

Image by Catherine Scott, (2012).

Access to health and social care services for Norfolk families with Autism

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Who we are and what we do

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

Acknowledgements

We are extremely grateful to all the families and parents across Norfolk who volunteered to be involved in this project. They openly shared their views and experiences of accessing services, for their child with ASD/suspected ASD and without whom this project would not have been successful. We would also like to acknowledge the advice and support we received from individuals, organisations and services across Norfolk who work with the Autism community, in particular Anne Ebbage, Rebecca Crossley and Sunbeams Play. Special thanks go to all the organisations and parent support groups that supported us to recruit parents to this project and welcomed us into their ongoing meetings.



Glossary of terms

Healthwatch Norfolk: is the independent consumer champion for anyone in Norfolk who uses health and social care services. We use the views and experiences of local people as evidence to influence improvements in service provision.

(AAPB) All Age Autism Partnership Board: is an inclusive board of service providers, service users, parents and carers, who raise awareness of autism within the wider community. The board influences local NHS commissioners with the aim of improving services, for children, young people and adults who have autism.

(ADHD) Attention Deficit hyperactivity Disorder: is a behavioural disorder that affects children and adolescents and can continue into adulthood. Symptoms include inattentiveness, hyperactivity and impulsiveness, meaning that children can be hyperactive and unable to control their impulses.

(ADOS) The Autism Diagnostic Observation Schedule: is a semi structured assessment for communication, social interaction and play for individuals who are suspected of having autism. This consists of standardised activities that allow behaviour to be observed.

(APA) American Psychiatric Association: is the leading organisation of psychiatrists in the world based in the United States. They created the DSM-5 commonly used to diagnose autism.

(ASD) Autism Spectrum Condition: is a lifelong developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around.

(CCG) Clinical Commissioning Group: the organisations that commission (pay for) local NHS services, including mental health services. There are seven CCGs in Norfolk and Suffolk.

(CAMHS) Children and Adolescence Mental Health Service: this is a specialist service offering assessment and treatment for children and young people who have emotional, behavioural or mental health difficulties.

(CCS) Cambridgeshire Community Services NHS Trust: This service provides a range of children's services to children and young people and families across Norfolk, health visiting and school nursing.

(DSM-5) Diagnostic and Statistical Manual of Mental Disorders: is a diagnostic tool/criteria created by APA that is commonly used in America and parts of the UK to diagnose Autism.

(EHCP) Education Health and Care Plan: This is a legal document that describes the support that will be provided to meet a child or young person's educational, health and social care needs.

(GP) General Practitioner: A doctor based in the community within a GP practice that treats patients and refers them on to additional services.

(GYWCCG) Great Yarmouth and Waveney Clinical Commissioning Group: the organisation that commission (pay for) local NHS services in Great Yarmouth and Waveney. They commission the ASD diagnostic pathway situated in Great Yarmouth.

(HMS) Hypermobility Syndrome: is a condition where individuals can move some or all of their joints beyond the normal range of a joint.

(ICD-10) World Health Organisations International Classification of Diseases 10: is a diagnostic tool/criteria that is commonly used in the UK to diagnose Autism.

(JPUH) James Paget University Hospital: is an acute trust (hospital) located in Gorleston, providing acute care for Great Yarmouth and surrounding areas.

JPUH diagnosis service: is a service based at the Newberry Child Development Centre in Great Yarmouth providing diagnostic services for children in Norfolk.

(LD) Learning disability: can affect the way an individual learns, understanding information and communicates. This can mean a reduced intellectual ability causing difficulty with everyday tasks and activities.

(JSNA) Joint Strategic Needs Assessment: is a document that looks at the current and future health and care needs of a local population to inform local planning and commissioning of services.

(NAS) National Autistic Society: is a national charity supporting autistic people and their families, their aim is to improve the lives of autistic people across the UK.

(NCC) Norfolk County Council: provides various health and social care for residents of Norfolk. Responsible for developing the AAPB and autism strategy for Norfolk.

(NCHC) Norfolk Community Health and Care NHS Trust: provide community based health and care services across Norfolk, including children's services. They provide the neurodevelopmental services used to diagnose children with autism in Norfolk.

NCHC (NDS) Neurodevelopmental Service: provides assessment for children to diagnose Autism and ADHD in Norfolk. This is provided at the Norwich community hospital, the fledglings building.

(NHOSC) Norfolk Health and Overview Scrutiny Committee: scrutinizes and challenges services relating to the needs and health of the population of Norfolk.

(NHSE) NHS England: oversees the budget, planning, delivery and day-to-day operation of the commissioning (funding) side of the NHS.

(NICE) The National Institute for Health and Care Excellence: provides national, evidence-based guidance and advice to improve health and social care.

The Newberry Child Development Centre: provides healthcare services for children who have additional needs providing a range of paediatric services at the centre and within the community. One autism diagnosis pathway is located within the development centre in Great Yarmouth.

(OT) Occupational Therapy: provides assessment and treatment for children to help improve fine motor skills, sensory skills, visual skills and sensory processing.

(PDA) Pathological Demand Avoidance: is a condition that is part of the autistic spectrum. Individuals share difficulties with others on the autism spectrum yet they can have an overwhelming need to avoid or resist everyday demands placed on them due to anxiety.

(SALT) Speech and Language Therapy: provides treatment and support for children and adults who have difficulties with communication, eating, drinking and swallowing. This service works with children, parents, carers and professionals to help individuals to communicate better. This service is predominately commissioned by East Coast Community Healthcare across Norfolk.

SystmOne: is a clinical computer system that is used by health professionals across the UK, predominately in General Practice.

Third sector and other organisations

Autism Anglia: is a charity providing support for children, adults and families affected by autism across East Anglia, from offices based in Colchester and Dereham. They aim to raise awareness and understanding of Autism through their advice line, events, and training.

ASD Helping Hands: is a charity based in Dereham offering support for families affected by ASD and ADHD. They host youth groups and family support groups providing guidance, practical advice and support for families, children and young people across the county.

Family Voice: is a voluntary organisation listening to families' experiences to improve education and health and social care services for children and young people with special educational needs. It is regarded as the parent carer forum for Norfolk.

(SenSi) Special Educational Needs Sensory Integration: a company providing Sensory Integration Therapy to children and young people across Norfolk and Suffolk with a team of therapists.

Sunbeams Play: are an Ofsted registered charity based in Great Yarmouth that support children and families living with ASD. They provide a fun, safe and caring environment for children aged 3-19. They support parents with information, education, benefits and behaviour, as well as holding parent programmes/courses.

Slice of Advice: a company providing an umbrella of local parent support groups across the Great Yarmouth area for parents of children with learning difficulties and ASD.

NAS West Norfolk branch: is a voluntary charity managed by parents of children with ASD, with a membership of families across West Norfolk who they work to support. They provide a variety of activities for families and individuals from coffee mornings (parent support) to swimming and play barn sessions for children.

Executive Summary

Autism (ASD) is 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, 2018b). No two people with ASD are the same, however autistic people share common difficulties in three areas: social interaction, social communication and imagination (Lai et al., 2014). Approximately 700,000 people are living with ASD in the UK today (1 in 100 people), resulting in 2.8 million lives being affected by ASD daily (NAS, 2018c). Across the United Kingdom (UK), evidence suggests there is generally good awareness of ASD, 99% have heard of it, but the understanding of the condition has not been so widespread (YouGov, 2015).

Nationally over recent years demands on ASD services for a diagnosis have amplified and families have experienced lengthy delays some reportedly waiting two years to be assessed and nearly four years for a diagnosis (BBC, 2018). These demands have been unsustainable and MPs have called for these 'scandalous' waiting times to urgently be addressed (Guardian, 2018). This demonstrates the profound impact this is having on the lives of autistic children across the UK and across Norfolk.

ASD is high on the agenda across Norfolk in light of the current developments of the formation of the autism partnership board (AAPB) and movements towards the creation of an autism strategy for Norfolk, in line with the Autism Act (2009). Local authorities and NHS services have a statutory duty to ensure that services are in place to meet the needs of individuals with ASD. In Norfolk, services have faced recent struggles to complete timely ASD diagnostic assessments. Demands are high and in September 2017 only 150 out of the 300 cases waiting could be assessed at any one time (BBC, 2017 & NHOSC, 2017).

Knapp et al. (2007) suggest that there are around 100,000 children with ASD in the UK, and one study suggests that 70% of children have at least one co-occurring condition linked to ASD (The Westminster Commission of Autism, 2016). As a result contact with health and social care services is crucial, but these services can prove difficult to access given the hidden nature of ASD and the associated lack of understanding by professionals in diagnosing ASD in the first instance. NHS England (NSHE) recently announced (August 2018) that autism and learning disabilities was one of their key clinical priorities for their improvement of services over the next ten years, pushing ASD into the spotlight of developing services nationally.

With an awareness of the national context of ASD and issues reported by local families to Healthwatch Norfolk we looked to explore this further. We wanted to explore families' perspectives and experiences of trying to access help and support for a child with ASD/suspected ASD (0-18 years old), from local health and social care services. Many individuals and families are affected by ASD and come into contact with a wide range of services. We wanted to understand whether families were getting the right help and support. A mixed-methods approach was adopted, involving quantitative and qualitative data capture through the use of patient questionnaires, attendance at parent support groups and local ASD public events. We wanted to reach out to parents across Norfolk and of the 170 families that

showed an interest. **A total of 112 families** completed a questionnaire representing **133 children across Norfolk**.

There were mixed views on accessing health and social care services demonstrating the contrast of experiences across Norfolk. Unfortunately many families had received what they regarded as poor services, and often felt that little had gone well. Despite this, some felt that once you got into 'the system' the service they received was good but there were never enough appointments to allow for timely access to services. The undertaking of this project and further analysis of patient feedback has clearly demonstrated five key findings:

1) This was closely linked to the frustration commonly held amongst parents about the long waits they experienced to access health and social care services including an ASD diagnosis. Many understood services are stretched but recalled the reality of what this meant for their child. This highlighted the need for services to change and improve locally, emphasising the need to listen and engage more with families and service users using the service.

2) Families felt that professionals did not understand what it was like to live with ASD and the effect this has on individual's everyday lives. Physically getting to an appointment could also prove a challenge, especially if it fell outside of the child's usual routine. It was felt that there was lack of understanding of ASD across all health and social care services, to facilitate attendance and effective communication at appointments.

3) Parents stated the need for reasonable adjustments to be made in health and social care services, with particular regard to waiting rooms in clinical settings. Waiting rooms in services were commonly referred to as noisy and unsuitable for children with ASD (who commonly experience sensory overload), especially when they found waiting quite difficult. Small changes to the environments could make a big difference to autistic children and parents felt this needed to be closely considered to improve services.

4) Frequently parents recalled not being aware of the process involved for an NHS ASD diagnosis, due to a lack of information and communication. The pathway process was not explained to them. They stated this needed to be addressed to understand what to expect from the service and to enable them to explain the process to their anxious child. A lack of communication also led to parents often feeling forgotten due to the considerably long waiting times they experienced and not knowing where they were in the process.

5) Many parents identified the lack of support available to the families across Norfolk, especially once the child has received a diagnosis. Many described the continuous fight they had to undertake to get the right support for their child. Some expressed the need for more support to wrap around the wider family unit, including the child's siblings. They believed the siblings received no support and needed help to understand and ensure that all of their children felt supported and comfortable.

1. Recommendations

Evidence	Recommendation	For
Lack of transparency and communication across the diagnosis pathways 1(a) Detailed feedback captured from families demonstrated families concern at the lack of information and communication they received when using diagnostic services. 1(b) Families stated there was no explanation of the processes involved or what happens next when they accessed the pathway. As a result, this led to confusion with families remaining unaware of what to expect from the service.	1. Leadership is required to coordinate more awareness of ASD diagnostic services, their process and procedures involved and openly share with families when accessing the service.	a) NCHC b) NCHC & JPUH
Lack of involvement of families & service users in the design of services Families' feedback identified the difficulties they faced when accessing services often due to a lack of awareness of autism. They recalled how waiting areas were often not suitable for their children (who experience sensory overload). Families highlighted the need for some environmental changes to be considered to enable clinical settings to become more autism friendly (all services). Premises should be developed accordingly with parents involved in the process.	2. As opportunities arise, involve parents in the redesign of services, buildings and waiting areas used for autistic patients.	NCHC & JPUH
Variation in understanding of autism from professionals/practitioners Many parents highlighted the general lack of awareness and understanding of ASD from professionals. Some parents felt that more training was required for professionals who may come into contact with an autistic patient. They recalled instances where professionals have not known how best to work with their child in appointments.	3. Leadership is required to provide training across all universal health and social care services.	All Acute Trusts All Community & Mental Health Trusts GP Practices NCC - Children's service
Lack of parent support programmes being accessed Families revealed that they were often offered a place on a parent support programme too late and therefore timely access needed to be improved. Some parents suggested these programmes were not always accessible (time and location) and parents should be actively involved in shaping these programmes. The use of digital platforms and webinars could enable more parents to access them.	4. The AAPB to monitor and ensure that parents are involved in a review of current parent support programmes to ensure they are accessible for all. E.g. considering digital platforms.	Commissioners AAPB
Lack of parent and service user involvement Families highlighted the need for parents to be listened to. They felt that they were not being listened to when it came to their child's health and social care needs yet they believed they often knew their child best.	5. The AAPB have responsibility to ensure recommendations are achieved in the development of the strategy for Norfolk and ensure that all service contracts are regularly monitored.	Commissioners AAPB

2. Why we looked at this

2.1 Autistic Spectrum Disorder in the UK today

It is believed that awareness of autism has grown leading to a generally good awareness across the United Kingdom (UK). It was reported that 99% of the general population have heard of autism (YouGov, 2015). However, the understanding of autism has not been so widespread, which suggests that the complexity of this spectrum condition and how it affects individuals is often not fully understood. There are many myths still surrounding autism such as believing all people with autism are the same and lack empathy, which has led to the lack of a true acceptance of autism across society.

