

CNTW Autism Consultation 2021-2022

Is CNTW an autism friendly organisation?

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Appendix 1: Is CNTW an autism friendly organisation consultation document

1. Introduction

Autistic people should be able to use general mental health services just like anyone else. The starting point should always be for mainstream services to support autistic people (people with autism). This should be done by making reasonable adjustments or providing specialist multi-disciplinary support, depending on what the person needs.

Autistic people with mental health needs should get the right care and support when receiving CNTW services.

The Greenlight Toolkit and NHSI (NHS Improvement) Learning Disability and Autism standards show that a lack of understanding of autism can lead to a variety of problems, from inappropriate responses, to poor services and support for individuals, their families and carers.

Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Disorder (ASD). Autism affects 1 in 60 people; it is a lifelong condition meaning that adults and older people are affected as well as children.

Autistic people are more at risk of a range of mental health disorders, including anxiety, depression and psychosis. The research shows that at least one in three autistic adults have severe mental health difficulties due to a lack of support. Anxiety affects 40% of autistic people and depression 30%. These conditions can cause serious distress and have a huge impact on people's everyday lives.

For many autistic people, mainstream public services can be hard to access. Some of this is due to a lack of understanding of autism among staff, however this is not the only factor. Many autistic adults do not have a diagnosis, and some have been misdiagnosed of other mental health conditions.

The Autism Consultation Project was commissioned by the Trust's Business Delivery Group to provide a conversation platform for autistic service users, their family and carers, and staff who are autistic or a carer of an autistic person, to express their views on whether they believe CNTW is an autism friendly organisation.

2. Purpose of the report

This report will provide details on the coproduction of the consultation themes, the process by which the consultation was undertaken, and the outcomes from the consultation. The delivery of this report is to inform the Trust's autism strategy or framework and increase awareness and understanding of autism across the Trust, to build a better future for autistic people so that they are fully supported when in CNTW's care.

An increased awareness around autism and how it affects behaviour and responses, will allow staff to adjust the way they deliver services.

3. Development of the consultation document

The consultation was developed by a steering group of autistic people, service users, carers, staff, and representatives from partner organisations which considered what CNTW should be asking, how it should be asked, and who the consultation would be aimed at.

The steering group agreed that the consultation would focus on six key themes to inform our understanding in respect of the question 'Is CNTW an autism friendly organisation'. Six inclusive and representative focus groups were set up to consider these themed work streams in more detail. Each of the focus groups retained a member(s) of the steering group, acting as facilitation leads, with additional service user, carer, staff and third sector representatives included within these work streams.

Work streams

- 1. Language and terminology
- 2. Diagnosis: What next?
- 3. Reasonable adjustments
- 4. Consistency and parity across localities and services
- 5. Staff knowledge, skills and experience
- 6. Working in CNTW

Each work stream focussed on one of the six themes, with each developing a series of questions in relation to their topic title. These questions were brought back to the steering group for consideration and agreement, then collated into one consultation document. Due to Covid challenges and service priorities this draft document was considered by a smaller but diverse group of service users, carers, and autistic staff from the steering group. This group made a number of considered amendments before the document was finalised in the form used at Appendix 1.

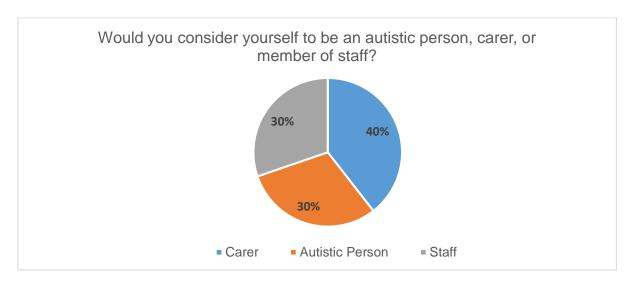
4. Consultation process

The consultation ran from October 2021 to the end of February 2022. The consultation document was sent out to service users, carers, staff and key partner organisations in both paper form, and as an online survey. In addition, the Trust's Patient and Carer Involvement Facilitators ran a number of focus groups specifically to support service users and carers provide their views and opinions in conversation.

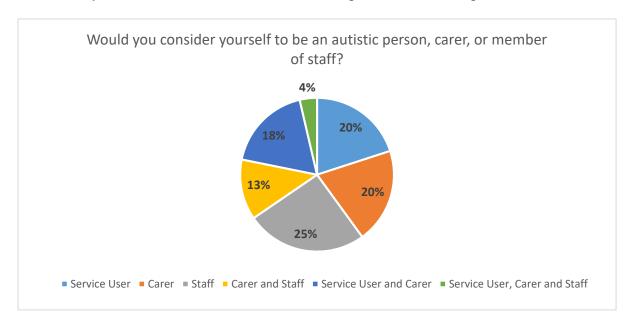
The online consultation document was completed by 57 individuals, and 5 focus groups were attended by 24 people. Those who completed the consultation as well as those who attended focus groups represented a balanced mix of autistic people, carers and CNTW staff.

