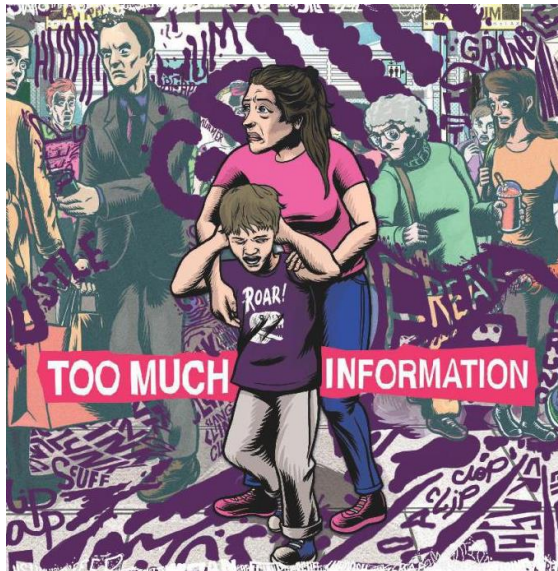


Images by the [National Autistic Society](#)



I'M NOT NAUGHTY. I'M AUTISTIC.

Scoping paper on services for people with Autism

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1. Introduction

This scoping paper represents an initial view of Autism Spectrum Disorder (ASD) and ASD services within Norfolk. The purpose of this document is to bring together information and evidence to form an understanding of Autism services and identify any areas of concern or gaps across services. To provide a justification if further work for Healthwatch Norfolk in working with adults, children, young people and families who have Autism is required.

Services for people with ASD has been identified as one of the three Healthwatch Norfolk 'priority projects' for the financial year 2017-2018. ASD services had been raised as a concern in recent years and we have been involved in limited meetings focused on ASD services in Norfolk and we continue to receive comments about services for people with ASD. This comes at a time where The Norfolk Autism Partnership Board (APB) has developed a Norfolk All Age Autism Strategy, in response to the National Autism Strategy, which aims to reflect the local need. This is currently underway and a process we hope to feed into.

2. National Context

2.1 What is autism?

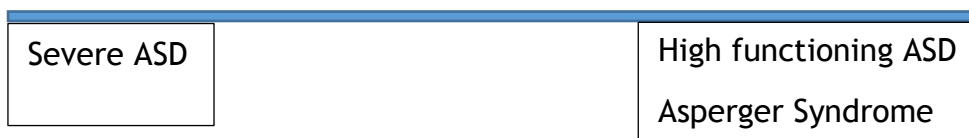
Autism is a spectrum condition and is often referred to as Autism, Autism Spectrum Disorder (ASD) or Autism Spectrum conditions and is often used interchangeably. There are many definitions of Autism and commonly in the United Kingdom (UK) is defined as a lifelong developmental disability that affects how a person communicates with and relates to other people and how they experience the world around them (NAS, 2017). Similarly the Autism Society of United States of America (USA) defines ASD as:

“Autism spectrum disorder (ASD) is a complex developmental disability; signs typically appear during early childhood and affect a person’s ability to communicate, and interact with others. ASD is defined by a certain set of behaviours and is a “spectrum condition” that affects individuals differently and to varying degrees”. (Autism Society of USA, 2016)

For the purposes of this report I will refer to autism as ASD. There are many myths surrounding autism and every individual with ASD is unique but they commonly present difficulties in three areas; Social interaction, social communication and imagination/repetitive behaviours and activities. **Autistic people see, hear and feel the world differently to others.** For individuals who are autistic, they are autistic for life; as ASD is not a disease or illness and cannot be cured. Often people feel that their ASD is a fundamental aspect of their identity. A formal diagnosis of ASD is used to understand individual's difficulties for both adults and children.

Over many years there has been a wide range of terms used and diagnosis labels associated with ASD such as autism, ASD, ASC, classic autism, high-functioning autism. This demonstrates a dependence upon which diagnosis tools have been used, commonly in the USA they use the American Psychiatric Association (APA) produces its own diagnostic manual, the Diagnostic and Statistical Manual of Mental Disorders

(DSM) which also influences practice here in the UK. The UK also commonly uses the World Health Organisation's International Classification of Diseases (ICD) criteria (ICD-10) as well as the DSM. Recently released the DSM-5 contains key changes to the diagnostic criteria meaning that previously autism and Asperger's syndrome were considered a separate diagnosis, yet the DSM-5 now encompasses all these terms under one umbrella term of Autistic Spectrum Disorder (ASD). This means that these different profiles make up the ASD profile from Severe ASD to High functioning ASD (Aspergers). Although ASD is now the most commonly given diagnostic term.



2.2 Prevalence of Autism

ASD is more common than people may have first thought the National Autistic Society (2016) suggest that there are approximately 700,000 people living in the UK with ASD. All figures are based on prevalence data on ASD. Another often reported figure is that that equates to 1 in 100 people however ASD appears to affect more males than females. These statistics are further confirmed as a new estimate for the prevalence of autism among adults 18 and over was established at 1.1% nationally (NHS Digital, 2012). This was derived from the Adult Psychiatric Morbidity survey 2007 in combination with another new study of the prevalence of autism among adults with learning disabilities. Knapp et al. (2007) suggest that there are around 100,000 children with ASD in the UK. Whilst four times as many boys as girls are diagnosed with ASD (ONS, 2004).

2.3 Legislation

There are a number of legislations in place across the UK and government policies focused on ASD, all of which follow this time line:

-
- **2009 Autism Act-** the first ever disability-specific law in England, placed a duty on government to produce a strategy.
 - **2010, Autism strategy - Fulfilling and rewarding lives: the strategy for adults with autism in England.** *The Government produced the first autism strategy for England.*
 - **2010, statutory guidance published:** *Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy.*
 - **2011-2012 NICE guidelines:** - Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, NICE clinical guidance. - NICE Guidance, Autism in under 19s: recognition, referral and diagnosis (2011), Autism in adults: diagnosis and management (2012).
 - **2014, Think autism strategy-** *update to 2010 strategy.*
 - **The Children and Families Act 2014 - a new special educational needs and disability (SEND) support system, covering education, health and social care.**
 - **2015, statutory guidance.**

2.4 How ASD affects individuals

For some autistic people the world feels very overwhelming and as a result this can cause them considerable anxiety, therefore everyday life can prove quite challenging and harder. They have difficulty relating to others and many autistic people begin to wonder why they are different, as a result can feel that others do not understand them. Other people seem to know, intuitively, how to communicate and interact with each other, yet they can struggle to build rapport with autistic people. Typically for some parents of a child with ASD say that others think their child is simple a 'naughty child' and autistic adults often find they are misunderstood.