Autism is often referred to as Autism Spectrum Disorder (ASD) or Autism Spectrum condition (ASC) and these names are frequently used interchangeably. For the purposes of this report autism will be referred to as ASD throughout and will encompass all autistic spectrum conditions. ASD is a condition that is known by many different names as the condition sits on a spectrum of severity. Across the spectrum there is a range of different autistic spectrum conditions (including Asperger's syndrome, Pervasive Developmental Disorder and Pathological Demand Avoidance) extending from severe to high functioning autism. Whilst all people with ASD share certain difficulties all individuals are unique. How each individual is affected is different (Lai et al., 2014).

Autistic people commonly present difficulties in three areas: social interaction, social communication and imagination. **Autistic people see, hear and feel the world differently to others**. For some the world feels very overwhelming, therefore everyday life and activities can prove quite challenging. To learn more about autism please watch this autism awareness video created by Alex Amelines (2017).

ASD is 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, 2018b). ASD is believed to be more common than people may have first thought, it is estimated that approximately 700,000 people are living with ASD in the UK today (1 in 100 people), taking into account their families this suggests that 2.8 million lives are affected by autism daily (NAS, 2018c).

Further developments of the prevalence of ASD among adults has revealed that 1.1% of the UK population have ASD (The NHS Information Centre, 2012). Knapp et al. (2007) suggest that there are around 100,000 children with ASD in the UK. ASD can commonly present during childhood. Individuals who are autistic, are autistic for life; as ASD is not a disease or illness and cannot be cured. ASD is more common in males currently as four times as many males as females are diagnosed with ASD (ONS, 2004). However, ASD in females is thought to be under recognised due to the differences in the signs and symptoms they present and a possible male bias in diagnostic tools (Lai et al., 2015).

Often people feel that ASD is a fundamental aspect of their identity, but a formal

diagnosis of ASD is used to understand individual difficulties. Over many years there has been a wide range of diagnostic labels associated with ASD due to variation in diagnostic tools utilised. In the USA the American Psychiatric Association (APA) produces its own diagnostic tool, the Diagnostic and Statistical Manual of Mental Disorders (DSM) which also influences practice here in the UK. Here in the UK, the World Health Organisation's International Classification of Diseases (ICD) criteria (ICD-10) is most commonly used, as well as the DSM. The DSM-5 contains key changes to the diagnostic criteria, 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 ASD. This indicates that a range of different profiles form the ASD profile, but today ASD is now the most commonly given diagnostic term.

A growing concern evidenced over recent years has been the lengthy waiting time that families are facing in order to receive an ASD diagnosis across the UK. The Guardian (2017) revealed families were having to wait up to 44 months for a diagnosis. This related specially to Teesside, however it was believed that unacceptable delays were a problem across the country and leading to a postcode lottery of services. In July 2018 it was reported again that delays were continuing to rise, with families waiting two years to be assessed and nearly four years for a diagnosis (BBC, 2018). This highlighted the variability of waiting times across different NHS trusts across the UK and was deemed as 'scandalous' by MP Norman Lamb, with the average wait of 574 days for a first appointment (Guardian, 2018). This demonstrates the profound impact this is having on the lives of autistic children across the UK.

Individuals can often have co-occurring conditionals associated with ASD that impact upon their needs. One study suggests that 70% of children have at least one co-occurring condition (The Westminster commission of Autism, 2016). Therefore access to health and social care services can be crucial, but at times proves difficult for children and their families to access. The autistic community can often find navigating the world around them a struggle, especially as the world is attuned for neuro-typical people (The Westminster commission of Autism, 2016). Due to the 'hidden' nature of ASD it can be difficult for health and social care services to make the reasonable adjustments patients require.

The Autism Act (2009) placed a duty on the government to produce an autism strategy across England with supporting statutory guidance on how to implement this. This meant that local authorities and NHS services have a statutory duty to ensure that things are in place to meet the needs of individuals with ASD. The first government strategy *'Fulfilling and rewarding lives: the strategy for adults with autism in England'* published in 2010 and later updated with *'Think Autism strategy'* in 2014. This was then followed by the latest statutory guidance being released in 2015.

In 2017 NICE proposed a new set of QOF indicators for potential inclusion in the NICE indicator menu for general practice and are currently being piloted. One was

focused on ASD and GP practices. This proposed that GP practices start maintaining a list of registered patients with a diagnosis of ASD (NICE, 2017). Following this NHS England (NHSE) announced recently (August 2018) that autism and learning disabilities will be a key clinical priority over the next ten years, across England (NAS, 2018d). This has put ASD at the forefront of their 10 year improvement plan, whilst raising awareness of ASD by bringing it under the spotlight of developing services nationally.

2.2 ASD context in Norfolk Today

Across Norfolk there is a population estimate of 898,400, and that 170,000 of those are children ages 0-17 years old (Norfolk Insight, 2017). There is little known about how many children locally have ASD in Norfolk as this information is often based on prevalence data alone (1,700 children). However, currently across Norfolk a joint strategic needs assessment (JSNA) is being undertaken for adults and children living with ASD. As a result more awareness should be developed upon completion of this in the near future.

The National Institute for Health and Social care Excellence (NICE) states within its clinical guidance that autism diagnosis should be started within three months of the GP referral, however these are simply guidelines and evidence has shown that waiting times are often longer. There has been increased awareness and discussion of ASD services across Norfolk in the recent years, particularly in light of recent demands being place on ASD diagnostic services. It was reported back in September 2017, that NHS ASD diagnostic services run by Norfolk community health and Care (NCHC) were struggling to cope with the demands placed on their service resulting in a back log of patients waiting for an ASD assessment. In September 2017 there were 300 cases waiting to be assessed, yet only 150 out of the 300 cases could be assessed at any one time (BBC, 2017). As a result ASD has been brought to the attention of many organisations and committees across including the Norfolk Health and Overview Scrutiny Committee (NHOSC) and regularly reviewed.

Currently in Norfolk work is being undertaken towards the development of an autism strategy for Norfolk, as despite the Autism act we still do not have an autism strategy in place. As a result Norfolk has developed an All Age Autism Partnership Board (AAPB) to inform the creation and implementation of an autism strategy and action plan to improve services across Norfolk. The board will be inclusive of service providers, service users, parents and carers to influence local NHS commissioners with the aim of improving services, for children, young people and adults whilst raising awareness of ASD.

In Norfolk there are a wide range of voluntary sector organisations that support local parents and families whose children have ASD. These services are often evolving and changing, some of which include ASD Helping Hands, Autism Anglia, Sunbeams Play and Asperger East Anglia. These services are vital in providing support for families across Norfolk as the only NHS services available are for a

diagnosis. Some of the diagnostic services provide parent support programmes offered through Norfolk County Council (NCC). They provide Early bird (an 11 week programme for parents and carers of pre-school children under the age of 5) and Cygnet courses (for parents and carers whose child has a diagnosis of ASD for school aged children (7-18 years old).

2.3 ASD diagnostic pathways for children in Norfolk

There is differentiation across Norfolk due to the five CCGs and as a result, there is no single service that patients can access which works across the whole of the county. Services are not the same and there is no one pathway for ASD in Norfolk, it is dependent upon where patients live as to which service they access. Currently Norfolk has two ASD diagnostic services which are commissioned by CCGs as a block contract with providers running until March 2019, one is run by the James Paget University Hospital Trust (JPUH) and the other is run by NCHC. The two services commissioned in Norfolk are:

- **NCHC: Neurodevelopmental service (NDS)** [Diagnostic pathway A] whilst this service covers the rest of Norfolk including Norwich CCG (NORCCG), North Norfolk CCG (NNCCG), South Norfolk CCG (SNCCG) and West Norfolk CCG (WNCCG).
- **JPUH: Joint pathway Child, family and Young People Mental Health Services (CFYP) and Community Paediatrics for diagnosis and ongoing support for CYP with neurodisabilities.** [Diagnostic pathway B] This service is for residents of Norfolk living within Great Yarmouth and Waveney CCG area (GYWCCG).

Diagnostic pathway A

Back when this project began, diagnosis pathway A originally consisted of three NCHC ASD diagnostic pathways to access determined by the child's age:

- 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.

This pathway comprises of a multidisciplinary team that is delivered by paediatricians, clinical psychologists, specialist nurses and family support workers alongside Speech and Language Therapy (SALT), psychology and teacher support.

For families to access an ASD diagnosis for their child they must be referred to a community paediatrician for an initial general assessment. Recognition of concerns about the child's development may be raised (and referred) by health visitors, family, early year's settings, GPs or schools. This referral led to an initial general assessment which is used to determine if a full ASD diagnosis assessment is warranted. This general paediatrician assessment resulted 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.

In April 2017 the diagnosis pathway A moved from Upton road along with other children's and young people's services and were permanently relocated to Norwich Community hospital. It was highlighted at a recent NHOSC meeting that NCHC recognised their service was under severe strain and could not keep up with demands for assessments. As a result, the clinical commissioning groups (CCGs) pooled additional investment into this diagnostic service with increased funding and staffing to support assessments being undertaken effectively. Work has continued to be undertaken to improve this service locally. However from December 2017 this diagnosis pathway changed and adjustments were made to the way staff deliver services. As a result of these changes occurring during the period of this project, it is still too early to evaluate the impact of these changes.

Diagnostic pathway B

This pathway is provided as part of the community paediatric service (see appendix 7.3). This service is an integrated pathway that provides multi-disciplinary assessments based on NICE guidance to make a diagnosis (see appendix 7.3). This new pathway enables children to be referred to one single point of access by their GPs 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 his or her age.

Children under five attend the new neurodevelopmental assessment clinic at the Newberry 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 by 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. How we did this

3.1 Aims

We chose this project as a priority because people told us local services for children with ASD or suspected ASD were unsatisfactory. We wanted to listen to families' experiences of trying to access help and support for a child with ASD/suspected ASD. The project focused around gathering parent's perspectives and experiences of local health and social care services in supporting their child's needs (0-18 years old). In doing this work, we wanted to acknowledge the complex journey that families had taken both pre and post diagnosis (ASD) in the search of support for their child. Many individuals and families are affected by ASD and come into contact with a wide range of services when trying to get the support their child needs. We aimed to find out how getting the right help and support at the right time can make a difference to families. The three main objectives of this work were to:

1. Gather families' experiences of accessing local health and social care services that support their child's needs, gathering views on what works well and what could be improved.

2. Explore family experiences of accessing ASD diagnostic services across Norfolk for their child or children.

3. Understand family experiences of ASD support services that they have tried to access or have used, highlighting any gaps in support.

3.2 Project approach

In undertaking this project, we followed 5 main steps (see figure 1), starting with a scoping exercise. This guided us to focus on engaging with parents who have a child/children with ASD or suspected ASD. The diagnosis pathway and support for children and their families emerged as a key topic with defined lines of enquiry for the project. It was clear early on that parental engagement was extremely important if we wanted to gather views and experiences of accessing support for their child with ASD.

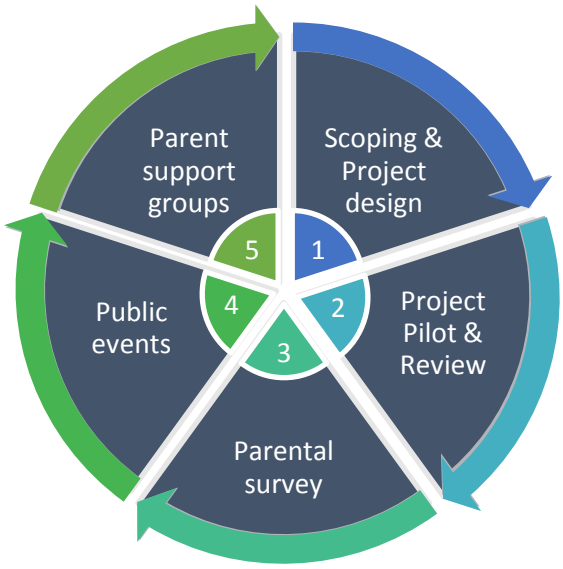


Figure 1. Parental engagement in shaping the project

We wanted to reach out to a wide range of parents across Norfolk, who may or may not be accessing support. It was evident that not every parent would be attending parent support groups, so a mixed methods approach was adopted to capture feedback from a range of sources. Accepting that the same approach may not suit all parents, we combined both qualitative and quantitative methods to enable a deeper level of understanding of parent's views, including:

- A parent questionnaire [online & paper copies]
- Attendance at parent support groups [held locally with open discussions]
- Attendance at local ASD public events [talking to parents one to one]



We analysed feedback regarding ASD services from our feedback centre, coupled with meeting a range of professions, we developed an informed questionnaire based on the recurring themes we wanted to explore further (Fig.1 Step Two). This helped to design a survey for parents which became the main source of engagement across the project. The parent questionnaire was developed through a pilot followed by review, as a suitable tool to use to gather parents feedback effectively. The questionnaire was then modified and finalised ready for distribution.