5. Consultation contributors

Those taking part in the consultation provided a measured representation of experience in respect of categorisation: autistic person, carer, and staff.



Many individuals indicated that they identified as being within more than one category, some as an 'autistic person and carer', 'staff and carer', or 'autistic person and staff'. Additionally some individuals identified as being in all three categories.



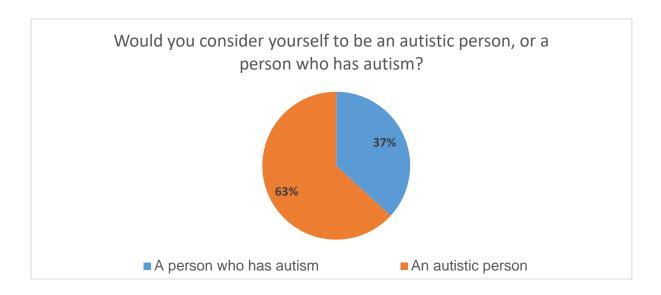
What we learnt

6. How people identified themselves in relation to autism

The steering group recognised from the outset that there are differing opinions in relation to how people prefer to identify themselves in respect of autism. In line with guidance from the National Autistic Society, it was felt that giving autistic people that choice was important to the consultation.

For the purposes of this report, 'autistic person' is used in reflection of what autistic people identified as the preferred term, however this is not meant to exclude those who prefer other terminology, for example a person with autism.

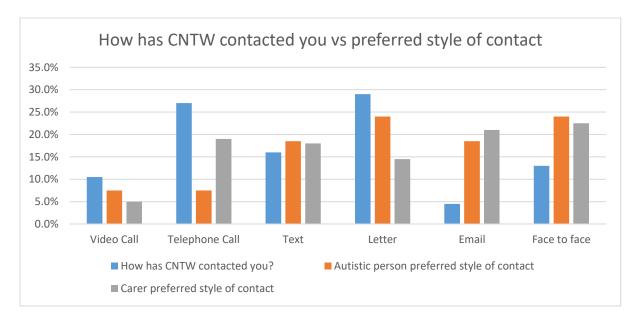
This difference of opinion was replicated in the consultation outcomes with 63% of the people 'with a diagnosis of autism' identifying as an 'autistic person' while 37% preferred the term 'a person who has autism'.



7. Theme 1: Language and Terminology

7.1 Preferred style of contact

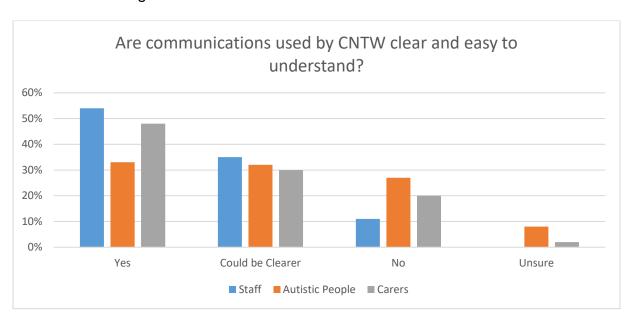
Responses demonstrate that there is disparity between how CNTW communicates with people when compared to their preferred style of contact. Whilst communicating by letter or text are preferred options of contact, telephone calls are not, yet telephone calls are identified as a significant choice by the Trust. Additionally both email and face to face communications are not shown as being fully employed, when the consultation established that they are significant and preferred options.



7.2 Understandable communications

The survey confirmed that only 33% of autistic people found communications to be clear and easy to understand. Notably only 54% of the staff responding felt that communications were clear and accessible.

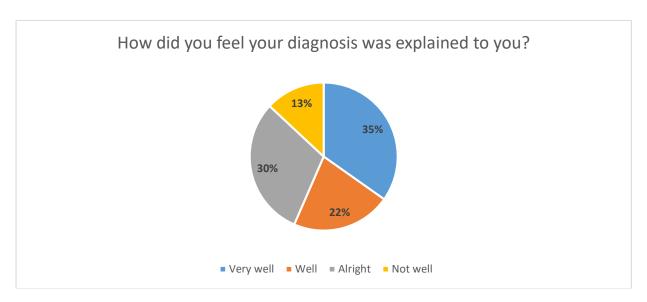
Narrative from the consultation provided a clear indication from autistic people and carers that communications require improvement. Main comments submitted relate to the use of jargon and abbreviations, and what they referred to as 'clinical speak', as well as there being too much information.