Generally speaking, autistic people have difficulties with social communication, interaction and imagination. Consequently they may face some of the following challenges:

- Interpreting both verbal and non-verbal language like gestures or tone of voice.
- May not understand jokes and sarcasm.
- Difficulty 'reading other people and therefore it's difficult to recognise and understand others feelings. They have difficulty expressing their own emotions.
- They may find it hard to form friendships and maintain relationships as they may want to interact with others but are unsure how to.
- They may not share interests with others and as a result may appear unresponsive or disengaged.
- They may have unusual or absent eye contact and expressions.
- They may find it difficult to start and maintain conversations.
- They will often understand more of what people say to them, than they are able to express.
- Some may have limited language, limited speech or no speech at all and communicate through alternative methods such as sign language.
- Some language may be repetitive.
- They may struggle with vagueness and think very literally as they prefer routine.
- They may have a fascination with objects and can be skilled in some non-social domains.
- They need more time to process information and act.
- They may appear uncomfortable with others and behave in ways that are seen as socially inappropriate.
- Many autistic people have intense and highly-focused interests, which can change over time such as art or music, to trains or computers.
- Autistic people may also experience sensory issues and may be over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain.
- May seek out time to be alone or prefer to be alone.

Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the ASD spectrum learn and develop and with the right sort of support, all can be helped to live a more fulfilling life.

2.5 Education and schooling

It's suggested that 70% children with ASD are in mainstream schools and the rest in special provision, yet there still is a lack of understanding of ASD in schools. In recent months it has been raised that ASD training and awareness has been missing in all teacher training and it was proposed that they add this to teacher training programmes, but there is little evidence of this so far. Particularly, as it's reported that 60% of teachers in England don't feel they have had adequate training to teach children with ASD. Yet only 11% of children with SEN in state funded schools have a diagnosis of ASD (DFE, 2014). Whilst 35% of teachers do believe it has become harder to access specialist support for children with ASD. Another concern is that children with ASD are at risk of exclusion from schools and education and are often subjected to bullying due to their ASD.

2.6 Other Healthwatch's:

As Autism is such a broad topic its unsurprising that there may be other local Healthwatch's out of the 152 that may have looked into their ASD services locally. Nationally, since 2014 33 local Healthwatch's have spoken to people to understand their experiences of ASD services and what improvements can be made. From this there are four many themes of concern, understanding and knowledge, waiting times, support for parents and carers and Communication and co-ordination. It was evident that across the country there is a lack of consistency of pathways of diagnosis and support for children and young people and there as no one unified service for ASD.



Image by Josh Johnsen from [Ambitious about autism](#)

3. Local Context

3.1 Population

As a county Norfolk has a population estimate of 892,900. It's believed that 169,300 of those are children aged 0-17 years old (Norfolk Insight, 2016). Nationally it is recognised that 1 in 100 people have Autism with a prevalence rate of 1.1%. There is little specific data that highlights how many children locally have ASD in Norfolk as this information is based on prevalence data alone. However, for adults in Norfolk it is estimated that 5,418 adults in Norfolk are predicted to have ASD by 2020 with 713 of these adults aged 18-24 (Public Health, 2011).

3.2 Norfolk ASD services commissioning

There is differentiation across Norfolk with the presence of 5 Clinical commissioning groups (CCGs). As a result, ASD services are not the same across the county and are dependent upon where you live, so there is no one pathway for people with ASD in Norfolk. ASD services in Norfolk are commissioned by CCGs as a block contract with providers and all contracts run until March 2019. In comparison, in one area of Norfolk ASD services are commissioned from the local acute trust. In Norfolk ASD services are for both children and adults but there are key limitations to this that we need to be aware of.

3.3 Adult's ASD services

Across Norfolk there is no adult service for adults with Autism. The only service that exists for adults is a diagnostic service for adults with Asperger's syndrome (a form of what used to be known as 'high functioning autism') and the service is called **Asperger Service Norfolk (ASN)**. ASN is jointly commissioned by CCGs and Norfolk County Council (NCC) provided by Norfolk Community Health and Care (NCHC). The service contains three main components; diagnosis, support and social care and as a result other organisations are involved and make up this service. NCHC undertake the diagnosis element of the service, whilst NCC are involved in the social care aspect of the service. Finally Asperger East Anglia provide the support for post diagnosis and pre-diagnosis. Asperger East Anglia are a charity that provide support, advice, guidance, information and training to individuals affected by Asperger syndrome across all of Norfolk.

Individuals would be referred to ASN via a health or social care professional, usually by a General Practitioner (GP). Following receipt of a referral, these referrals are then assessed and triaged for priority as there is a waiting list in place within the service. Diagnosis is undertaken by a clinical psychologist and again this is purely a diagnostic pathway for adults. But where appropriate adults will be assessed for additional support through a social care assessment as this service provides a package of advice, care planning and support. For those adults waiting for a diagnosis on the waiting list the service also holds educational events to give adults an understanding of Asperger's and how to live life with Asperger's syndrome.

This highlights a gap in provision of services for adults with autism in Norfolk which is something we have received little feedback from the public. Only in recent months have we been made aware of this concern raised by a member of the public.

3.4 Children's ASD services

In March 2017 it was acknowledged that all children's and young people services based at Upton road have been permanently relocated to Norwich Community hospital since April 2017. The children's ASD diagnostic pathway service and the children's ADHD Psychology service were both affected by this relocation and now reside at the Norwich community hospital.