Following this the 3 key components of the engagement commenced and steps three, four and five all ran concurrently with one another. The parent survey was launched late November 2017 and remained open until mid-March 2018. During this time we also attended some parent support groups and local Autism related events talking to the groups and individual parents to gather their experiences.

3.3 Parent questionnaire

Families told us they have busy lives. By using a questionnaire, it was hoped that a larger proportion of parents would be able to 'have their say' at a pace and time convenient to them. We met with professionals working within services and diagnostic pathways to piece together a clearer picture of services available in Norfolk. Using this feedback and involving some key voluntary sector organisations working in this area, we devised a draft questionnaire for parents' feedback. Questions were then refined through discussions with Healthwatch Norfolk staff, parents and voluntary sector staff. This was then piloted at a local parent support group in West Norfolk, amendments were made and the final questionnaire followed.

The questionnaire was administered by Healthwatch Norfolk to parents in a variety of ways utilising both paper and online questionnaires. We shared this questionnaire with contacts developed when scoping this work and key voluntary sector organisations working with parents directly, such as Family voice, Sunbeams Play, Autism Anglia and ASD helping hands. Links to the online questionnaire were also shared with local parent support groups, our newsletter and social media. The questionnaire remained open for 16 weeks including the Christmas break. After completion all questionnaires received were collated; and securely stored at HWN offices until needed for analysis.

3.4 Parent Support groups

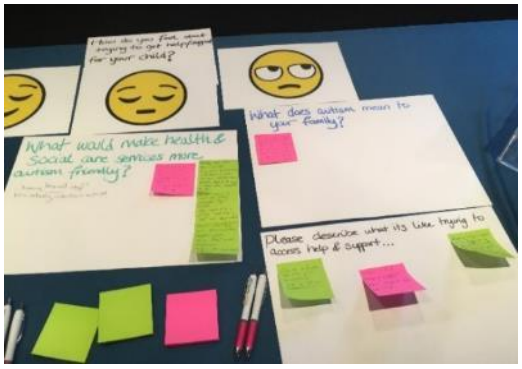
For the duration of the project we also attended some local parent support groups across Norfolk. At these groups we were able to address groups of parents to share information about the project and gather family's experiences of trying to access help. This gave us an opportunity to promote the parent questionnaire, whilst also speaking to parents individually, face to face, to gather their views. Many parents were comfortable in describing their family's story and notes were taken whilst they were doing (so to add to the data we had from the questionnaire).

3.5 ASD public events

In undertaking this project we also attended a collection of local public events that were related to ASD, as another means to capture valuable experiences from families. Some events were attended at the beginning of the project and were used to inform future planning of this work, enabling us to better understand those areas we might need to focus on. We employed some creative ideas to reach out to parents such as using post-it note boards, and selfie frames to enable parents to share their messages. This helped us build a snapshot of what the journey looked like for each family, when searching for support for their child.



HWN stall at local autism event.





Images of activities & feedback at our HWN stall at local autism event.

3.6 Data processing and analysis

All completed paper copies of the survey we received were input alongside the online responses to aid processing and analysis of all parents' feedback. The parent survey was analysed using descriptive statistics for all closed questions. All qualitative data was manually coded, input and organised into NVIVO for content analysis, where a coding model was created (see figure 2).

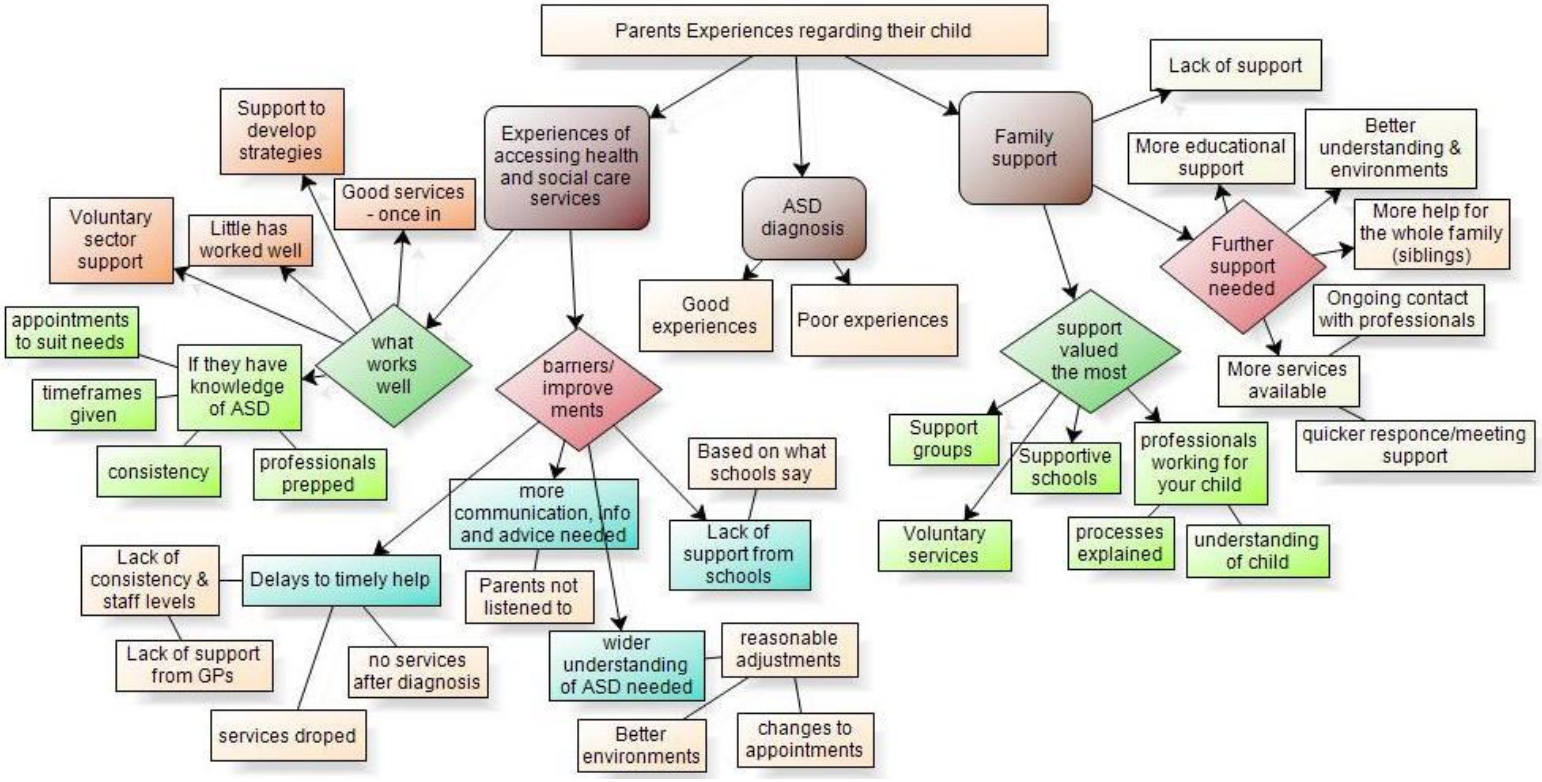


Figure 2. Coding model used for analysis

3.7 Strengths and limitations

HWN recognises that this project has some limitations and strengths. The project **was not** an evaluation of local services across Norfolk and how services support patients with ASD however, it did focus on family's experiences of accessing a wide range of health and social care services, what worked well and what could be improved. This project relied on parents volunteering to give their time to share their views with HWN, providing a snapshot of parent's experiences. Therefore this may not be truly representative for the whole population of Norfolk parents with a child or children who have ASD/suspected ASD. However, this project has depicted a detailed insight and indication of the feelings of families trying to access support for their autistic children/children. The mixed methods approach has maximised the opportunity of parents to be involved and allowed us to develop a greater understanding of the difficulties families have faced, adding value and importance to every comment we have received.

4. What we found out

4.1 About the families

A total of 170 responses were received of which 58 were ultimately excluded from final analysis (**112**) because they were incomplete. In total, 133 children were represented in the end sample of 112 questionnaire responses. All participants were asked for the first half of their postcode in order to map the reach of this project across the county of Norfolk. Figure 3 demonstrates where families were situated in Norfolk.

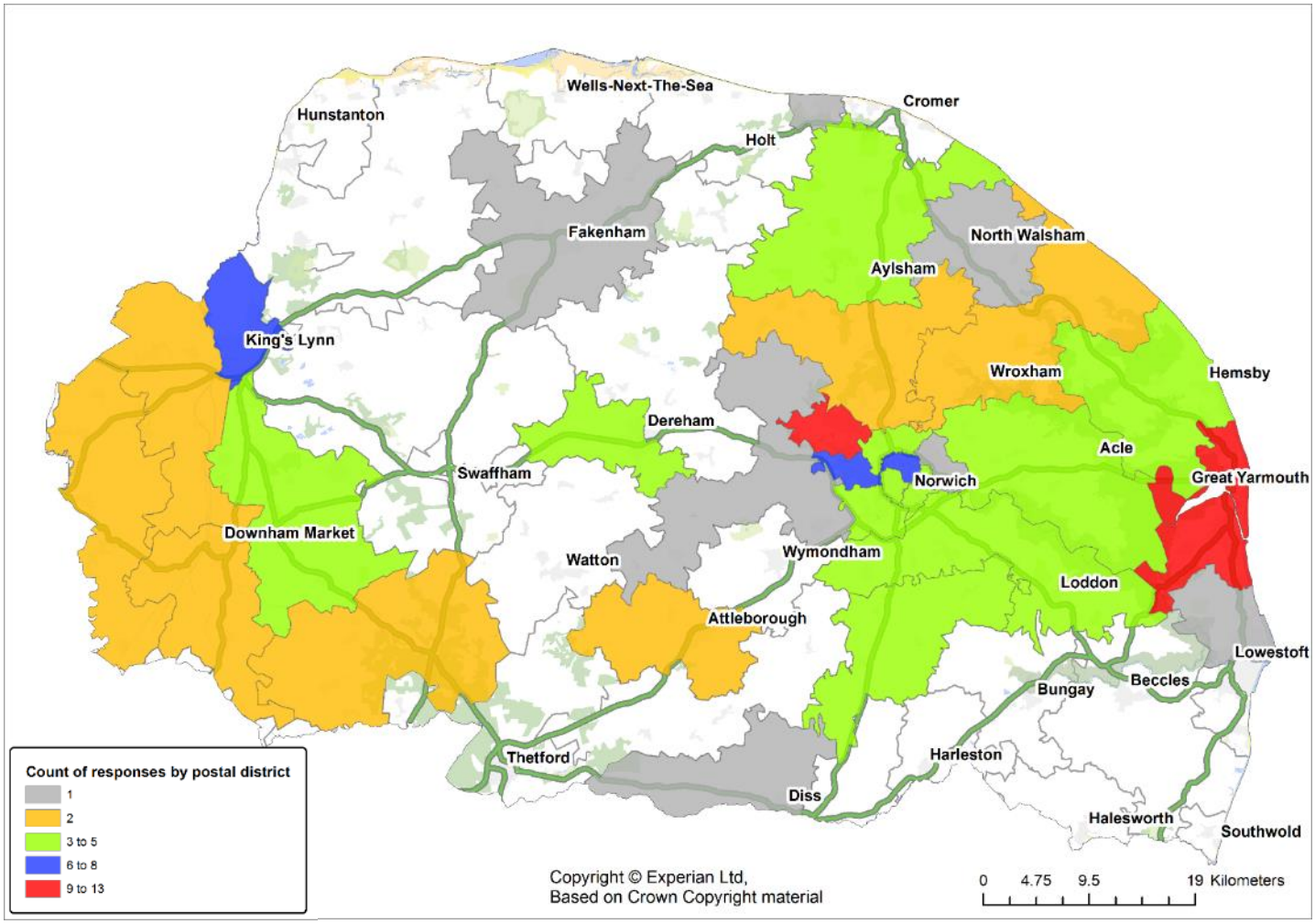


Figure 3. Where families were living across Norfolk who were involved in this project.

Parent's gender, age and ethnicity

Eighty four respondents were female (94%), two respondents were male (2%). Twenty six individuals did not disclose their gender, therefore males were clearly underrepresented in this sample. Respondents ranged from the ages of 22 to 60, with an average (mean) age of 41 (see figure 4). Twenty eight individuals did not detail their age.

The ethnicity of the respondents was predominantly White British (83 respondents, 95%). Twenty seven individuals did not disclose their ethnicity. Of those that shared their demographic details with us, this group of parents corresponded closely to the percentage of White British residents living within the county (96%).