8. Theme 2: Diagnosis: What next?

8.1 Diagnosis

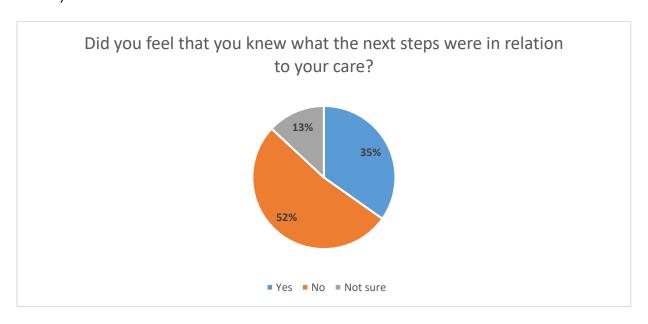
Autistic people receiving their diagnosis of autism, whilst in Trust services, were asked how well they felt it was explained to them. 57% felt this was managed well or very well.



8.2 Next steps

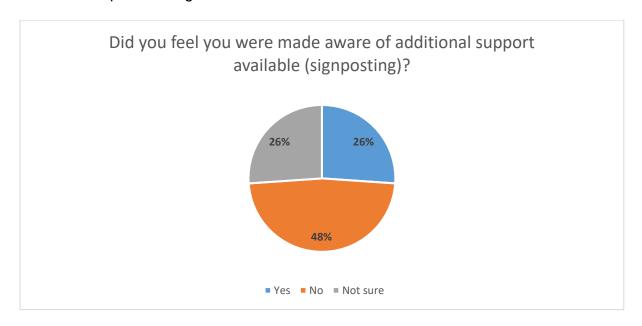
Only 35% of the people, who stated they had received their diagnosis whilst in Trust services, felt that they knew what the next steps were in respect of their care. However some of the people who stated they did understand the next steps, confirmed that this

was actually due to further information being provided at follow-up (in the next question asked).



8.3 Additional support

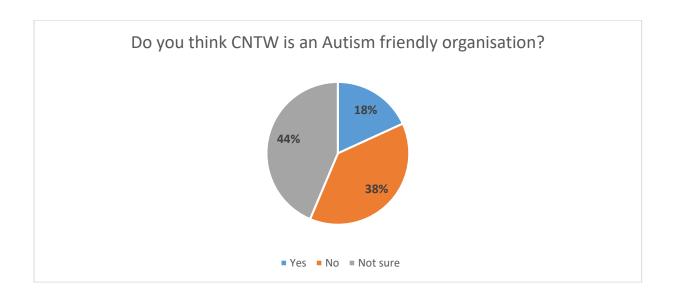
Only 26% of people contributing to the consultation, who were diagnosed whilst in Trust services, stated that they were made aware of additional support available to them, with examples identified in the narrative of signposting, information packs, booklets, links to other organisations such as the National Autistic Society, as well as details of helpful reading.



9. Theme 3: Reasonable Adjustments

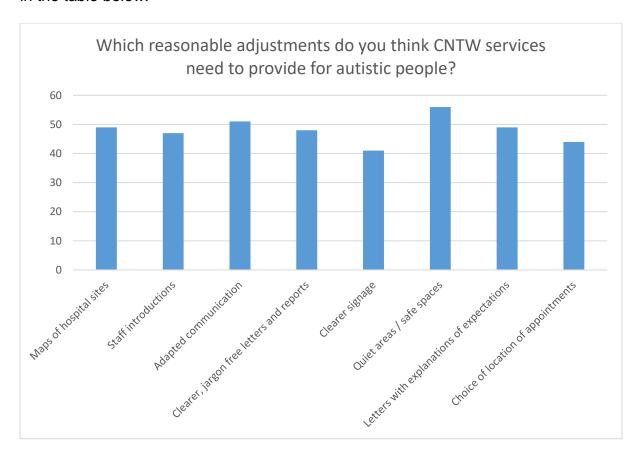
9.1 Autism friendly organisation

All contributors to the consultation were asked if they believed the Trust to be an autism friendly organisation, with 18% confirming that they did.



9.2 Needed reasonable adjustments

The consultation found that 8 reasonable adjustments were consistently identified in responses, which contributors believed would improve patient experience, as provided in the table below.

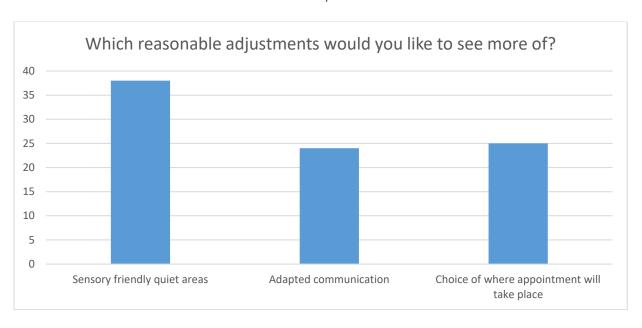


Additional suggestions for improvement also included:

- Providing a list of adjustments available so people can consider options before attending appointments
- Keeping to appointment times
- Choice of time for appointments
- Longer appointments
- Engagement with family and carers
- Photos of buildings and waiting areas to accompany maps

9.3 Key reasonable adjustments

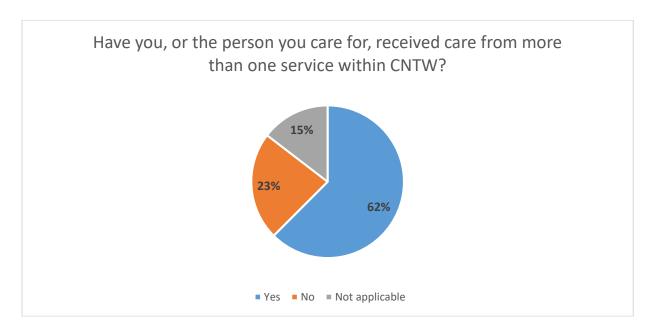
The consultation identified the importance of offering each person a choice of adjustments as everyone is different and approaches must be adapted for individual needs. The top 3 priorities identified by this consultation were consistent with previous conversations with service users and carers, as shown in the table below:



10. Theme 4: Consistency and parity across localities and services

10.1 Experience of more than one service

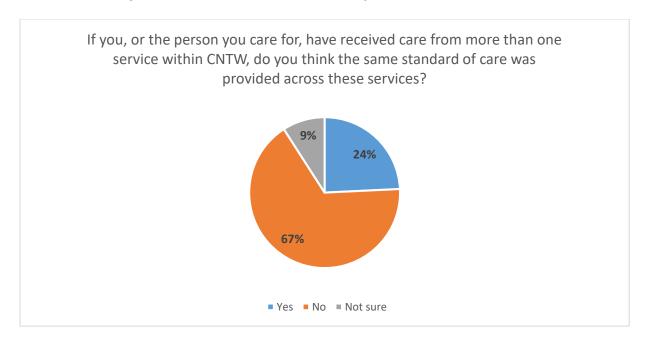
Responses in respect of consistency and parity across services reaffirmed that autism and mental health are strongly linked. A theme being that many people stated they had transitioned from Children and Young Peoples Services to Adult Mental Health. 62% of those taking part in the consultation confirmed that they had received care from more than one service.



10.2 Standard of care across services

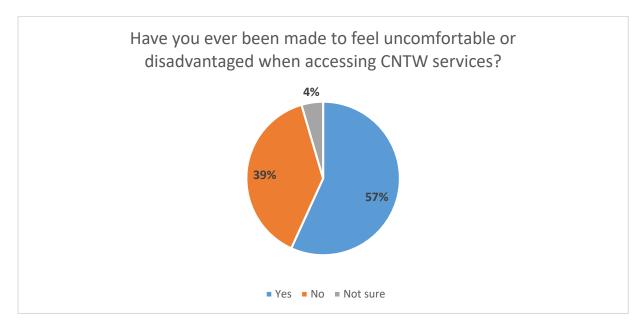
67% of those who had received care from more than one service, stated they experienced distinct differences across teams and services. Experience in the Autism Diagnostic Service was seen as positive (up to the point of diagnosis) with both service users and carers. However the same standards were not found in other CNTW services, an example being the reasonable adjustments made for the autism assessment, were not made in other parts of CNTW.

"One hospital admission (but not all) allowed me to take my weighted blanket, communication cards and fidget items, which helped - this was not consistent across sites even though the same Trust" – Focus Group contributor.



10.3 Made to feel uncomfortable or disadvantaged

57% of those who had received care stated they had been made to feel uncomfortable or disadvantaged when accessing services, the narrative reinforcing the previous point regarding disparity between services and reasonable adjustments not being provided in many cases.



11. Theme 5: Staff knowledge, skills and experience

11.1 Staff knowledge and understanding of autism

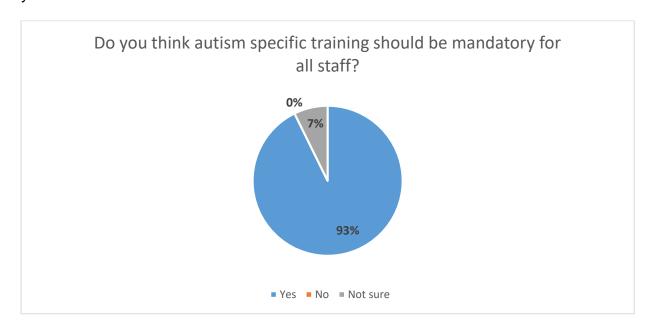
Gaps in staff knowledge were identified as an issue in the standard of care provided by services, key comments were:

- More understanding needed of autism and sensory needs
- o 'Cynicism' around autism and questioning a person's diagnosis
- Need for staff training to be identified for competence and confidence
- Need for more flexibility from staff with regards to possible additional issues
- Reiteration that mental health and autism are strongly linked, but services are not



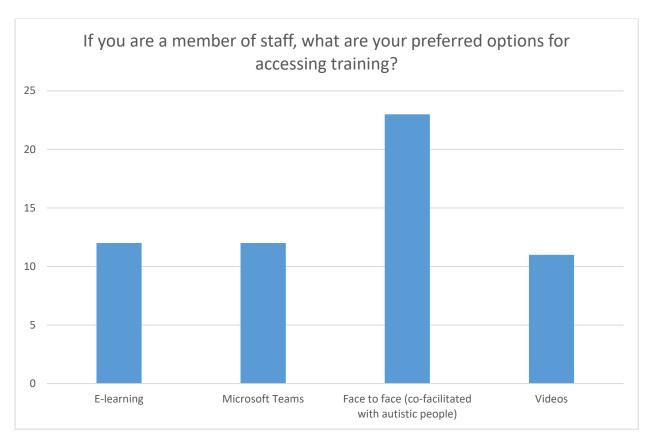
11.2 Mandatory training for staff

Those taking part were all asked to consider if they felt there was a need and benefit to have mandatory autism training for staff, the result was emphatic with 93% stating yes.



11.3 Staff's preferred options for training delivery

The staff involved in the consultation were asked to identify their preferred options for the delivery of autism training with the results provided in the table below. The narrative illustrated a strong emphasis in respect of the need for co-facilitation with autistic people. Add some quotes to support strong emphasis

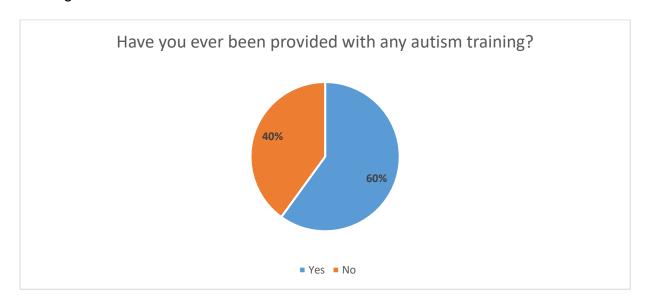


12. Theme 6: Working in CNTW

Theme 6 of the consultation was open to Trust staff to provide their views and contributions.

12.1 Autism training for staff

Staff were asked to confirm if they had received any autism training, with 60% of those taking part confirming they had. It was noted in comments that autism awareness training is insufficient to meet staff needs.



Staff provided details of the training they had undertaken, which identified that training was not systematic or coordinated, all responses provided below:

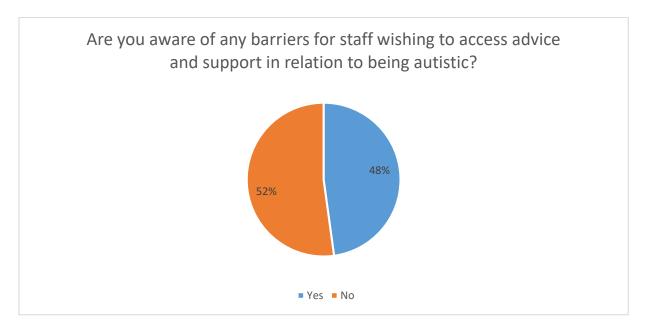
- AIM (Autism in Mind)
- Online training (unspecified)
- o BPS (British Psychological Society)
- CPD (Continuing Professional Development) through autism and Learning Disability network
- Sheffield Hallum University post graduate certificate in understanding Autism Spectrum Disorder
- Kieron Rose
- On the job training
- o Online
- Core professional training
- Reasonable adjustments training
- Planning
- o 3-5 course
- o I've had quite a bit of training over the years
- Can't remember autism awareness?

12.2 Barriers to staff support

Staff were asked if they felt there were any barriers to accessing advice and support in relation to them being autistic, with 52% of those responding stating that there were potential barriers for them.

Their narrative conveyed the following issues:

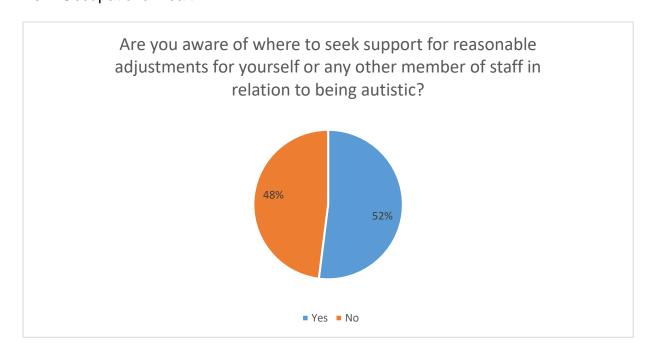
- Not knowing how to access
- Anxiety around accessing
- Anxiety around asking for support
- Unclear communication of how to access
- Stigma
- Lack of support in the first place
- o Fear that any response would be unhelpful