Recently all 5 CCGs have agreed to collaborate with a single leadership team for children's, young peoples and maternity services in Norfolk. This is targeted to improve integrated working across the county of Norfolk and Great Yarmouth and Waveney CCG (GYWCCG) are leading this. ASD diagnosis pathways in Norfolk focus on assessment and diagnosis specifically for children and young people and there is some variation in these pathways. This indicates that there is no single pathway that covers the county, so therefore the route patients take will depend upon where they live in Norfolk. Due to this factor, there are two routes to ASD diagnostic services for children in Norfolk. For the case of this scoping paper I have identified these pathways as Pathway A and Pathway B. Pathway B provides one route for residents living in GYWCCG, whilst Pathway A covers the rest of Norfolk including Norwich CCG (NORCCG), North Norfolk CCG (NNCCG), South Norfolk CCG (SNCCG) and West Norfolk CCG (WNCCG).



3.4.1 Pathway A

A new pathway for 'assessment and diagnosis of autism for children and young people' was designed in 2012 for all CCG areas except GYWCCG. This was following the publication of new NICE guidance in 2011 on recognition, referral and diagnosis of autism in children and young people. The pathway was developed collaboratively with health, education and social care providers and was then later updated in 2016 to 'pathway for referral assessment and support of possible autism in children and young people'. This was due to the restructuring of services locally and further NICE guidance updated in 2013.

Currently the main pathway for ASD diagnostic services in Norfolk (Pathway A) covers 4 out of the 5 CCGs and is provided by Norfolk Community Health and Care (NCHC). This comprises of three ASD diagnostic pathways (see Appendix 7.1):

- ASD Diagnostic Pathway: Age 1-5
- ASD Diagnostic Pathway: Age 6-18
- ASD Diagnostic Pathway: Child and Adolescent Mental Health Services (CAMHS) for children with a mental health disorder.

Pathways for children aged 1-18 are provided by NCHC and the CAMHS pathway is provided by Norfolk and Suffolk Foundation Trust (NSFT) with the exception of Thetford, in which services are commissioned from Suffolk Community Healthcare

(HOSC paper, 2017). This is an issue we need to bear in mind throughout the project to quantify if there are any differing experiences.

These pathways (Pathway A) comprise of a multidisciplinary team that's delivered by paediatricians, clinical psychologists, specialist nurses and family support workers alongside speech and language therapy, psychology and teacher support. For families to access an ASD diagnosis for their child they must be referred by their GP to a community paediatrician for an initial general assessment. Recognition of concerns of the child's development may be raised by Health visitors, family, early year's settings, GPs or schools. This referral will then lead to an initial general assessment which is used to determine if a full ASD diagnosis assessment is warranted. This general paediatrician assessment will result in the child being seen by a community paediatrician, clinical psychologist or nurse initially and this is aimed to be within an 18 week waiting time.

If it's indicated that it's likely the child may have ASD, then the referral is passed to the ASD pathway (NCHC) and multi-disciplinary team. They will then look to gather further information from the referrer, parents, early year's settings, and schools. This referral then needs to be accepted based on the information provided. Those children that do not meet the requirement for a full ASD assessment will then be referred to an alternative service. In a full ASD assessment the child will be seen by two professionals in different environments and this assessment will be NICE compliant. Once the child has their assessment, feedback will be given face to face regarding the outcome of the assessment to the parents and carers. Each family then receives a post diagnostic support meeting with 6 weeks after their child's diagnosis for advice and information.

For those accessing the CAMHS pathway the child may already be known to the CAMHS service. In these instances where the question of ASD is raised CAMHS will liaise with the ASD pathway/panel to plan the assessment and in some instances may complete the diagnostic work, whilst the ASD co-ordinator will register the request for an assessment.

3.4.2 Sensory processing and Assessments

All ASD diagnostic assessments undertaken by NCHC include a general assessment of children's sensory sensitivities, particularly as many children with ASD have difficulties with sensory issues. However, in Norfolk Sensory Integration Therapy (SIT) is not routinely funded. SIT has been a subject of controversy as there is little scientific evidence to support utilising SIT. Norfolk Public Health were asked to review SIT and make recommendations to inform future evidence and funding, in 2014. They found there is no national guidance for SIT and a lack of evidence surrounding cost effectiveness.

3.4.3 Pathway B

In 2016 GYWCCG carried out a community paediatric review which resulted in positive feedback. The ASD Pathway in GYWCCG has always been provided as part of the community paediatric. This then resulted in a review of the ASD pathway and skill mix available within the area and consequently there has been a redesign of the pathway for individuals trying to access an ASD diagnosis in GYWCCG, resulting in greater collaboration between NSFT & James Paget University Hospital (JPUH). As a result of this they have also developed a neurodevelopmental assessment clinic for under five year olds and this new service has helped reduce delays for patients.

One component that's not evident in pathway A is a parent and carer voice. This is something GYWCCG has recognised and a new addition to this ASD pathway was to introduce a parent carer forum, which meet quarterly to embed parent's voice into the ASD service.

This new pathway and service has now been implemented (see Appendix 7.3). This is an integrated pathway that provides multi-disciplinary assessments based on NICE guidance to make a diagnosis. The pathway is a joint pathway integrating CAMHS into on single pathway. This joint pathway is called: *Joint pathway Child, family and young people mental health services (CFYP) and community Paediatrics for diagnosis and ongoing support for CYP with neurodisabilities.*

This new pathway enables children to be referred to one single point of access by their GP across Great Yarmouth and Waveney. This means that all children are referred to the same point. Referrals are then jointly triaged by a community paediatrician and CFYP for mental health input. Where an ASD assessment is necessary, the route the child takes will be governed by their age. For children under five they attend the new neurodevelopmental assessment clinic at the Newbury child development centre in Gorleston where joint assessments by the paediatrician, speech and language therapist and psychologist are undertaken. For children aged over five years, this is undertaken by a Great Yarmouth and Waveney multi-disciplinary group consisting of a paediatrician, a speech and language therapist and a psychologist. Schools now also have to provide an educational psychology report before they refer into the community paediatric service, which is then considered at the multi-disciplinary group.

Following assessment feedback is given to families face to face. Follow up is then arranged by the community paediatric team. In GYWCCG they also commission Family Action to provide support for families awaiting for a diagnosis and post diagnosis, they provide positive behaviour support programmes.

3.5 Post diagnostic support in Norfolk

Post diagnostic support is limited nationally and particularly so in Norfolk. As identified earlier the ASD services in Norfolk are specifically designed for diagnosis and assessment and those pathways do not provide post diagnostic support. Much of the post diagnostic support comes from the voluntary sector which has caused

concern as many of these organisations are not funded to provide tailored post diagnostic support.