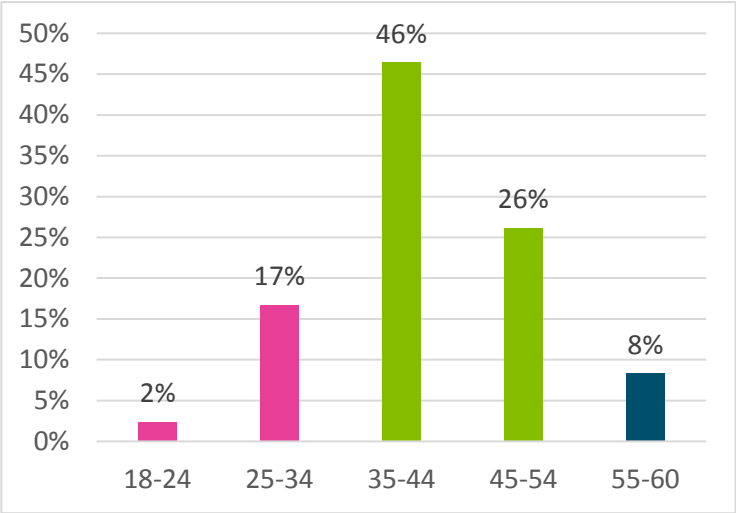


Figure 4. Age of parents involved

About the child/children within the families

Within the families involved there were 133 children, ranging from the ages of 1 to 18 years old. The average (mean) age was 10 years old whilst the most commonly reported age (mode) was 7 years old. Thirty eight percent (38%) of the children were aged between 6-10 years old and a further 34% were aged between 11-15 years old. Figure 5 demonstrates the age groups of children from the families involved in this project.

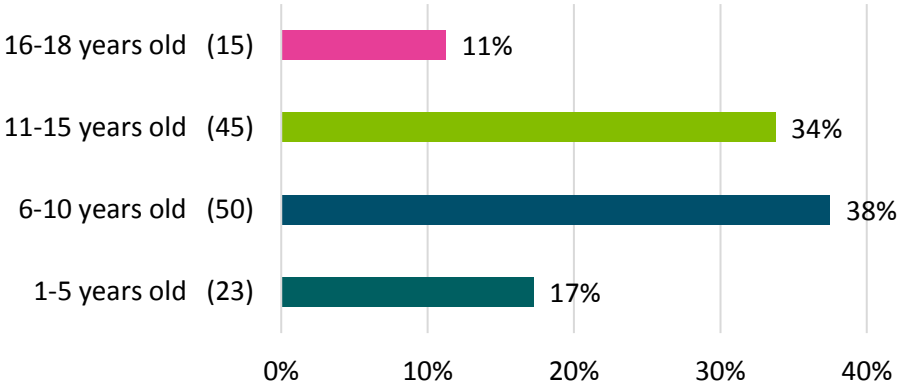


Figure 5. Age of Children from the families involved.

4.2 Using health and social care services

When asked about what health and social care services they had accessed within the last two years, it was clear from the feedback that families were commonly accessing a wide range. This included general services such as the GP, dentist and hospital as well as more specialised services such as CAMHS, SALT and community paediatricians. This might be as expected, since individuals with autism can often have co-occurring conditions that impact upon their needs such as; epilepsy, obsessive compulsive disorder (OCD), learning difficulties (LD), dyspraxia and Attention deficit hyperactivity disorder (ADHD), therefore they may need more support with managing their health (NAS, 2018a).

4.2.1 What has worked well?

There were mixed views on services according to families' feedback. The services families had come into contact with received a wide range of overall ratings from 'very poor' to 'very good', demonstrating the contrast of experiences encountered across Norfolk. Unfortunately many families had received what they regarded as poor services. This was often remembered as there being a lack of understanding and awareness of ASD within services as well as a lack of services. Often services were dropped from families resulting in being left with no alternative to move forwards. Consequently this resulted in parents highlighting their concerns that 'very little had gone well' with health and social care services locally. Frequently parents openly described accessing services as a battle and fight for them and their child, particularly those struggling to get help and support for the first time *"You can't get into the system to get help!"*

- *"Nothing as still have no proper support for my son due to this he is currently out of education."*
- *"Nothing has worked well. Every service is flawed and underfunded."*
- *"We have faced with a lot of barriers or red tape. As a single parent bringing up 4 boys, 3 of which are ASD. I have to fight to get help. To get respite for the children and myself. As I have no family network to support me. It has been a real uphill struggle."*

One parent described being unable to find positives from their experiences due to a lack of support and involvement from health and social care services, often only questioning the families parenting.

> *"Not sure I can think of anything! It took 2 years to get a diagnosis from the time they said he needed an assessment. Our only contact with Social Services was when he was younger (pre-diagnosis) and I was sent on a parenting course (which didn't really help much except for me to realise that his behaviour wasn't because I didn't know how to parent)."*

- **Accessing services is difficult but good once you are in**

Families recognised the difficulties they had faced upon trying to access health and social care services, they expressed a feeling that there were never enough appointments to provide timely access for their child. Yet once families were 'in the system' and in contact with and utilising services they received good care. *"Fighting for my child, Newberry is a good place but getting in there is like getting blood from a stone not enough appointments."*

> *"When you actually get to see the clinical psychologists, the quality of the diagnostic service and care is fantastic - knowledgeable people who communicate well with the child and parents. The problem with the assessment process is how long it takes…"*

Families felt that some services worked well in developing positive practical strategies to enable the child and work with the family. In these instances parents sensed that the professionals were working in the best interest of their child and working well together. For instance one parent described how services involved had worked alongside her child and the positive impact this had on her child and her ability to cope with her feelings and her condition; *"Sensi support on a weekly basis including support from speech and language therapy. This has helped my child to develop strategies to regulate her emotions and the clinical psychologist worked really well with my child."*

- **The importance of understanding ASD and the child**

Parents reported some health and social care services as 'very good' such as hospitals and community dentistry services. Some families spoke favourably of accessing services where professionals seemed to have an awareness of ASD. They emphasised the benefits this had on their experiences as a family and the differences this made to support their child's needs to get the help they required. *"Daughter has HMS/Dyspraxia/ADHD with autistic tendencies/Tinnitus we have used the out of hours and ambulance service and all have been very patient and understanding with her". **[Out of hours]*** and *"Daughter swallowed a battery due to her speech delay and suspected ASD they kept her in overnight because they knew that it would be difficult for her to tell us something was wrong. They were wonderful."* **[NNUH].** One family highlighted how health visitors spotted the signs of ASD and listened to the families concerns, *"We as parents were listened to. We were seen at home an assessment carried out after we felt our daughter was displaying signs of ASD". **[Health visitor** -Cambridgeshire community services].*

It was acknowledged that professionals with an understanding of ASD were supportive and patient when working with children, allowing them to further understand a child's needs and behaviours. *"It has worked well when the professionals have been patient and understand my boy's needs. They have been supportive and understood when my boys have displayed anxious or challenging behaviour."* Parents said that services they accessed were good when they understood the struggles they faced and listened to the child, supporting and enabling them to start to trust and build a relationship with the professional. *"When people listen to [my child], are patient with him and tell him what to expect. When there are facilities which can entertain him when is waiting"* and *"People understanding. If someone understands and sympathize with you and the struggles you face, you almost feel like you can relax and build a relationship with the person."*

Consistency of staff was also seen as another vital tool to enable an understanding of ASD and the child, *"inconsistency with social workers…in five months we have had three social workers!"* One family expressed what a difference working with the same professional has made to their family and how they valued their support.

"We have had a paediatrician who knows my children and has known my daughter since she was little. She has listened and understood the complexity of the presentation of the condition. She has been the only one who has helped us."

- **Appointments – processes explained and approach adapted**

A spotlight was placed on the value to amending appointments and processes to meet the needs of autistic children when they came into contact with health and social care services. Parents described the difference it could make if you have a professional with an understanding of ASD and the child, using this to develop and alter their practice. One parent highlighted a good experience where a service, explained a procedure and equipment they were to use directly with the child first. *"In attending CDU/Jenny Lind being able to look at equipment and have it explained first (like scales/height measure) before using it has worked well."* Similarly one parent vividly portrayed the traumatic experience her child had been through in the past, how this had improved now that there was a clear diagnosis of ASD, meaning services were more understanding of his needs and were actively trying to reduce anxiety.

> *"When visiting the N&N A&E or Clinics now my son has a diagnosis I tell staff they are brilliant with him before this he would go through traumatic experience of being restrained. My son regularly attends ADHD clinic they also support and give advice on ideas to support my son educationally even though Autism is not their area they have brilliant ideas and sometimes write supporting letters to help him access what he needs the fact he has ASD as well they help make suitable appointment times also to reduce the levels of my son's anxiety I am concerned when my son hits adult services how he will be supported."*

Other examples parents gave included giving the child and family a timeframe of how long they may have to wait at the service for their appointment. This was particularly useful in one parent's view if a professional was able to physically tell them.

> *"Also being given a timeframe of how long he will need to wait (obviously appointments don't always run on time), but he gets very agitated when we go past the 'time' of the appointment (even if I explain it is just a delay, and he's not been forgotten) and he will insist on going up to reception and keep asking, which can come across as being a bit aggressive or 'shirty' but is really just anxiety, so knowing the expected wait times from someone or something "official" (not just his mum) is useful."*

Another parent found it very good when services had planned their child's appointment towards the start or end of the day, to try to reduce anxiety and

waiting times, as well as using other professionals to work with the child in appointments to enable a more successful meeting.

> *"The community paediatrician was considerate in that she deliberately put our son's appointment at the beginning or end of clinics so she could spend time with him and he wouldn't have to wait too long in the waiting room (although in our experience him being put first on the list was more successful as she overran on the day we were last on her list and our son was climbing the walls nearly with anxiety about why he hadn't gone in yet). The second time we saw her she also had a doctor observing and he essentially spent the whole appointment with our son drawing so that I could talk to the paediatrician which was a big help."*

- **Reasonable adjustments – environmental changes in waiting rooms**

Our findings demonstrate that environmental factors can have a big impact on children when accessing health and social care services. Noise and lighting within waiting areas were commonly seen as big influences on children's ASD and sensory processing which could often result in children becoming over stimulated and unable to cope due to their sensory needs. One parent recalled how beneficial it was to their child to have access to a quieter waiting room when using a hospital service in Norfolk.

> *"Using children's ward, great staff, allow for full parental involvement. Has special area for the older children. This was particularly useful for my 16 year old son who does not like the noise and mess made in a normal children's clinic/ward for small children and babies' toddlers etc."* **[JPUH]**

4.2.2 Barriers and improvements needed

One issue indicated and evidenced strongly throughout parent responses were the barriers families faced when trying to access help and support for children with ASD. One parent stressed that *"No one seems to want to help and never follow up on anything"* whilst another felt that there were *"…barriers all the time"*. With such barriers in place parents recounted the effect and drain this can have on families, having to push and fight for the services that your child is entitled to.

> *"Accessing them. There now seems to be so many barriers/hurdles put in place that you have to 'jump' before you can access the services that you need/your child is entitled to. If you are not a determined parent it is too easy to fall by the wayside. Once you do get accepted by a service you then have months of waiting time before you get an appointment. The whole process is taking too long."*

- **More availability of integrated services**

One aspect of services that stood out which often linked to poor experiences from parents' perspectives, was not being directed to any services that could help. Where it was clear that the child needed some help and support in a timely manner but getting access to the right service often proved problematic. One parent recalled trying to access help after a diagnosis of ASD but was unable to get any support or advice on what health and social care services could help with sleep issues her child was facing; *"Was diagnosed then told that they can't do anymore so being discharged then went back for help and got told couldn't help with sleep issues but couldn't give me any one who could." [Child development centre Upton road Norwich].* One family emphasised the lack of services/support available to them despite the child being unable to attend school due to their difficulties.



> *"Unable to get referred when son clearly needed help. GP desperately trying to get our son referred and anxiety extreme and depressed and unable to go to school. The whole family being effected. Son stating not wanting to be alive and tried to self-harm but still was told not suitable to be referred."*

Families expressed the realities of living with a child with ASD and the lack of services available to help their child often with families unable to access services, *"we get no other help other than medication. There should be more things available that help parents/carers with their children. i.e. help with different strategies."* Many families highlighted the lack of services available across Norfolk resulting in being left to cope once a diagnosis is received, some described as being dropped from services, whilst their child continued to develop and their needs change. One parent described being promised support post diagnosis and

this never materialised; *"Some sort of follow up service post diagnosis, I was promised a call to see how things were going last June when given my son's diagnosis and it still hasn't happened!"*

> *"Shorter waiting times, more support post-diagnosis, preventative mental health care acknowledging these children are more at risk. Also this is a lifelong condition but once you have a diagnosis you are discharged from health and social care and expected to cope with a child whose needs are changing as they grow up. Voluntary support services are all that is available."*

Often families described ASD as a barrier to accessing services. Many health and social care services are reported to suggest they are unable to help and work with a child because of their ASD, as they are not the specialists on ASD. This has resulted in families being bounced from service to service as it seems like there is no single service to offer help and take responsibility. *"Six referrals to CAMHS, yet it had to get to the point where we couldn't cope but CAMHS say they can't help because it sounds like ASD"* and *"refusal to support due to ASD putting all issues down to this need, rather than looking at other possible causes."*

> *"We have been pushed from service to service for a long while and my daughter now believes that no one can help her so what's the point. There is also a huge wait to be seen by anybody that it's difficult to feel that you are getting anywhere. Staff shortages and funding cuts do not help as there is no consistency for children who need it the most."*

This became particularly apparent when parents described the difficulties their child often faced when trying to engage with professionals because of their ASD. Despite this it was often recalled how services would start to work with a child but services were so quick to be removed and therefore discharged, particularly relating to health and social care services.