12.3 Reasonable adjustments for staff

Staff were asked if they knew where to seek support for reasonable adjustments, with 52% stating that they did and identifying options of:

- Discussion with line manager
- o Human Resources
- Equality and diversity representatives
- Occupational health



13. Focus Groups

The Involvement Service facilitated a series of focus groups to support further discussion and provide a platform for service users and carers who preferred this option for sharing their views. 5 key topic areas linked to the themes of the consultation documents shaped these discussions:

- 1. What does good communication from CNTW (or other care providers) look like?
- 2. What happened after your diagnosis?
- 3. Have reasonable adjustments been made for you (changes made to improve the service you receive)?
- 4. Have you used any other services in CNTW apart from the Autism service? If so, what was you experience?
- 5. Do you think CNTW is an Autism friendly organisation?

During January and February 2022, 5 focus groups were held in support of 24 attendees, 10 of whom were autistic and 14 were a carer or parent of an autistic person (1 of the participants was both autistic and a carer of an autistic person). The main themes from these discussions are provided in the tables below.

13.1 What does good communication look like?

Themes	Key Comments
1. Person Centred	Feeling listened to
	Named person for contact
	Provide clear information/expectations at all stages
	Family involvement
	Respectful
	Validate what a person is saying
	Not having to repeat story, consistent staff member to talk with
2. Accessibility	 Meeting in a safe environment to promote open communication
	Offering times suitable to person's needs
	Reducing unnecessary contact (book next
	appointment at the end of the session)
	Sensory friendly environments
3. Inclusivity	Asking the person how they would like to receive their information
	Allow people to process information
	Simple, clear language
	Asking the person how they wish to be contacted
	Staff need to be specific when asking for information
	The need for advocacy

13.2 What happened after your diagnosis?

Themes	Key Comments
1. Support	 Highlighted the lack of support whilst undergoing diagnosis (long process) Support not readily available post diagnosis Support should be timely, considered and specific to
	the person's needs More community support is needed Parity for advocacy
Continuing care expectations	 The need for follow up reviews Developmental expectation needs should be discussed Consistent information being made available post diagnosis

13.3 Have reasonable adjustments been made for you?

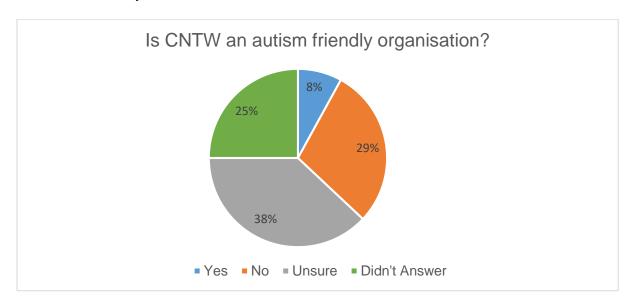
Themes	Key Comments				
1. Consistency across	Disparity within teams with knowledge and				
the Trust	understanding				
	An identified need to learn from each other				
	Standardising reasonable adjustments across sites				
2. Accessibility	Environments need to be considered				
	Lengthy waiting times to be seen (for first				
	appointment)				
	Joined up approach with school, services and family				
	to ensure consistency				
	All leaflets need to be accessible				
3. Person centred	Preparing people for appointments				
	Value the person's needs				
	Promoting a good first experience				
	Consider alternative ways to engage				

13.4 Have you used any other services apart from the Autism service?

Themes	Key Comments
1. Autism awareness	 More education is needed for staff and the general public Reactive rather than proactive Utilising people with lived experience There is a need for advocacy for Autistic people in all services
2. Communication	 Voice of the person not being heard Better communication between teams Staff need to be clear when introducing themselves

13.5 Is CNTW an Autism friendly organisation?

Focus group attendees were asked if they believed the Trust to be an autism friendly organisation, with 8% confirming that they did, compared to 18% of those completing the on-line survey.



14. Examples of Focus Groups comments

"Staff time being put aside to learn about Autism and how the service can better support. The service should have more education available for staff and the general public"

"People who have the keys to the support don't always understand Autism"

"Generally, the services offer reactive rather than proactive support. They react to something happening rather than helping to prevent it from happening in the first place"

"Positive impact of using lived experience individuals. How can we use lived experience, Peer Support Workers with Autism who can support services with making things better for all"

"Some people can be really strong at advocating for Autism and supporting others but really struggle to voice opinions and views of themselves"

"Shouldn't make assumptions of a person, should just speak to them about how they feel! There needs to be good access to advocacy for people who do not have that strong voice that others can have"

"Having someone sit with you and ask you what would help you the most, even if it was a Peer, someone who had been through the process."