NCC provide parent support programmes for parents and carers with an ASD diagnosis for their child. From this statement it is clear this identifies another gap in provision in support that parents are able to access. Particularly so if their child does not have a diagnosis of ASD yet it's suspected they may have ASD, where can those families get support? Currently there are two parent support programmes offered by NCC and others; Early Bird and Cygnet.

Early Bird- Is a NAS Registered training programme that's delivered locally in Norfolk by East Coast Community Healthcare (ECCH) and NCC. This is an 11 week programme for parents and carers of pre-school children (Children under the age of 5) who have a diagnosis of ASD and the programme is held in venues in Norwich and Kings Lynn.

Cygnet- This is the next free parenting support programme for parents and carers whose child has a diagnosis of ASD for school aged children (7-18 years old). This is a five week course that is jointly delivered by health and education.

According to NCC website they also provide the Norfolk Steps and Norfolk Steps-positive handling training, however it seems that this programme may no longer exist in Norfolk. The Norfolk steps programme is for parents and carers that have a child with Special Educational Needs (SEN) whose behaviours are challenging and are aged 4-18 years old. This is a two session programme that's designed for parents and carers to better understand their child's behaviour. This indicates another gap of provision that there is limited if not no support around behaviour management and challenging behaviour, that parents are able to easily access regarding their child's ASD. Another concern is that this information is still displayed on the NCC website advertising its availability. Also when browsing through the NCC website at the autism pages its concerning that there is no record of how parents can access these courses other than the support events page '*Dates/times/venues for the sessions are advertised within our [Support events](#) page*' that people are directed to that does not contain any information about these support programmes.

3.6 Voluntary Sector ASD services

Across Norfolk there are a range of voluntary sector organisations that support local parents and families whose children have ASD, there is no definitive list of these services as services in the voluntary sector are ever changing. These are just a few of the main charities that have a presence in Norfolk:

- **West Norfolk branch of National Autistic Society (NAS)** - *The National Autistic Association is the UK's leading charity for autistic people and their families. They provide information, support, services for Autistic people and campaign to make the world better for Autistic people (National Autistic society, 2017).* The West Norfolk NAS is a voluntary charity run by parents and carers who all have children on the ASD spectrum and currently have 300 member families across West Norfolk. Locally they arrange various activities for families and individuals affected by ASD such as swimming, play barn sessions and music sessions. They also have daily coffee mornings, training courses and workshops to support parents and carers.

- **Autism Anglia** - Is a regional charity which provides a wide range of autism specific services to children, adults and families. The charity aims to raise awareness and understanding of Autism through events, signposting and by providing training to professionals and organisations. They also provide a range of services to enable autistic people to live independently and maintain a dedicated autism advice line that has no funding and relies on fundraising locally. The charity covers all of Norfolk with a small team and have a regional head office and Doucecroft school in Colchester, with the Norfolk office based in Dereham. For parents without an ASD diagnosis for their child this services is limited on advice they can give (Autism Anglia, 2014).
- **Asperger East Anglia** - Offers assistance for everyone with or suspected to have Asperger syndrome working with people of all ages across the whole county of Norfolk based at the Charing cross Centre in Norwich. They provide an integrated service that works in partnership with other services and the NHS as they are a key partner in the Asperger Service Norfolk providing pre and post diagnosis support. They also provide support for Education, adult services, diagnosis whilst maintaining child and youth groups and adult support groups. This is currently a stretched service due to funding and staffing resources.
- **ASD Helping Hands** - Is a voluntary organisation that offers a wide variety of individual support packages which includes guidance, practical advice and support for families, children and young people affected by ASD. This organisation is based in Dereham and provides support across the county, they also have a range of family support groups and youth groups aimed to provide support for all. They support individuals at any stage of the diagnosis process and including support for all across the spectrum including Attention Deficit Hyperactivity Disorder (ADHD) and co-morbidity conditions through their family support team.
- **Sunbeams Play** - this charity was set up as it was revealed that there was a lack of provision in the East to provide a safe environment for children to access to enable parents and carers respite. They provide a fun, safe and caring environment for children and work on a 1:3 staff ratio and can take 15 children in one session. They are Ofsted registered and provide support for children aged 3-19. They provide a weekly parent support group and give information and advice on diagnosis, education, benefits and behaviour. They also offer parent programmes and training to parents and professionals and are based in Great Yarmouth (Sunbeams Play, 2017).

3.7 Current status and capacity of Norfolk ASD Services

3.7.1 ASN service: ASN is the only diagnostic service for adults in Norfolk for those with suspected Asperger syndrome. When adults are referred to the services they are placed on a waiting list and triaged based on priority. It is evident from talking to staff from Asperger's East Anglia that there are frustrations with delays in assessments and a possible length of 2 years, to receive a diagnosis and be discharged from the pathway.

3.7.2 Pathway A: (NNCCG, SNCCG, WNCCG & NORCCG ASD service)

At the NHOSC meeting the leaders of the service recognised that services have not kept up with local need, so they are working with NCHC to ensure there is greater scrutiny and oversight upon the service. **CCGs have agreed to provide more funding to increase staff for assessments to address issues currently.**

Demand

Over the last 5 years demand for ASD diagnosis assessments has increased which the service believes is due to greater awareness of ASD pathway by families and referrers. Plus increased parent expectations of post diagnostic support, thinking they will receive further support once their child is diagnosed. They also suggest that parents believe "in the value of a diagnosis as a means to leverage disability benefits as well as further educational and social care" p116 (NHOSC, 2017). NCHC indicate that their recent yearly figures from 2015- 2016 and 2016-2017 have not shown a significant change in the overall number of referrals, therefore they believe this may be plateauing with effective triage in place they report 80% of children are accepted for a ASD assessment.