> *"CAMHS have a neurodevelopmental disorder team but if your child cannot engage…anxiety due to Autism and bye. SALT only do to 'Functional speech' then bye. No work around emotions/social skills anxiety. No psychology help. No OT help for motor difficulties. No support from County Council. Previously told does not meet criteria as not LD."*
>
> *"Referred to the Newberry and the doctor just dismissed then referred us to Silverwood to see in six months' time. He had Play therapy and then family therapy which worked well but there was only one session in two months, that's it and he's been discharged."*

- **More timely access to all NHS services**

A frustration commonly held amongst this group of parents was the long wait many experienced to be able to access health and social care services including an ASD diagnosis. *"The length of time between appointments and diagnosis is too long, our daughter would be able to access so much more if her diagnosis was quicker."* Many understood that the services are under pressure and stretched but recalled the reality of what this meant for the child and there family. Delays in accessing specialist education and delays of receiving critical services input, all at the time when early intervention was key to children's ongoing development. *"The paediatrician who has also been very good but we are seeing him next week for the first time in 9 months..."*

> *"My son can't get into the SEN school he needs to transfer to without the formal diagnosis. The wait time is outrageous and is having a detrimental effect on both his educational needs and emotional/health needs. Despite complaining about this dire service, nothing can be done to speed it up."*
>
> *"The service is overstretched and so the waiting lists are long and it is difficult to get a timely assessment, which has put us in our current situation of having to move on to adult services as there is no way he will be assessed in the 4 months until his 18th birthday."*

This in turn seemed to have a knock on effect to all appointments meaning that there were long periods of time where families had no contact or very little contact with services until their next available appointment. This caused concerns as parents often described how quickly things could change for their child as they developed. *"Waiting times, I understand that it takes a while to gather information that is needed, I also recognise that waiting lists are very high, which in turn makes waiting times in-between appointments very lengthy."*

- **More clearer communication, information and advice**

It was also recognised that communication could be improved when accessing health and social care services, including communication with parents and families, communication with individuals with ASD and communication from service provider to service provider. It was apparent that it was very frustrating for families to feel like they are no further forward when using health and social care services. *"Lack of communication between departments. Lack of communication with parents so that we know what's happening behind the scenes so that we don't feel as if are forgotten yet again."* Another parent highlighted the need to repeat 'your story' each time they used a service and it felt like services were often disjointed. *"More communication between the different professionals you see, otherwise you have to explain yourself multiple times over which is quite tedious."*

One parent described how a service focused on conveying what the parents should be doing without highlighting what the service would do to support this. *"…Speech and language who are pointless and saw her at nursery in July, and gave me a list of everything we already do, but didn't even tell me what they were doing."* One parent urged for more communication between professionals to follow up on what parents were promised in meetings across the NHS; *"lack of communication between consultants, no one following through on areas of support or investigation for cause of health issues that is promised, trying to discharge because have a diagnosis."* One parent highlighted the confusion caused by a lack of communication from services:

> *"Play therapists actually being available, staff listening when a medical procedure is needed to what support the individual child will need, not having two year waits for dental surgery with still no date due to poor communication (separate to the appointment noted) involving multiple hospitals and still poor communication and sent round in circles…"*

In further support of the above statements about communication, one barrier evidenced very strongly was the importance of parent's voices and the sentiment that many parents felt they were not listened to by professionals. They felt their voices often had little impact. *"The feeling that I am not being listened to or taken seriously. I am just one of many parents that they are trying to process."* Some parents felt 'brushed off' at appointments that had often taken many weeks or months to reach, *"Takes a long time for an appointment, or to be felt although you're 'taken seriously' by a medical professional, not just brushed off."*

One parent recalled the difficulties they had due to a lack of understanding around ASD when accessing appointments as her child struggled to trust new people and work with them *"My child's anxiety about new people and new situations. Being asked by professionals to 'let my child speak for herself' when she can't or doesn't want to."* Parents signified that on many occasions *"…a lot of blame [came] towards us as parents…"* yet they felt they often knew their child best and knew what was usual behaviour for them and therefore proposed that their word should be just as valuable as anyone else's. *"As a parent, I do know what I'm taking about in relation to my child. I understand them and live with them. As their carer my views should be taken seriously."*

This was one parent's exchange on how health and social care appointments usually occur based on their experiences:

> *"As my son is 16 my concerns were second as his voice had the most power. But as he finds communication with strangers difficult it often showed he was disengaged or rude or not bothered. So as a parent I spoke. I found that the doctors or other professionals think that I as a parent exaggerate the issues raised and the situations that my son were/or was in/or is in, was not that bad or dangerous."*

Overall some parents stated that knowing where and what to access in order to help your son or daughter was one of the biggest barriers in reference to health and social care services that needed to be overcome. *"More support. Knowing where to go to get help. What help is out there"* and *"single point of access- clear information and signposting, an allocated family worker."* For one parent the NHS diagnostic pathway for ASD proved quite confusing due to a lack of communication and information given to parents throughout the process; *"having more support/communication during the assessment period. No one explained or gave us information on the process/timescales/what needed to be carried out."* (See Appendix 7.2 for family case study.)

- **More continuity of staff**

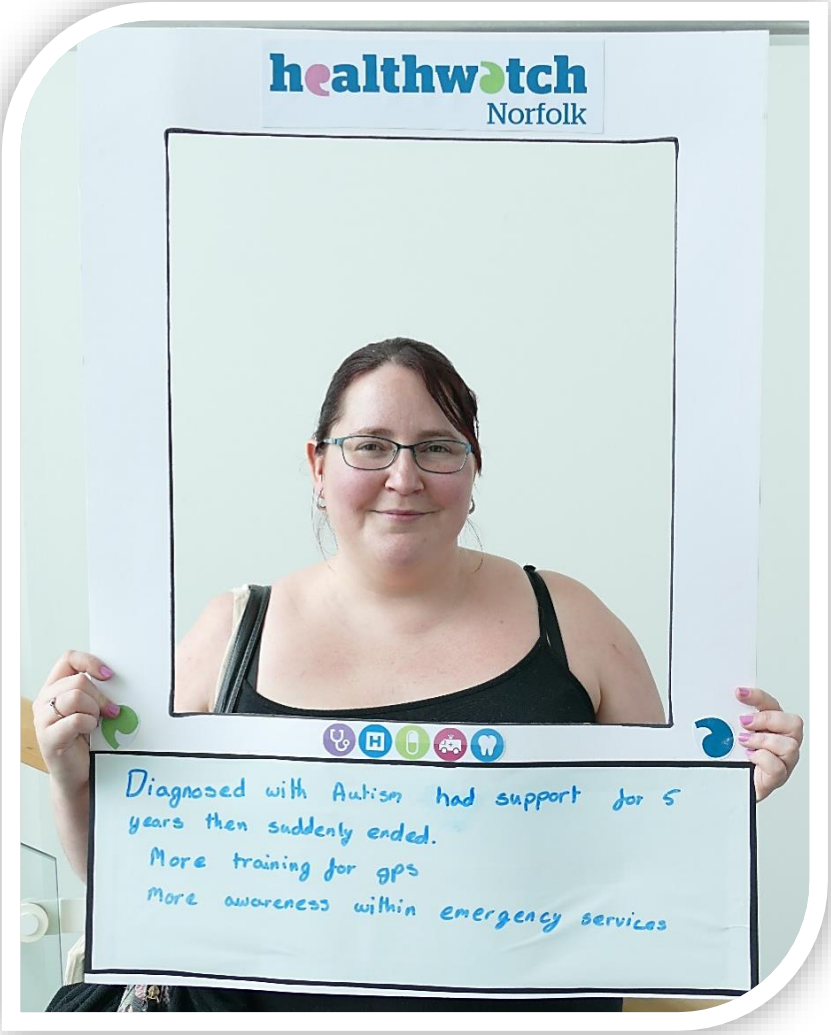
An opinion evidenced throughout this project was the lack of ongoing consistency in staff working in NHS services related to an ASD diagnosis or SALT. Families recalled from their experiences there was a high turnover of staff working within health and social care services, which resulted in their child being seen by a wide range of staff from various services. *"Too many people involved…not knowing what each other are doing, constant changing of criteria, long or closed waiting lists and poor communication plus a lack of staffed services available/huge turnover of staff or untrained."* This caused further concern with notes sometimes not being read prior to an appointment, yet these were often vital to understanding the child and their behaviour. It was felt quite strongly by parents that this was where their voice was important at acknowledging what was usual for their child.

> *"The staff changes is a big one. They read notes and sometimes unless they know the child they make an assumption and sometimes unnecessary referrals get made when actually it's just child being the norm for them. Notes are read as they are written there is no personality attached to them. If there was more explanation of child's character then the above would not happen."*
>
> *"…understanding when children are struggling during an appointment, actually reading a child's notes before appointment, so if they are not who they see for neurological difficulties they understand why the child may be behaving the way they are."*

For individuals living with ASD continuity of care is of great importance as families described how their child can struggle to develop relationships and without this they may not begin to work with professionals until they feel comfortable to do so. Parents felt that there was no continuity of care for those that needed it most, often due to lack of funding or changes in services therefore *"...a greater emphasis on continuity..."* was required to improve services locally.

- **More understanding from General Practice**

One common theme that arose from parent's feedback was the lack of awareness of ASD within General Practice, specifically when consulting with a General Practitioner (GP). It was noted that GPs are extremely busy and overloaded currently but some parents found that some GPs had little understanding of ASD. *"Everywhere is a barrier. I've struggled to get past the GP."* GPs were not always aware of the signs of ASD and how they might best support and interact with patients with ASD during their consultations. *"The GP just says take her to A&E, everything's always put down to their special needs."* And *"...upon attending our local GP he doesn't understand X [the child] issues."* They recalled often struggling to understand the needs of ASD children and how to support them locally. At times parents recounted the lack of awareness of referral processes for ASD diagnosis.



> *"Bit of a fight with the GP to write a letter and refer us on to instigate an appointment somewhere. The referral was sent to Silverwood but I was told that the GP hadn't sent the referral so I had to chase this with the GP and then it did get sent across."*

In May 2016 a resource pack was created by The Royal College of General Practitioners (RCGP) to raise awareness of ASD in General Practice. It contained resources to enable practices to become autism friendly and was posted out to all practices across the UK (RCGP, 2016). Interestingly, from discussions with some local Practice Managers in Norfolk none seemed to recall receiving this resource. This was not surprising given all the mail and other things General Practice receive on a day to day basis. As a result of developing this resource, there is an online resource available for anyone to access but is targeted at General Practice,

however this online toolkit may need updating and adapting due to when it was originally pieced together back in 2015/2016 (RCGP, 2018).

Alongside this, parents expressed their anxiety towards General Practice as it seemed for the majority there was no basic awareness of ASD and no clear understanding of what this means for patients accessing their service. It was felt that this was something that needed to be addressed locally. One parent went on to describe how recently she had some difficulties with her child and the GP practice due to their age. She explained that they wanted to do a medication review but they would not talk to the parent because her child was 16. The parent emphasised the lack of understanding at the practice as despite his age due to his ASD he would not be capable of talking about his health needs and understanding what is asked of him. Despite these comments surrounding GPs some parents did highlight some very supportive GPs that they valued whilst some felt *"Kinder GP's who have more time to listen and are not under so much pressure themselves"* were required across Norfolk.

> *"Now our son has been discharged from the ASD assessment team, our only recourse if we need any further help will be going back to the GP. This fills me with dread because firstly the GP practice is not well trained on ASD (they failed to notice his autism for 12 years and prescribed beta blockers for anxiety). Secondly I fear a long waiting list for whatever service might be needed. I have heard so many horror stories about the lack of support for children post-diagnosis."*
>
> *"I was told by a GP that they weren't referring to CAMHS as the service was at breaking point. I was offered another service which I said I'd already been in touch with and we didn't meet there criteria. No alternative was given for my child with autism." **[Hellesdon medical practice]***

- **More understanding of ASD and difficulties faced in appointments**

One experience that stood out across all families' feedback was the lack of understanding of ASD across all health and social care services. One parent expressed a flaw some professionals held thinking that they understand autism, when realistically they had a limited understanding. *"…little insight into their own shortcomings in terms of up-to-date knowledge about autism and Asperger's. They believe they 'know about' autism, but what little they know is usually out of date and often accompanied by unconscious prejudice against people with autism.*

Families felt that professionals did not understand what it was like to live with ASD and the effect this has on individual's everyday lives causing difficulties in completing everyday tasks. *"For someone to understand ASD, ASD traits sensory needs, and to understand how everyday things that people without ASD find easy c*

children with ASD can find it extremely difficult." In support of this parents stated that their children's differences could also make attending appointments quite challenging, particularly if the child wants to escape due to being sensory overloaded; *"Her speech delay is a massive barrier. It's difficult for me to understand most things let alone someone else. She also doesn't like being in one place for a length of time so she becomes restless and will try to escape."*

One parent felt quite strongly that attitudes need to change around ASD and that professionals need to be aware of the effect their interaction can have on a child.