"Complaints around medication from service users with Autism can often be ignored and individuals can feel like their voice isn't being heard"

"Experience has been variable. Better communication between teams would help immensely".

"A lot of services are available, but they don't talk to each other"

"Throughout the Trust staff need to introduce themselves properly, might be clear to the family that someone is a nurse but it isn't always as clear for the individual with Autism"

15. Acknowledgement

This project would not have been possible without the contributions made by autistic people, their families, staff and voluntary organisations. Significant thanks must be given to those involved in the Autism Consultation Project Steering Group, who provided the direction and considerable knowledge to effectively support the application of this project.

We must also thank the Involvement Service for their facilitation of the Steering Group and consultation focus groups, as well as those who took the time to contribute to this discussion platform.

16. Conclusion

This piece of co-produced work was commissioned to outline the current perceptions of those who use CNTW services to establish the nature to which CNTW is an autism friendly organisation. This work was also intended to make further consideration of how this work might influence the CNTW autism strategy thus ensuring that CNTW is an organisation that can be proud of its relationship with and support of the autistic community, be that people who use our services, those that care for them, and our staff, if autistic themselves, or supporting those who are autistic.

The project outcomes provide a baseline of the current position and they demonstrate that the Trust has a long way to go to be the best that it can be for the people that matter the most.

The consultation has reaffirmed that there is continuing debate in relation to how people prefer to identify themselves in respect of autism: personal opinions in respect of 'autistic person' or a 'person with autism'.

17. Suggested next steps and further considerations

We still have a way to go to make the changes that need to be made to ensure that CNTW can proudly state that it is an autism friendly organisation, with an informed strategy to meet the needs of the people that matter.

- a. The project should be recognised as a baseline assessment against which any future changes can be monitored to demonstrate further support of the strategy.
- b. The Trust might consider developing an Autism specific charter to outline its commitment to support the needs of all autistic people.
- c. The Trust should give further consideration to the use of preferred language for autistic people e.g. 'autistic people' as opposed to 'people with autism'.

In addition to these considerations, further recommendations following the themed outcomes of the consultation are as given below:

Language and Terminology:

- Removal of jargon and abbreviations from all communications
- Preferred communication methods to be established from initial referral by each and every service

Diagnosis:

- Clear pathway is identified and provides confirmation of appropriate additional support in a clear and timely manner following diagnosis
- Improved signposting at diagnosis to voluntary sector support services with the aim of reducing mental health impact

Reasonable adjustments:

Environment

- Private, safe and quiet waiting areas for individuals and their family
- Maps provided in advance of appointments
- Clear accessible signage to relevant service on sites (which is consistent to any communication i.e. appointment for 'bloods' yet signage is 'phlebotomy')

Process

- ➤ Advance notice of what will happen in an appointment and an offer of reasonable adjustments
- > Appointment times are adhered to by services
- > Consideration of extended sessions and out of office scheduling where possible to reflect needs

Staff:

- > Standardised, coordinated, co-produced and co-facilitated staff training
- Consideration of mandatory staff awareness training
- Consideration of support for staff who are autistic to obtain reasonable adjustments

CNTW Autism Consultation Project Consultation Document

This consultation is anonymous, w have told us.	/hich me	eans that no-one will know w	hat you				
About you							
If you are happy to do so, please le the following questions.	et us kno	ow a bit about yourself by an	swering				
1. Would you consider yourself to appropriate to you):	be (ple	ase identify as many options	as				
An Autistic Person		A person who has Autism					
A carer or family member of someone who is autistic or a person with autism		A member of staff					
2. Which locality do you live in?							
North Cumbria		North (Northumberland and North Tyneside)					
Central (Newcastle and Gateshead)		South (Sunderland and South Tyneside)					
3. Which services have you receive	ved care	from, if this applies					
Prefer not to say							
4. Which service/ward do you wor	rk in, if t	his applies					
		Prefer not to say					

5. Is there anything else you would like to tell us about you?					

Section 1 – Language and terminology

How the Trust communicates with you or your family before and during an appointment.

1. How has CNTW communicated with you before an appointment? (please tick as many as apply)					
Telephone call		Video call			
Text		Letter			
Face to face		Not applicable			
Other (please state)					
2. What is your preferred style of	f contact	? (please tick as many as app	ly)		
Telephone call		Video call			
Text		Letter			
Face to face		Not applicable			
Other (please state)					
2 What has been seen as a single		dia	al lass		
3. What has been your experience CNTW services in relation to:	e or wor	aing and communication use	ару		
Signage (e.g. are signs clear and easy to follow)					
Posters and leaflets (e.g. are they easy to read and follow)					
Staff (e.g. when they talk to you are staff easy to understand)					
Written communications such as letters and reports (e.g. are they easy to read and follow without jargon and abbreviations)					
Do you have any other comments in relation to communication?					