Diagnosis delays

Despite this, it's still evident that diagnosis for ASD is taking too long and as a result they now have a backlog of referrals: (Data from August 2017)

- Almost 300 cases are still waiting to begin their assessment.
- The pathway can only accept 150 assessment at any one time.
- Many families are experiencing a wait of at least two years from acceptance for assessment to completion of the process.
- Currently there is a total of **639 children** that are awaiting discussion or assessment (see Appendix 7.2).
- The current waiting times from first GP referral to a generic assessment by a paediatrician, are aiming to meet the 18 weeks target within the next two to three months.
- The length of time for assessment may be variable depending on the age of the child. The timescale for an ASD assessment to be completed is dependent on each patient, currently this can be a maximum of 24 months.
- The main waiting times seem to be for children aged 4-18 who have been accepted for a full ASD assessment and are waiting (see table 1).
- Approximately 90% are waiting for specialist ASD assessment.

Other concerns:

- NCHC also highlight that a significant number of cases are waiting more than eight months for their first or second assessment to complete their diagnosis.
- Since April 2017 there has been no programme of support available to families while their child is waiting for their diagnostic assessment to complete and this is currently under review by the CCGs.
- There is no patient/parent/carer feedback from this service and this was highlighted as a concern at the NHOSC meeting. The CCGs said that they are looking to try an initiate a group for this.
- Since 2014 - 53 complaints recorded by NCHC, main themes include:
 - 1) The length of wait for an assessment.
 - 2) Support for emotional/behavioural difficulties associated with autism.
 - 3) Non-confirmation of independent assessments. There are rarely any complaints about the quality of the current service provided.

3.7.3 Pathway B

Following national issues with recruitment of community paediatricians, locally paediatricians work across both community and acute care. The team have also managed to recruit further staff including SALT and psychology to add to the skill mix. In GY&WCCG they report that between 2009-2015, 541 children/young people have been diagnosed with ASD. At this time, there is 322 children who have a diagnosis of ASD in Great Yarmouth and Waveney (JHSC, 2017). There are a further 151 children in Great Yarmouth and Waveney who have received a new diagnosis of ASD.

Waiting lists and waiting times are also evident in this pathway. In 2016, Pathway B recounted waiting times of less than 18 weeks between referral and assessment. Currently the waiting time is 12 weeks which identifies an improvement upon last year. For families awaiting for feedback upon diagnosis and assessment after an assessment has taken place, the current wait has been reduced to eight months. This is an improvement on the previous year's waiting times of one year. Families now also have the support of the neurodevelopmental assessment team whilst assessments are being undertaken and it's reported to have received positive feedback from families. This new service and model pathway has been discussed at the parent and carer forum (in February, 2017) and has received positive feedback from parents and continues to do so.

3.7.4 Voluntary sector

It was clear from communication we have received from a limited number of voluntary sector organisations that support and champion the needs of local people with autism, that the voluntary sector is under strain locally. Voluntary sector services are being asked to provide addition support that they just don't have the capacity to undertake. They are not funded to provide post diagnostic support and funding for many is limited and they therefore rely on fundraising and donations. Particularly services such as Asperger East Anglia and ASD Helping Hands.

3.7.5 Post diagnostic support

Across Norfolk its evident post diagnostic support is limited, yet this is something that many parents would benefit from and place value in. Training support programmes of Early Bird and Cygnet are available to parents, however availability is unknown and waiting lists are also in place locally. This is all at a time where parents, carers and families have received some life changing news of a diagnosis of ASD; early intervention and timely support is critical. Currently, pathway A provides one session of post diagnostic support within 6 weeks of diagnosis. We are led to believe that this support may take the form of a group session presentation style event, held in Norwich and Norwich alone. It's rumoured that parents often don't access this support due to its location, particularly when you consider the breadth of the county. Plus it's believed that if you can get post diagnostic support right for children then this is likely to lead to a possible decrease on needs later in life on adult services.

3.7.6 Parent service user feedback

Parents and carers whose children are accessing these ASD services across the county have views and experiences that shape what we are aware of locally:

- Lots of parent support groups out there are voluntary run. Pathway B has a parent forum linked to the pathway. Yet for Pathway A there is a **clear lack of parent and carer feedback** - no forum.
- CAMHS pathway service can cause problems as many behaviours can be highlighted as a result of their supposed ASD therefore are no longer able to access CAMHS services so are dropped off the list. Many may need CAMHS support but may not be accepted because of their ASD.
- There's a gap in CAMHS support as many children are signposted to Point 1 but the service says they can't meet their needs and deal with demand, consequently no support is provided.
- Parents are frustrated by delays with diagnosis and lack of communication during the process is evident, consequently they feel let down by services.
- Post diagnostic support is lacking- 1 session is provided as a follow up in a group presentation style event, believed to always be held in Norwich. Location is an issue with a big county of Norfolk.
- Post diagnostic training programmes have waiting lists and there are concerns about changes to the way parents can now access these.
- Parents want SIT therapy and unable to access as there's no national guidance. Many are paying and working with SENSI to get the service.
- There's a lack of understanding in GPs and poor awareness of where to make referrals to.
- Parents find it hard to get an Education, Health and Care Plan (EHCP) with or without a diagnosis.
- There's a lack of understanding across schools.
- Parents find it difficult to access respite for their children.
- Lack of understanding across services locally and need timely support.
- Concerns have been raised regarding SALT services and patient/parent dissatisfaction with the service, particularly around issues concerning continuity of care and delays.

- Some Norfolk dentistry services seem to support autistic patients well in Norfolk.

There are some possible gaps across ASD service in Norfolk that have become apparent from this scoping paper:

- Timely support, no adult services for ASD generally (diagnostic)
- No All age autism strategy yet in place
- Lack of understanding across services and lack of referral awareness
- Lack of post diagnostic support

3.8 Autism under the spotlight in Norfolk

The landscape and awareness of ASD services in Norfolk is quite a complex area that has been brought to the attention of local services, organisations and committees across Norfolk. Autism services is very much in the spotlight in Norfolk. Autism Services has been on the agenda this year and last year at the **Norfolk Health and Overview Scrutiny Committee (NHOSC)** and the **Great Yarmouth & Waveney Joint Health Scrutiny Committee (GY&WJHSC)**.

Autism was added to NHOSC future work agenda in February 2017 following concerns raised by a member about waiting times for assessment and diagnosis and the availability of treatments. NHOSC last looked at Norfolk ASD services in October 2012 following a scrutiny review after initial concerns were raised by Autism Anglia in 2011. Following the NHOSC meeting on 7th September where ASD services were discussed, it was raised that the committee wanted an update on ASD services the CCGS have recognised the service is stretched and as a result are submitting more resources and funding to support this service. Therefore, the NHOSC has requested that an update on ASD services in the near future.