"People to have the patience to understand that with autism you are going to get behaviours. It's going to take people who have autism a lot longer to be looked at. They don't always understand what's going on. Things they hear see [and] smell are going to upset or make them curious and may need time to touch, smell possibly lick etc for them to process their surroundings. And people's attitude towards autism need to change. They may feel like they are having a bad time treating someone with autism but that's nothing compared to the child with autism is actually going through. They are acting this way because they don't understand, don't feel safe or it's out of their daily routine. So please be patient with them."

Further to this families portrayed some of the difficulties they faced due to a lack of understanding, however physically getting children to an appointment could also prove a challenge, especially if it fell outside of the child's usual routine. *"Getting them to an appointment that is not routine. School time appointments don't work as that's not our routine."* For many families of children living with ASD, routine is vital and enables them to cope better in their surroundings, therefore you can imagine the anxiety and tension caused by taking a child to somewhere new. It was

also acknowledged that having the child present at appointment was important, but making them feel included and involved was key as one parent recounted a poor experience they received: *"…Appointments where the specialist does not talk over the child's head. They should be involved in the questioning, or taken out if this is not appropriate. My daughter did not like us sharing her intimate details in front of her."*

Waiting areas in services were commonly referred to as noisy and unsuitable for children with ASD (who often experience sensory overload), especially when they found waiting quite difficult. Parents suggested that when making a service autism friendly the environment and waiting areas need to be closely considered, to be more approachable for children and reduce the distress caused.

> *"Busy waiting areas, long waits, nothing to entertain the children, distress because they feel like they are waiting in a babies room due to only provisions being for preschool children, when having to attend with both children alone staff become distracted by their behaviour and fail to complete appointments."*

4.3 ASD Diagnosis

Families were asked if their child had an ASD diagnosis. Of the 112 families, 97 chose to share this information whilst 15 families did not share any details. Interestingly for this sample of families, 63% (61) had received a diagnosis of ASD for their child, compared to the 32% (31) who did not have a diagnosis. A small number of families had sought a diagnosis privately (5%) whilst the majority were diagnosed through the NHS (63%). It was unclear if families had no diagnosis because they were still waiting in the process or because they had been denied it once on the one of Norfolk diagnosis pathways. It is difficult to disaggregate which service is offering a speedier diagnosis due to the number that have responded.

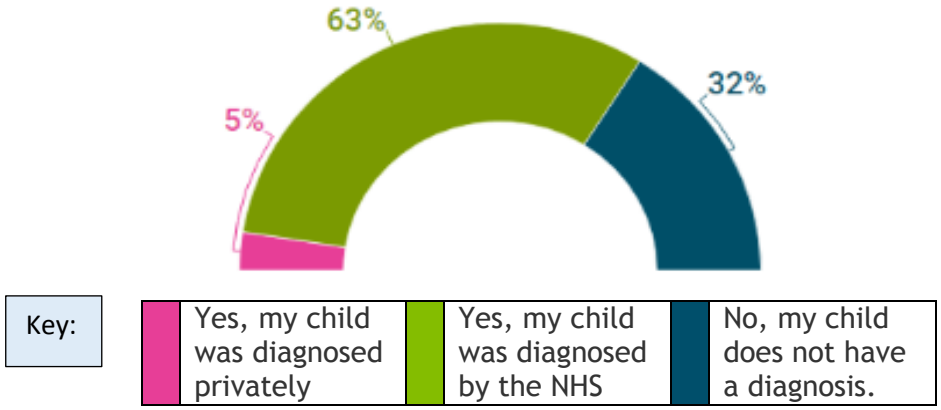


Figure 6. Does your child have an ASD diagnosis?

Families in Norfolk seeking an ASD diagnosis were using one of two NHS diagnostic pathways dependent upon where they lived in the county. For the families

involved in this project there was an uneven split between those accessing the Great Yarmouth and Waveney services through the JPUH and those accessing the other pathway operated by NCHC across the rest of Norfolk. Of the 61 families that had received a diagnosis, **17 families were accessing services from JPUH** and **44 families were accessing services from NCHC**.

Families were asked how old their child was when they were referred for a diagnosis, 97 families chose to share this information which equated to a total of 107 out of the 133 children. Children were most likely to be referred for a diagnosis between the ages of 2 and 10 years old. Most frequently children were referred when they were aged 2-6 years. Sixteen percent (16%) of children were 4 years old, 15% were 3 years old, 14% were 2 years old and 10% were 6 years old. There were fewer occurrences of children being referred once they had hit secondary school age, 12 years old and above (see table 1).

Age of Child (years)	% of children
1	1%
2	13%
3	14%
4	16%
5	7%
6	10%
7	8%
8	6%
9	6%

Age of Child (years)	% of children
10	6%
11	3%
12	6%
13	2%
14	0%
15	1%
16	0%
17	2%
18	0

Table 1. Age of children when referred for ASD diagnosis.

Of the 112 families involved in this work, 96 families identified how long they had waited to receive a diagnosis of ASD for their child. 91 families were accessing NHS services for a diagnosis and reported waiting between 3-6 months to over 5 years, this demonstrated clear differences in waiting time for all families in Norfolk. This does not included 5 families who had an ASD diagnosis undertaken privately.

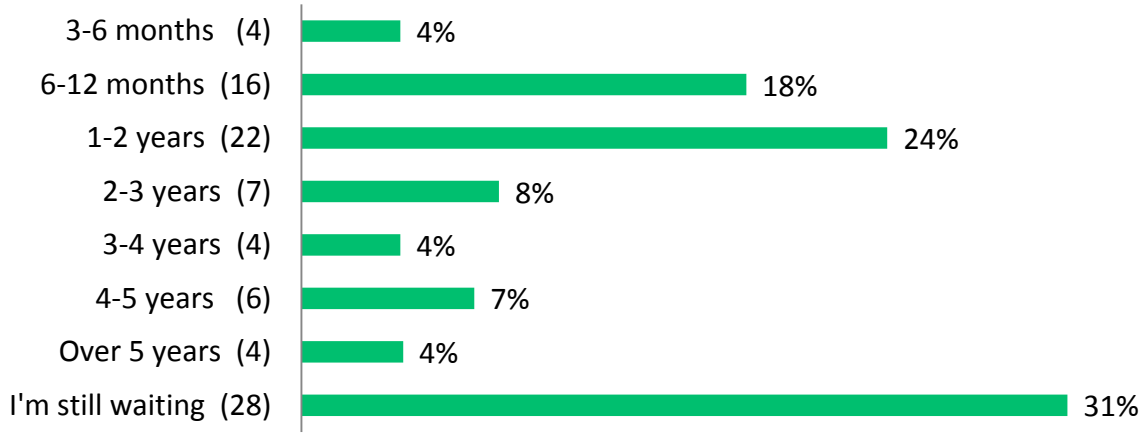


Figure 7. How long families reported waiting for an ASD diagnosis in Norfolk.

It was promising to see that 56% (42 families) had waited less than 2 years, however unjustifiably this is still a very long period of time in a child's life. Despite this, there were still 31% (28) of families who were still waiting for an ASD diagnosis but it is unclear how long they have been waiting for within the system (waiting list). It is alarming to note that 21% (21 families) had waited between 2-5 years plus until they eventually received a diagnosis, of which 4 of those 21 families had to wait over 5 years. Families have reported that this process can have a knock on effect on children's education and development, particularly so if children are not receiving appropriate support within the school environment during the wait for a diagnosis, meaning that for some children they may be out of education completely.

Our findings indicate that 50% (42 families) of families rated ASD diagnostic services in Norfolk as 'very poor or poor' across Norfolk, compared to 27% (22) rating them as 'neither good nor bad' (based on 83 families of the 112 who chose to rate their experiences). A further 22% (19) felt the services were 'very good or good' based on their experiences (see figure 8). This suggests that many families were not happy with the service they had accessed and this rating may be directly linked to the lengthy waiting times currently reported for ASD diagnosis across Norfolk.

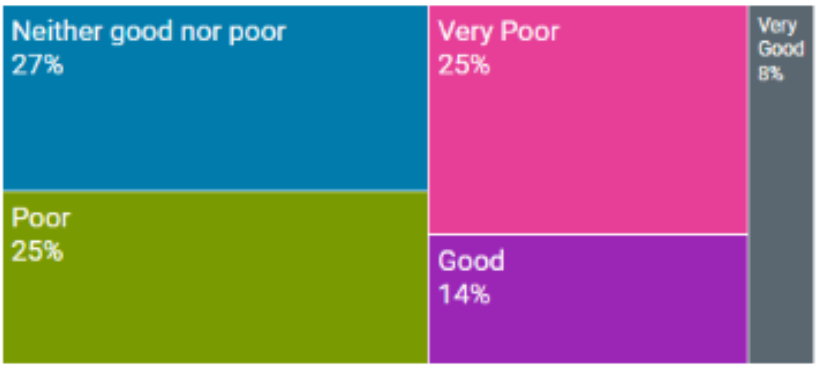


Figure 8. Families overall rating of diagnostic services.

This is inevitable that it may influence parent's views of the services if they are unable to access timely help and support for their child when it is needed. In contrast there were 8% of families (7) who had a 'very good' experience according to our feedback we received.

From the detailed feedback we received from parents about the ASD diagnosis process, it was clear that there could be some learning and developments made by improving communication. Frequently parents recalled not being aware of the process for the diagnosis and this commonly was not explained to them, *"You're on a pathway but no one tells you what direction, where you are going!"* Parents stated that more communication was required, especially to explain the timescales and process involved due to the considerably long waiting times. *"Having more support/communication during the assessment period. No one explained or gave us information on the process/timescales/what needed to be carried out."*

Parents felt this needed to be addressed in order to improve the services. Parents need to be aware of the process, particularly so they can talk to their child and explain what may happen too. Parents saw this as vital to enable them to answer questions their child may have and reduce their anxiety. *"The only thing I would improve is by having a plan/chart available to show the diagnosis process and the various steps along the way....as I was always wondering what the 'next stage' in the process would be."* ***[NCHC pathway]***

> *"Timely services. Accurate and timely information - in our referral to community paediatrics and referral to the ASD panel you do not know how long you are going to be waiting or what will happen when you finally get an appointment. E.g. we didn't know what assessments our son might have on the ASD pathway until we received a letter inviting us to an ADOS assessment [autism diagnosis observation schedule] or what might be needed other than this. Waiting is slightly more bearable if you know what you are waiting for and how long you might have to wait. Our son asked us questions about the process and we could not answer them because we didn't know ourselves. When we rang the ASD panel phone number for an update a polite answer phone message said not to leave a message they were too busy."* **[NCHC pathway]**

One parent described the frustration the lack of communication caused and the repeated times they had tried and tried to contact the service *"18 months is a long time and I'm still waiting, you just need to keep phoning and phoning"*.

Some families suggested that waiting such long periods of time without warning, all whilst this was affecting the child's day to day life and education was unfair *"you don't treat an animal like it why treat a child or adult like this…all that childhood gone without services given!"*. One parent felt they were not taken seriously and was just another family on the list. *"The feeling that I am not being listened to or taken seriously. I am just one of many parents that they are trying to process."* And one parent implied that this was such a lengthy and complex process that it may be too much for some families to cope with, *"some parents just close their eyes to it, the process is so complex for them that some will just give up and it is too much for them to register, cope with and digest."*

> *"Nothing has worked well. Every service is flawed and underfunded. We have been waiting 18 months for an ASD pathway assessment and still no idea how long we will be waiting despite enquiring and complaining about the service. Can't even speak to the pathway coordinator by phone."* **[NCHC pathway]**

Commonly we received more experiences of a lack of communication within the NCHC pathway, however one parent did highlight some concerns with regard to the Newberry centre and the JPUH pathway regarding communication in written reports. The parent described the importance of continuity of care for children undergoing an assessment but critically for ensuring that reports were completed accurately an appropriately too. *"Quicker appointments with continuity of care so you don't have to repeat yourself. Reports written to be accurate and not containing other children's names or sent to places your child doesn't attend (confidentiality issue)."* ***[JPUH pathway]***

There were mixed experiences of the NCHC diagnostic pathway and as you will see below some snippets of experiences from four families using the service, often issues relating to delays and processes not being explained.



"Lack of communication between different services. No support for parents who are waiting for a diagnosis. When we finally after 4 years received the diagnosis of ASD we we're briefly told about it and given several leaflets and sent home to sort it out for yourselves. It's really stressful having a child with special needs so to be finally diagnosed and given leaflets and shown the door is so overwhelming." ***[NCHC pathway]***

"I have rated it very poor because of the length of time waiting for the diagnosis. In particular it took 18 months to get an ADOS which took 60 minutes to then complete the diagnosis - why did we have to wait so long for an hour's assessment?" ***[NCHC pathway]***





"The staff were friendly and explained what they were going to be doing. It appeared to be well coordinated and we did not have to wait too long between appointments. [My child] was seen be a variety of professionals in a couple of settings. We were asked lots of questions about [My child's] history etc. The one thing I found difficult in the process was that it felt very negative about [my child], it was all about what was challenging and difficult, which I accept is was allows the professionals to make the diagnosis, however I think it needs to be acknowledged by professionals what is good about the child. On reflection, I think it made me feel more defensive and I overcompensated when talking about [My child] because I did not like hearing so many negative things about my child. I think it made my acceptance of the diagnosis a little harder." ***[NCHC pathway]***

"I think it was good that lots of evidence was gathered e.g. Nursery report, parents views, observations at home and nursery, paediatrician assessments. I feel very pleased that my boys (twins) were diagnosed before they started school. The only thing I would improve is by having a plan/chart available to show the diagnosis process and the various steps along the way....as I was always wondering what the 'next stage' in the process would be." ***[NCHC pathway]***



There were mixed experiences of the JPUH diagnostic pathway and as you will see below are some snippets of experiences from four families using the service.