4. What do you think would help improve communications with autistic people in relation to:				
Signage (e.g. are signs clear and easy to follow)				
Posters and leaflets (e.g. are they easy to read and follow)				
Staff (e.g. when they talk to you are staff easy to understand)				
Written communications such as letters and reports (e.g. are they easy to read and follow without jargon and abbreviations)				
Do you have any other comments in relation to how communication could be improved?				
appointment regarding la	hat could be done to help autistic people at an nguage and terminology? For example, how and having a written action plan?			

Section 2 – Diagnosis: What next?

Diagnosis is the process of determining which condition explains a person's symptoms.

1. Was your autism diagnosed by CNTW? (if no, please go to section 3)								
Yes		No Not applicable						
	2a. When you were diagnosed how was this communicated to you (such as a letter, call, email, verbally)?							
2b. How did yo	u feel your	diagnosis was	explained [·]	to you?				
3. Did you feel care?	that you kr	new what the ne	xt steps w	ere in relation to	your			
Yes		No		Not sure				
4a. Did you fee (signposting)?	l you were	made aware of a	additional	support availabl	le			
Yes		No		Not applicable				
4b. If yes, what	informatio	on or support we	ere you info	ormed about?				
5. Were reason	able adjus	tments discusse	ed?					

Yes		No		Not sure	
5b. If yes, what	reasonabl	e adjustments v	vere discus	ssed or put into	place?

Section 3 – Reasonable adjustments: Admission, therapy, staffing and environment

A reasonable adjustment is a change that is made to improve or enhance the service you receive, taking into account your particular needs, to prevent disadvantage.

1. Do you think CNTW is an Autism friendly organisation?							
Yes		No			Not sure		
2. Do you think CNTW asks how it can help autistic people based on their needs?							
Yes		No	0		Not sure		
3. Which reason provide for auti					W services need	l to	
Maps of hospital	sites			Staff introd	ductions		
Adapted commu	nication				Clearer, jargon free letters and reports		
Clearer signage				Quiet area	Quiet areas / safe spaces		
Letters with expl expectations	anations of			Location of advance			
Other (please sta	ate)						
4. Is there anything CNTW staff could ask autistic people and their carers when discussing reasonable adjustments?							

Section 4 – Consistency and parity across localities and services: facilities, awareness and acceptance

Equal access to the most effective care and treatment. 1a. Have you, a family member or person you care for ever been offered reasonable adjustments when contacted by CNTW in advance of attending services? (for example, offering a sensory friendly quiet area) Yes No Not sure 1b. If yes, which of these adjustments were offered Sensory friendly quiet areas Adapted Communication Choice of where appointment will take place Other please state 2. Which reasonable adjustments would you like to see more of? Sensory friendly quiet areas **Adapted Communication** Choice of where appointment will take place Other please state 3. Have you ever been made to feel uncomfortable or disadvantaged when accessing CNTW services? Yes No Not sure 1a. Have you or the person you care for received care from more than one service within CNTW? Not applicable Yes No

1b. Do you think the same standard of care was provided across these services?								
Yes		No			Not sure			
2. If yes, which of these adjustments were offered								
Sensory friendly quiet areas			Adapted Communication					
Choice of where appointment will take place								
Other please sta	ite							
3. Which reasonable adjustments would you like to see more of?								
Sensory friendly	quiet areas	8		Adapted C	Communication			
Choice of where take place	appointme	ent will						
Other please sta	ite							

Section 5 – Staff knowledge, skills and experience: co-produced and co-delivered training

The understanding of autism through education or work experience

1. Do you think that the staff who provided care to yourself, a family member or someone you care for had knowledge and understanding of Autism?								
Yes		N	0		Not applicable			
2. Where do you feel are the biggest gaps in staff knowledge and understanding?								
3. What do you	think migh	nt help s	taff imp	rove their	knowledge?			
4a. Do you think autism specific training should be mandatory for all staff?								
Yes		No			Not sure			
4b. If you are a member of staff, what are your preferred options for accessing training?								
E-learning	E-learning			Microsoft Teams				
Face to face (co-facilitated with autistic people)			Videos					
Other (please state)								

Section 6 – Working in CNTW

Section to be completed by CNTW staff only

1. Do you currently work in CNTW?							
Yes		No					
2. Have you ever been provided with any autism training?							
Yes		No					
Please specify							
3. Are you aware of where to seek support for reasonable adjustments for yourself or any other member of staff in relation to being autistic?							
Yes		No					
Please specify							
4. Are you aware of any barriers for staff wishing to access advice and support in relation to being autistic?							
Yes		No					
Please specify							
5. If you have invited candidates to interview, have you offered reasonable adjustments throughout the recruitment process?							
Yes		No					
Please specify							