The GY&WJHSC looked at ASD services in July 2014 and again in July 2016 where waiting times, diagnosis cases, capacity and resourcing were all discussed. Back in July 2016 it was the CCGS intention to undertake a full clinical service review of ASD services, there were concerns regarding difficulties recruiting community paediatricians. There was concern regarding commissioning across Norfolk and Suffolk for ASD services as services in Great Yarmouth and Waveney would be working with two county councils. An update was reported back to the GY&WJHSC on progress in July 2017 highlighting that many actions were requested from that meeting and they have listened to the concerns and a number of improvements have been made.

Further development of ASD services in Pathway A is currently underway and highlighted at the recent NHOSC meeting due to a recognition that the service is under severe strain and therefore cannot keep up with the demand for assessments, leading to a number of children and families waiting for long durations for a diagnosis. The CCGS have recognised this and are putting additional resources in place to address the backlog of assessments and concerns in this area of the diagnosis pathway. It is key we are aware and understand that currently work is underway to improve this pathway in Norfolk and it will be crucial to monitor and receive an update on this throughout the project.

CAMHS services are undergoing a complete redesign- key mental health commissioners have highlighted that *ALL CAMHS services* are currently undergoing a redesign of services. This will also include the ASD CAMHS pathway. This is key that we are aware of this process throughout the project and can therefore be mindful of it. Finally, there is **the Norfolk Autism Partnership Board (APB) - and the development of a Norfolk All Age Autism Strategy**. In Norfolk we currently don't have an Autism strategy and so the APB are currently developing this. Another area of consideration is the recent Family voice report to NHOSC on 7th September on Speech and language therapy (SALT) services in Norfolk resulting in a high percentage of dissatisfaction amongst parents and carers whose child has accessed the SALT services.

4. Key lines of enquiry for Healthwatch Norfolk

'*Services for people with Autistic Spectrum Disorders (ASD)*' has such a wide ranging focus for this topic of concern, therefore there are many directions this project could take. It seems ASD alone is a complex condition, meaning that what works for one individual will not work for the next as every individual is unique. ASD affects people differently. It was also evident that locally there are many influencing components that form the ASD services leading to multiple ASD diagnostic pathways across Norfolk. These pathways could make these services difficult to navigate for both professionals, families and children. The limited research we have undertaken to date has clearly demonstrated that ASD is such a wide spectrum and this topic alone could warrant further work, far more than can be achieved in the short period of this project. This is why it is important to highlight key areas of concern for Norfolk surrounding ASD services.

From the research to date these key lines of enquiry for ASD services priority project have emerged:

- What are the views and experiences of parents/carers and families on assessing local ASD services for their child?
- What do parents/carers and families need in terms of support pre and post diagnosis?
- Have parents/carers and families encountered any health & social care services that demonstrate an increased awareness of autism?
- From the perspectives of parents/carers and families what works well in services that are autism aware?
- What is GPs general awareness and understanding of autism and referral pathways for ASD in Norfolk?
- Are any GP services in Norfolk developing their practice to be autism friendly?
- How can Healthwatch Norfolk develop their practice to enhance Autism awareness?

5. Outline of Project Approach

To summarise, the information in this paper identifies the complex nature of ASD and ASD services both locally and nationally. From this there are three clear themes and messages that will be used to guide and shape our future work presenting as gaps in services locally. Firstly, is the **need to focus on children, parents, carers and families**. It appears that currently across Norfolk there is no funding set aside for Autism services which highlights challenges commissioners face in developing services. There is a gap in provision of services for adults with autism, with one ASN service for adults with Asperger Syndrome to access for information and diagnosis.

We have ASD diagnostic pathways for children in Norfolk but this paper has shown they are under pressure due to capacity and demands not matching. For some this has led to lengthy delays in diagnosis and support locally for families. Bearing this in mind, we need to ensure that the project is both targeted and focussed. With such a wide array of possibilities it is vitally important that we focus it down to one particular area based on children, parents and families.

It is also clear that there is a lack of parent/carer service user feedback on ASD services in Norfolk. There is a lack of data about how parents and carers view their child's experiences of accessing the services. This was also noted and challenged at the NHOSC meeting in September (NHOSC, 2017) and consequently CCGs/services were asked to consider this. Therefore, this is a key opportunity to provide support into the local context and work around ASD. This would also be a prime opportunity to equally feed into the APB and the All Age Autism strategy that are currently being developed in Norfolk, especially as this area of work would meet most if not all of our five key functions: gathering views, working with other organisations, underrepresented groups, Information and signposting and making services better.

Post diagnostic support is limited in Norfolk and it's apparent that parents and carers have many concerns regarding this. This is further justified by the confusion that remains concerning how parents and carers can access some of the parent training programmes offer by NCC. SIT is also therapy that many parents feel would benefit their child but cannot access as there's no national guidance. It is important to gain a greater understanding of what post diagnostic support is being accessed and what support parents feel they need. It is clear that parents are frustrated by delays/waiting times particularly regarding diagnosis and assessments across the county. It's important to consider that the CCGs are driving extra measures in place to help improve the service therefore, this may be something we may need to revisit in the near future; especially if that's developed outside of the timeline of the project.

Finally, the main concern from this scoping paper has highlighted issues around understanding of ASD. As an organisation it's evident that we may be able to adjust our environments and work going forward to meet the needs of individuals with ASD, developed through increased awareness and training. Equally, it's evident that there is a lack of understanding from General Practice and GPs across Norfolk, due to possible confusion around referrals. For many people GPs are the first point of contact within the health and social care system, so it is vital that awareness is increased locally, particularly as GPs are the lead referrer for ASD diagnosis.