"GP referral was prompt. Community paediatric review was comprehensive. Speech therapy service was excellent. Specialist nursery setting was made available to support observational element of diagnostic pathway. My only criticism was the amount of pressure required from me to move to diagnosis outcome. Delivery of outcome was brief, sense of relief followed by sense of isolation and no information about what support available from that point forward." ***[JPUH pathway]***

"Newberry clinic have been fantastic for my son from the first appointment. (There has been so many paediatrician, OT, physiotherapist appointments etc) to his diagnosis they have been so supportive and very helpful couldn't rate them enough." ***[JPUH pathway]***





"I started to notice that there was something different with my child at a very young age around 18months but health professionals wouldn't listen telling me it was normal behaviour, my son finally got referred to Newberry clinic at 6 years old by GP, it then took a further 18 months to get diagnosis. Which we was then given a leaflet for autism Anglia and told that was it, it was up to school now, that was 2 years ago, since then my son has been excluded 6 times and still doesn't receive the right support in school." ***[JPUH pathway]***

"It takes a lot of appointments & a lot of repetitive explaining before you feel as though professionals are actually taking your concerns on board. We have also felt quite patronised whilst explaining ourselves during a paediatrician appointments. There's also a certain feeling of "here's your diagnosis, off you go" and you're checked off a list to be forgotten. This is also a small issue for me personally, but when my child was diagnosed the paediatrician said "unfortunately he is on the spectrum". The use of the word "unfortunately" felt a little insensitive to me, perhaps a better choice of words is advised…" ***[JPUH pathway]***



4.4 Family Support

4.4.1 What support parents tried to access

Parents clearly conveyed how important support was and feedback shows it was crucial for the families involved in this work. Families had regularly tried to access support in a number of different ways from a range of sources, for example from parent support groups to specialist sensory support for the child. Most commonly parents were reaching out for support through voluntary sector organisations (63) and parent support groups (51), see figure 9. This reflects the picture of Norfolk's ASD services highlighting the lack of available support services for families living with children with ASD. As a result this is having a serious impact on the voluntary sector specifically organisations like ASD helping hands and Autism Anglia, who are now also stretched and struggling to meet the demands placed on them. Many parents have also expressed the vital role parent support groups have played in being welcomed to a group where there is an understanding of ASD and a place where no judgement is placed on families.

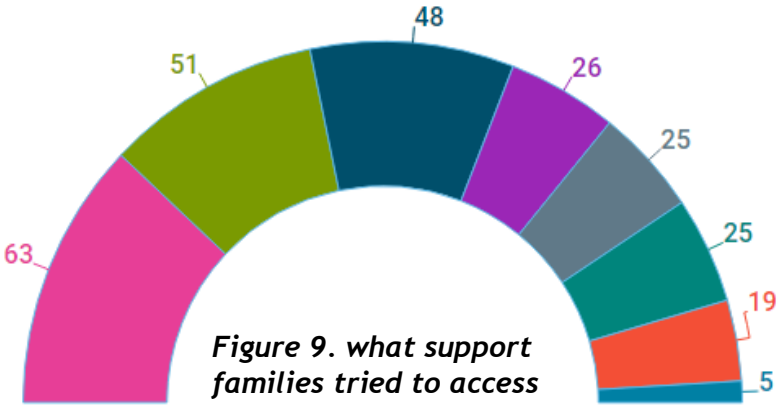


Figure 9. what support families tried to access

Key:	Voluntary sector	Parent support groups	Something else	Sensory support
	Norfolk Steps	Early bird course	Cygnet course	Not accessed support

A further 48 families highlighted that they had accessed alternative support to that listed in the parent questionnaire. This was phrased as accessing something else but it was not always clearly identified what it was parents had accessed. Some highlighted gathering online support through Facebook groups and at children's centres and their child attending youth groups. Whilst a few described having to pay for support to help and enable their child. Over a third of parents from this sample had commonly accessed parenting support programmes (44), such as the Early Bird (25) and Cygnet courses (19) specifically designed for parents with a child with ASD.

Families were asked how well the support they accessed met their needs as a parent and their child's needs. It was promising to see that most of the support accessed was viewed as 'good' or 'very good', with Parent support groups and voluntary sector support rated most highly as 'good' or 'very good' (see figure 10).

However, there was a mixed response to parenting support programmes across Norfolk. Interestingly, despite some positive overall ratings of parent support programmes, some families shared further detailed comments about their experiences. Some families highlighted frustration with some of the programmes due to waiting times and being unable to access courses, *"…we have been told we can't access the early bird course until our daughter is diagnosed so we are still waiting." "I was booked on cygnet course in 2016. Then got told the course had been cancelled and I would be informed of next date. I never heard back!"*

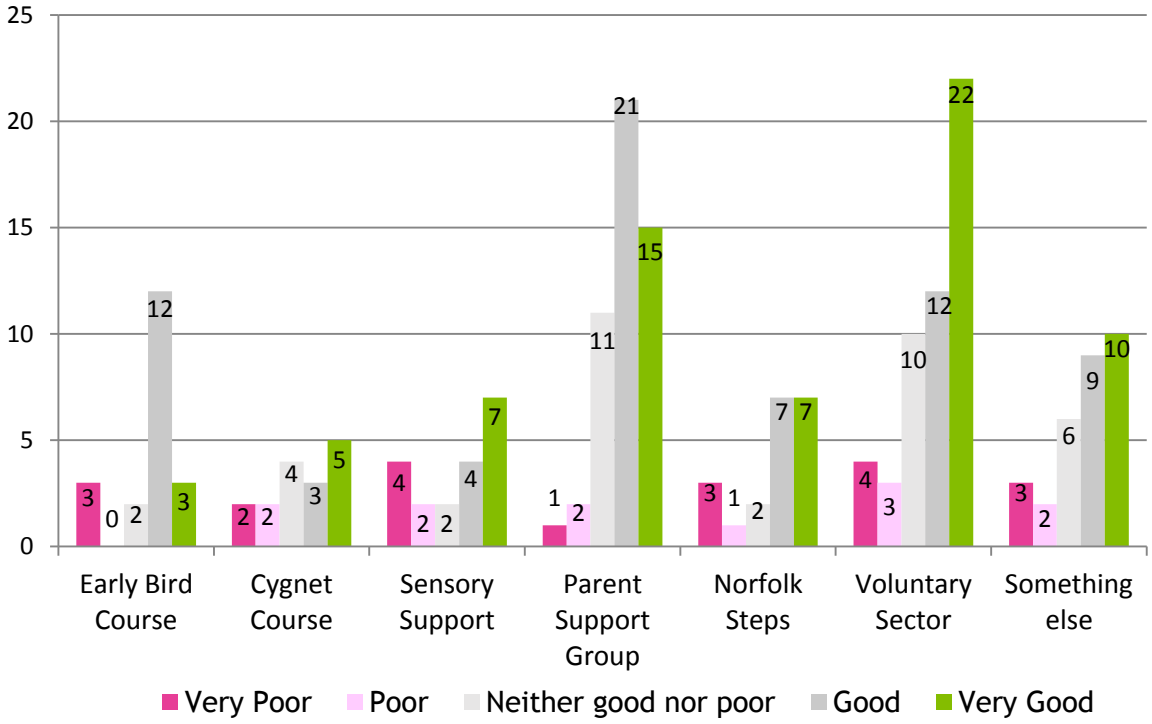


Figure 10. Families rating of support they had accessed

Others had been unable to access them due to the arrangements of the course *"Early bird was only offered on the days I work. I could not find anything to help on appropriate days or places…no one ever responded to emails."* Whilst some felt that the courses came too late, as parents reported having to wait two years after diagnosis to access it, which meant that the content often proved far less useful. One parent raised their concerns with course content often not demonstrating what they experience with their children at home, particularly in relation to gender difference and the way that autism presents in girls and boys. *"All the information is aimed at boys with ASD. My daughter displays very differently but that wasn't even suggested. I was left very confused by what I was learning not matching with what I knew at home."*

As evidenced earlier in this report frequently parents described having to fight to get the help and services the child needs and deserves, this in no different in respect of accessing support. Families recognised that there is little support available locally through the NHS, particularly post diagnosis. They described the feeling of being 'dropped in the ocean' and left to survive on their own. One parent recalled the only way to receive support was to pay for it, *"I have had to pay to get the right support for my children so that they learn and develop the skills they need to live."* In contrast, another parent felt there was support available but it was not easy to access. Linked to this one parent believed that the support available often depended on the severity of the presenting ASD. They felt that often individuals with 'high functioning ASD' could receive little support as they are seen to be managing which was not always the case. In her experience she and her family have been the ones providing reassurance in support of their child, *"as we are a thriving family and managing well, people are reluctant to help."*



"The degree in which my child is on the spectrum very much determines the amount of support you get. My son is high functioning and generally doing very well in mainstream school. This is through our continuous support of our son and being trained and working in the area myself so having capacity and the knowledge base to work with him to build on his difficulties. I feel if your child is high functioning, they are forgotten and just falls under the radar. They are deemed as 'coping', forgotten and then routinely discharged. This is completely wrong. Just because your child is functioning does not mean that there isn't hidden difficulties and emotional needs, not to mention worn out parents emotionally that have held their child throughout and require reassurance and support."

The impact on families

Parents highlighted the negative impact and toll accessing services for their autistic child could take on the family as a whole, and felt that commissioners need to understand this, *"commissioners needing to have better understanding of Autism (whatever IQ) and impact on child and families."* The lack of support available to families was seen as frustrating as one parent identified that they needed the support to help cope with the child at home, yet most of the emphasis was on the support within the school environment which is quite structured and follows a similar routine, quite different to the home environment. *"…Told the school have to support the child, but what do I do when at home?"*

Many of these parents were working and found themselves *"having to take time off work (unpaid) to attend appointments."* For others it was the constant range of appointments they were accessing that had caused stress on the family all at a time where they were trying to cope with their child's behaviour, *"back and forth all the while [and] you have a parent trying to cope with a child bouncing off the wall."* In some circumstances, a few families highlighted that in order to continue to support their child to access the right help, some had to stop working. Parents often spoke of the isolating impact they felt as a family, *"I feel like I'm housebound as [my child] doesn't leave the house."* feeling they were on their own and that no one was there to support them through this tough time. *"We are still incredibly isolated and my son hardly leaves the house. I wish there was more support available for him to access."* and *"Bringing up a child with special educational needs breaks families, marriages can't cope, parents can't cope. My child used to attack siblings and I have no family support…I feel like I'm stuck in a prison, it's like I live on my own."*

Others recalled their frustration at the judgement they received from individuals within the community often seeing their child as naughty due to a lack of awareness and understanding of ASD.

> *"I hate the judgement you get, I can't go out nowadays you feel like you need a sign on them. I say 'yes he has autism if you don't like it you can go.' They say they weren't around the diagnosis so they don't exist there's nothing wrong your son he's just naughty."*

Interestingly when discussing the ASD diagnosis assessment process one parent highlighted the impact that assessment had on their own thoughts of their child possibly having ASD. They openly suggested they were nervous about the ASD assessment for their child and had almost 'buried their head in the sand' with regards to its outcome. Despite this they spoke of the benefit of observing their child within the assessment process, behind a mirror window with professionals highlighting their concerns and how that day changed his life.

"As a parent sitting behind the mirror I was in 80% denial, picking up bits with help, parents pick up on so much behind the mirror. One hour and that changed my life that day, now no more denial. Every person should be given that opportunity."

4.4.2 Support families valued the most

- **Voluntary sector support**

When asked about what support families valued most there were five key common themes that emerged from families experiences. However one parent described being very grateful for all the support they received. *"I value all the help I have received equally as it has all played a big part to our everyday lives…"* It was clear that families valued support from voluntary sector organisations especially with regard to accessing more information and advice. *"Voluntary support has been the most helpful and informative."* A range of charities across Norfolk work with children with ASD and their families and often parents are reliant upon these organisations to provide advice and support due to a lack of NHS services being available once diagnosed. Often parents will call upon these charities before and during the ASD diagnosis process perhaps when they are unsure of where to access help for their child. *"Volunteer services have kept me sane while I fight for everything."*

Some parents recalled the valuable insight voluntary organisations have provided their child in developing skills and awareness and friendships in some instances. *"Membership of the NAS it give us a great outlet for our little boy." and "sunbeams play as they support the whole family and offer training social and support activities for us all."* One parent spoke of the value their child received in being able to access social activities and develop social skills and develop further as a person, *"my daughter has received support from…Fast Forward at Open (Nansa) and Fusion at the Base (Break). These have been invaluable with helping her develop her social skills."* Yet parents acknowledged that voluntary services were overstretched so support could be patchy at times *"ASD helping hands well informed just sadly too many families to try and help so not consistent."* One parent strongly expressed how their family could have been lost without the support of ASD Helping hands (charity) to fight for services for her child.

