into the final document.