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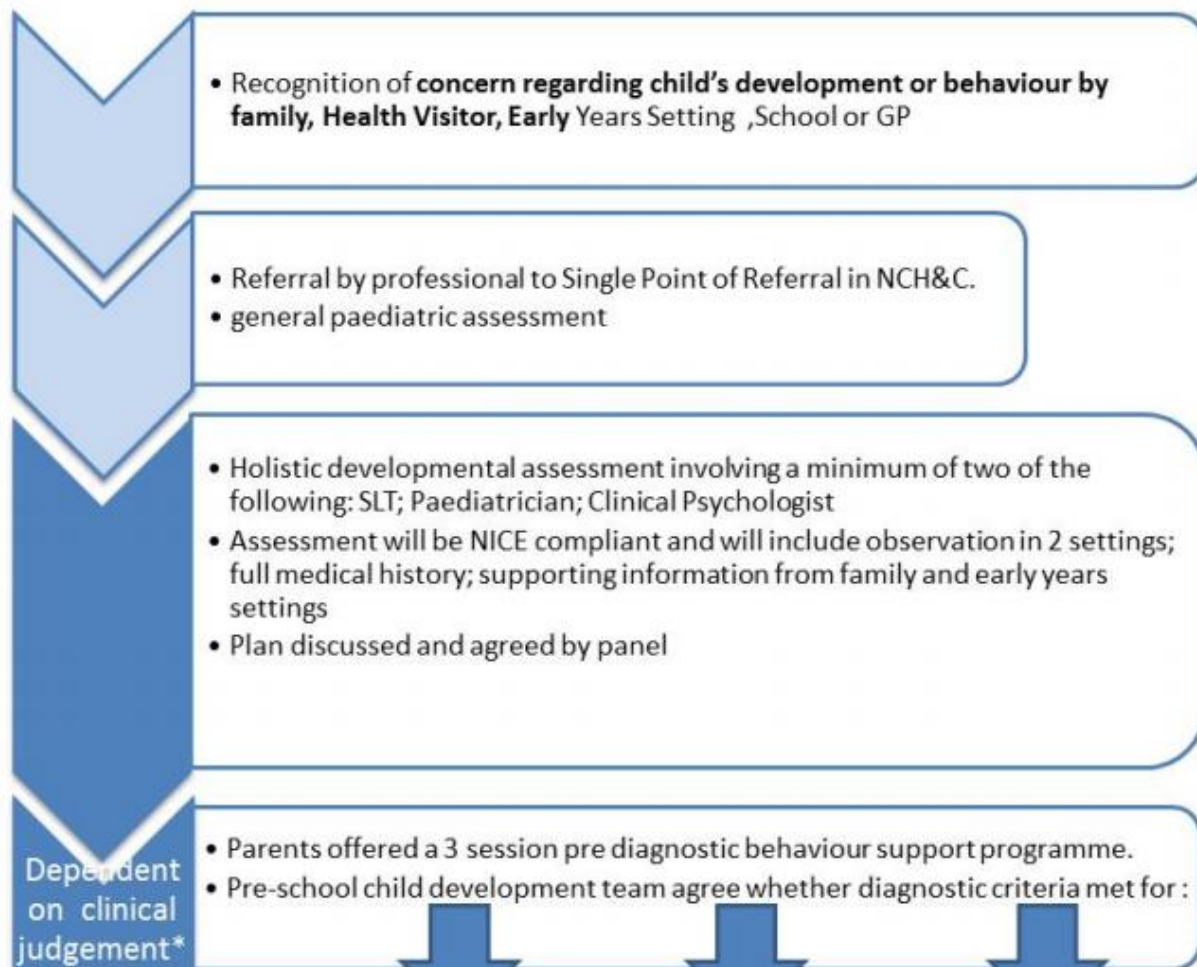
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7: Appendix:

Appendix 7.1- Pathway A

ASD Diagnostic Pathway : Age 1- 6



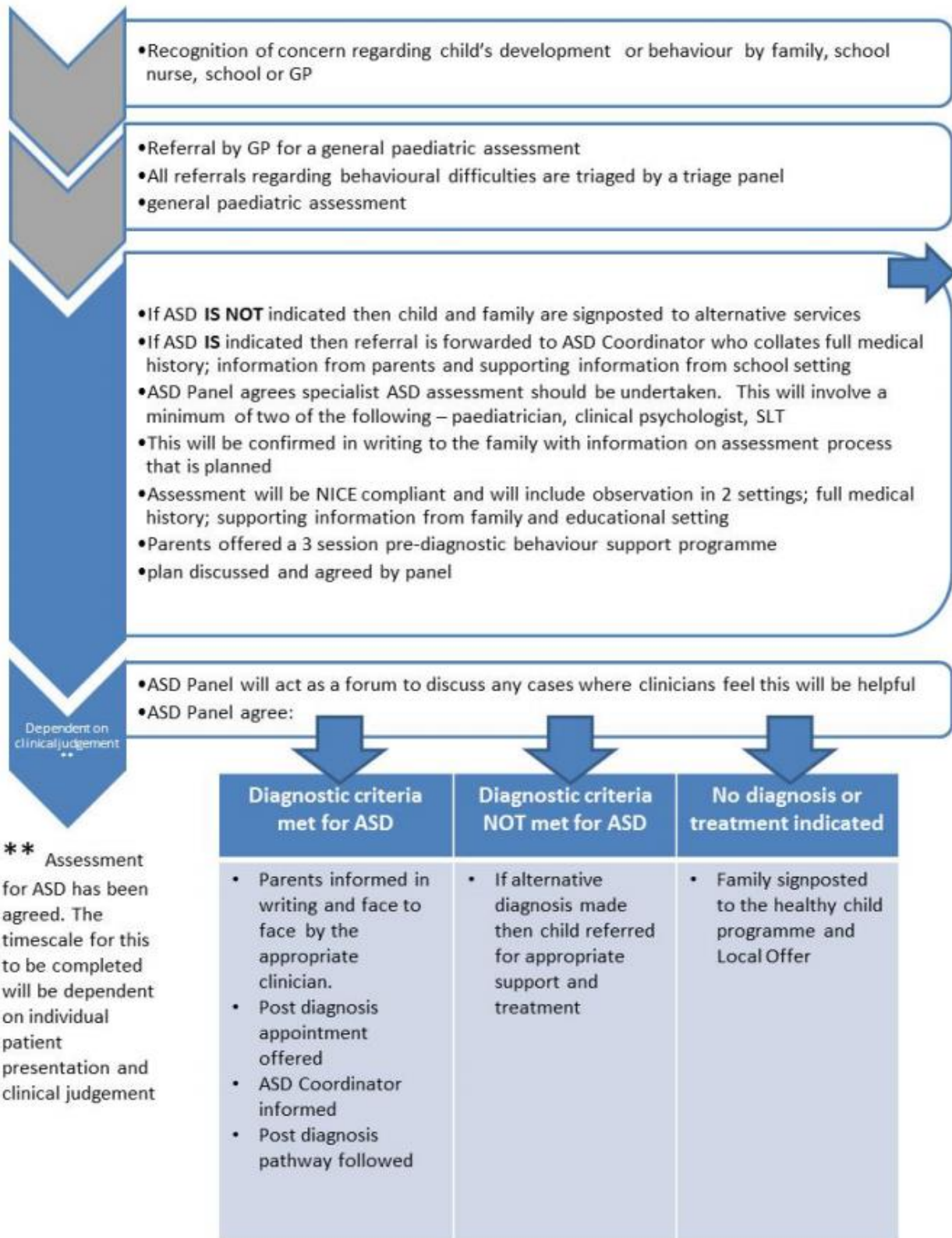
Dependent on clinical judgement*

ASD	Complex Developmental Disorder	No diagnosis or treatment indicated
<ul style="list-style-type: none"> Parents informed in writing and face to face Post diagnosis appointment offered ASD Coordinator informed Post diagnosis pathway followed 	<ul style="list-style-type: none"> Referred for appropriate support and treatment 	<ul style="list-style-type: none"> Family signposted to the Healthy Child Programme and Local Offer

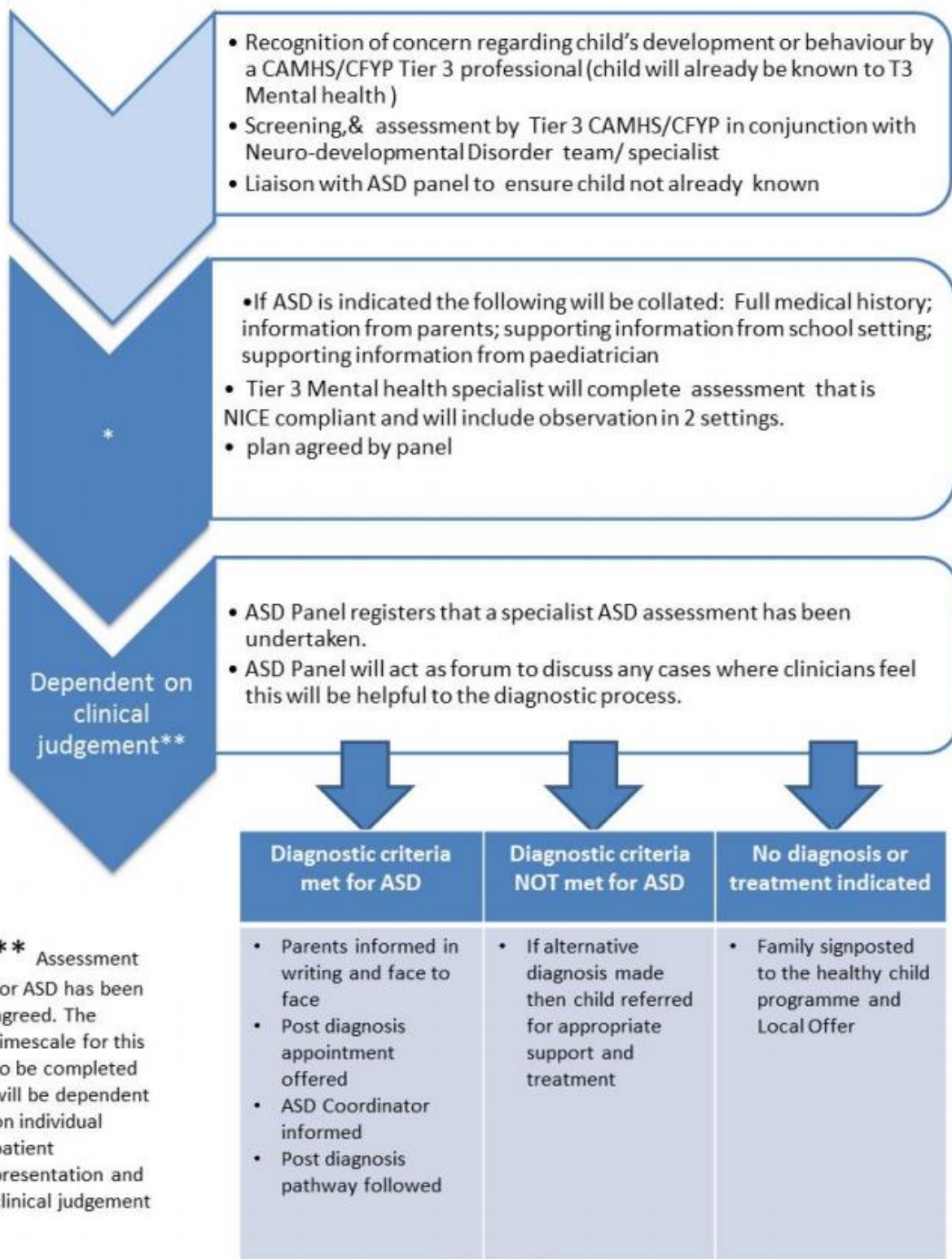
** Assessment for ASD has been agreed. The timescale for this to be completed will be dependent on individual patient presentation and clinical judgement

pathway v4

ASD Diagnostic Pathway : Age 6 - 18



ASD Pathway : CAMHS for Children with a Mental Health disorder



pathway v4

Appendix 7.2- Pathway A waiting lists

7.1 Numbers of children on the waiting list as of 8 August 2017:

	Referred in - awaiting discussion and decision by team to accept for full assessment	Accepted for full assessment - awaiting start of first assessment	Assessment Started (= accepted onto pathway and first assessment underway)
Preschool - West 1- 4yrs	1	18	8
Preschool - Central 1 - 4yrs	1	20	35
School age - West 4 - 18yrs	19	186	53
School age - Central 4 - 18yrs	54	192	52
Total	75	416	148

* Table taken from NHOSC paper September 2017 (HNOSC, 2017).

Joint Pathway Child, Family & Young People Mental Health Services (CFYP) & Community Paediatrics For Diagnosis & On-Going Support For CYP With Neurodisabilities