"ASD helping hands advocate advisor has been the most amazing relief in our fight for education, health and social care, and a diagnosis for our son. Services have been appalling and without ASDHH we would be in a much worse situation."

It was suggested that many parents just want to be able to talk to people who understand and can support them throughout the journey and the use of online forums has enabled this. This parent suggested she valued the Facebook group organised by collective parents in Norfolk who have a child with ASD or suspected ASD. *"Facebook groups - all parents really want is to talk to people who understand and can offer support during this ridiculous wait."* It is not surprising that parents are reaching out for support in this way due to the digital world we now live in and it may be that digital platforms could be utilised more to help support parents in similar ways.

This view was strengthened by one parent who expressed, "v*oluntary support groups, knowing there are people out there experiencing the same problems as us and giving support to each other really helps."* One important factor in the support parents received from the group was the lack of judgement. Parents were made to feel welcome and openly share their triumphs and tribulations.

> *"The ASD group we attend once a month, however this was found by myself, not through the NHS. It is good because we are with other children with ASD and parents that don't judge and understand our children and our lives."*
>
> *"Parent support groups. Now we have a diagnosis having somewhere you can go to seek advice and let off some much needed steam (at points) from people that are also living similar home lives/having the same experiences."*
>
> *"…other parents as you're not told anything you learn it from other people the fact you can speak to other people in the same boat you seem to have to fight for any kind of help or support and it's draining."*

Some parents emphasised that without parent support groups families would be lost *"You get a diagnosis…if you didn't come to a group like this you'd have no idea. No help out there…where would you go!"* and that each support group was actually provided a very valuable resource and service to parents which would be costly to replicate across the NHS. *"The only support we have is each other, if Norfolk County Council were to replicate this service imagine what it would cost. In some groups parents expect a fee."*

Professionals and families understanding ASD and the child

An opinion evidenced throughout this project was the importance of professionals understanding ASD and understanding how to work with a child with possible ASD. Linked to this was the importance of families and parents developing a higher level of understanding of their child and their needs in order to help and support them effectively to achieve their potential. In order for this to be achieved it was felt that professionals also needed to work with the wider family. *"SENSI because they have been so helpful to us all as a family."*

For one family a young carers group had proven to be a valued support to enable understanding for their sibling "My daughter attends a young carers group which gives her some respite and has helped her to be more patient and understanding with her brother." One parent recalled by developing a deeper understanding of their daughter they have been able to develop practice strategies to implement. It is these practical advice and tips that parents feel are significant. *"We have gained valuable insight into how our daughter thinks and feels as well as strategies to help her through each day, learning as best she can."*

Parents stressed how supportive it can be to feel that the professional is doing all they can for your child and taking parents' views seriously. One family felt without one key professional they would have no support and that did not bear thinking about.

> *"Seeing a CAMHS psychiatrist because he has given our son medication and has tried to get him therapy and also is constantly researching therapy we can try at home, but he unable to get him the therapy he actually needs for his OCD but without him we have nothing."*

Some parents urged the need for professionals to understand and build a relationship with their child to enable progress to be established, otherwise children will not work with them. *"They have lost faith in service within health and social care. He never wants to talk to a social worker again!"* In contrast, two parents demonstrated how it can work in practice:

> *"Early help have been the most consistent and have tried hard to develop a relationship with my daughter and understand her needs but also have provided support for the family."*
>
> *"Independent counselling. My son happily engages 'this is my safe place where I can relax 'why can't social workers be more like [the counsellor] and connect with me instead of ticking boxes on their clipboard and trying to patronise me'."*

- **Supportive schools**

Finally, some parents had experienced support from education and local schools to help support their child and recalled the positive impact this has had on their family. Yet for one family this was the only help they had received highlighting the lack of support available *"I have not really received any support from any of the services in Norfolk apart from our son's school!"* One family explained the difference it made having a school that was able to take on their concerns and spot the signs of ASD and act upon what they had seen, *"We have been lucky as moved up from Essex and within a term the school had realised she had issues and pushed heavily to help us."* Many families are trying to access Education, Health and care plans (EHCP) to identify and put in place support for children within the school environment one parent felt that her child's school were very supportive in assisting with this process as they had an understanding of their child and their needs. *"School. They know and understand [my child]. They have helped me with applying for the EHCP and they are easily accessible."*

4.4.3 Further support parents felt they needed

Families portrayed the lack of support available to them and demonstrated a need for further support going forwards. It was evidenced that they felt they needed support in five key areas:



> *"Personally I feel there is very little support out there for children with a diagnosis of ASD. It can be very isolating for parents. It appears you get your child's diagnosis after the usual battle and conflicting theories of what's wrong with your child to then be left on the shelf to deal with all the difficulties. The only help and support I've found beneficially was all dependant on the individual offering the help."*

As mentioned previous families felt that health and social care services lacked a basic understanding of ASD and how to work with autistic children when attending appointments. They felt that "m*ost services just don't realise what having or living with autism [is like] and how it can affect each individual."* Parents highlighted that to an autistic child, a clinical environment can be very scary and over stimulating and therefore felt that every effort should be made to make reasonable adjustments to the environment clinicians are working in to make it more accessible for children. *"Better support when in hospital environment which*

can be incredibly stressful for my child. Having a child with complex medical needs as well as likely autism means they are likely to experience situations that are incredibly scary." One parent described the difficulties their child has in attending medical appointments particularly at the opticians.

> *"Our son does not like missing school to go to appointments that makes him anxious, so sometimes it hard to get an appointments with services that do not have many hours outside of school hours. Our son was referred by an optician to orthoptics at the NNUH in December 2016 and he is still not discharged despite it being highly unlikely anything is wrong. This is because our son is very sensitive to having a light shone in his eyes and thus they haven't been able to see in his eyes properly. I feel he is wasting their time but maybe if they had more time on one occasion to work with him then he could be discharged and this would save time in the long run."*

It was also recognised that having a 'back up plan' would be useful for services if appointments did not go well. Parents felt that it can be very difficult managing an appointment, communicating with the professionals and caring for their child to ensure that they feel safe in appointments. If services were more aware of the impact of the clinical environment and the issues with waiting in busy waiting rooms and more flexible in supporting families when attending appointments, this would be beneficial. One parent felt that a follow up telephone conversation could prove effective in these instances if required.

> *"Think it would be a good idea to have someone with us when we go to hospital, paediatrician appointments to take notes as I find it so hard to concentrate as it takes a lot of effort to just contain him in the room, to stop him damaging property and to make sure he doesn't hurt the professional. It would be good to have a plan if a service didn't work well for us to be given an alternative."*
>
> *"My child also ADHD. Trying to have a very important rare meeting with a professional plus with a child bouncing off the walls is very hard. Telephone appointments in conjunction with the child's appointment would help with this."*

- More support for the whole family

Some families expressed the need for more support to wrap around the wider family including the child's siblings. Parents recalled the importance of keeping a good balance within the family dynamic to ensure that all of their children felt supported and comfortable. To achieve this within a family with an autistic child required consistency and routine, as without this, meltdowns would occur, *"I need professionals to be consistent and have regular contact as otherwise it really*

upsets the balance of my family at keeping meltdowns to a minimum." Many families came to realise the effect it has had on the rest if the family, especially the siblings, who often received no support. *"My other two have to put up with a lot but don't appear to get any support."* and *"The children need more groups and also family groups to be able to go to as I have learnt it affects siblings just as much."*

- More communication, information and advice

Our evidence demonstrates that accessing health and social care services can be quite complex and challenging for families with ASD or additional needs. It can be particularly complicated accessing ASD diagnostic services in order to receive a diagnosis for your child. With this in mind parents urged for clearer communication, information and advice to enable families to navigate health services more effectively across Norfolk, especially as the child continues to develop. *"Some advice as to how to cope and what services I might be entitled to."*

> *"It's difficult to ask for specific things as you're not sure what is available or what help could be beneficial. Would be handy to have someone to point you in the right direction when you have come across challenging behaviour you're not sure how to deal with. As things pop up from nowhere all the time."*

In relation to the ASD diagnostic service across Norfolk, parents felt that the process could be improved by providing more information during the process, as parents' view was *"If you don't say what's going to happen? They don't tell you."* This was particularly frustrating as parents noted the need to understand the assessment process and timescales to support their child *"Having more support/communication during the assessment period. No one explained or gave us information on the process/timescales/what needed to be carried out." One parent clarified the need for clear information due to her own autism and in circumstances where the parent also has autism clearer information is vital so that they can understand how to help their child. "Why can't they keep parents informed? Touch base with them. Just say if there could be a six outcomes but they don't know until the result, just say that. I have Asperger's so I just need to know what's happening…"*

Many parents also highlighted the need to have more information about what is available locally in terms of support. It seemed to be the case in regard to accessing parent support groups as parents were often trying to find a local group close to them particularly if they lived out on the coast or in very rural parts pf Norfolk. *"Better signposted information packs of local support or groups available."*

- More services with ongoing contact

SALT and Occupational Therapy (OT) were often alluded to as vital support that was lacking across Norfolk and possibly overstretched. Parents believed that these services needed to have a more timely impact on the child which just wasn't currently happening with the current provision across Norfolk. *"NHS OT and SALT intervention these are practically non-existent in our area..."* and *"more OT and SALT. The NHS provision is laughable."* Parents also urged the need for more services due to delays in current provision found across the county, *"Timely assessment then intervention. Early intervention is key to a good outcome. Having to wait five months already with no actual help or support is just lost time."* One parent identified one service that was supporting families well and highlighted that it was disappointing that this service was not available across all of the county. *"Sunbeams Play have been excellent in offering support for the whole family not just my son, it's a shame that the local authority cannot provide such an essential service when there is clearly a high level of need."*

Parents had heightened concerns over being able to continue to access support and services as things changed and their child develops. This was particularly the case with regard to puberty and further difficulties that can occur throughout childhood. *"Regular check-ups especially around puberty/teenage to adult years."* They felt they needed some ongoing contact or a way to get back into services effectively, rather than being discharged from service to service. *"Ongoing therapies not being discharged from every service."*

> *"impossibly long referral times and then very little in way of provision other than initial assessments, there seems to be no resource for ongoing or continuous support, my son is significantly affected by ASD and is not able to function even on many basic daily tasks yet receives nothing."*

Linked to the need for more services they suggested needing further support with challenging behaviour and strategies to help families cope with this behaviour when it occurred. *"The support needed with challenging behaviour is not there at all!"* Some felt they needed an ASD specialist service that could support this as otherwise they did not know where to get this support from *"…a service to support children with ASD would be nice."* and *"a specialist ASD support like there use to be."*

> *"Someone to be on the end of the phone for challenging behaviour, to be able to come to school and carry on working with and using strategies to help them grow. And help parents and teachers cope with new issues that arise throughout the years."*

- More access to Education and specialist provision

There was a sense that further support was needed from Education and schools. Some families expressed that they felt 'let down' by schools who have in families' eyes 'failed their children' in some instances. *"More support within the education system - that is where my child has been let down the most."* One parent described the lack of understanding in schools that was evident from their experiences, as children are often recognised as just being naughty within the school environment.

> *"Health and social care get it right, it's the education system we have always struggled with. Teachers not really understanding the difference in needs of ASD...boys with Asperger's are just seen at school as being bad or naughty. Teaching staff have very stereotypical ideas of what ASD is."*

It was also recognised that schools have their own budgets and agendas and at times it was difficult to establish what support was right for their child's education. They felt the red tape and budgets can at times overshadow supporting a child effectively.

> *"Support to identify the appropriate educational support he needs to be able to fulfil his potential in school. Unfortunately I am not sure we will get this from those in a place best to know this as schools have their own agenda in terms of trying to keep within the limited budgets and councils don't want to pay for support if they can get away without doing so…"*

Masking behaviour was also noted in the school environment. This is where a child may manage to cope within the school day and then behave very differently within the home environment, causing great concern to parents. Parents recalled their parenting also coming into question in instances where their child may have been masking their behaviour in school, which had a knock on effect later during the ASD assessment process. *"She's always been in mainstream and just seen as eccentric, she can mask her behaviour at school and would be hell at home and never slept. Parent seen as the issue because of other family issues."* The opinion was held by some parents that more attention should be paid to how their child behaves at home, rather than how they are at school. This was crucial during the assessment process when undergoing a diagnosis as schools are assessed to submit evidence regarding that child within their schooling. *"Rely more on what parents are telling you, not relying on school reports - especially when many children mask in school."*

> *"…as my son has sensory needs he behaves different in school as he is scared and releases when he gets home, it would be nice if more reference to observed behaviours in clinics would be used rather than in a school where a child tries to fit in."*

One parent gave a vivid example of the difficulties she had faced due to a lack of support from her child's school and as a result her child had missed substantial time in education and had been excluded all of which the parent was fighting to overturn.

> *"No Education in the last 15 months and not allowed to go into the school…they won't diagnose PDA as they say he is too young to be diagnosed. He was excluded from school, SALT called in at nursery and OT discharged. Newberry referred to OT as they said they can't get involved and we are just going round in a viscous circle. Changed his permanent exclusion to a fixed term one as I fought it and they have now recalled it. There is no support in place so I can't send him back to school."*

4.5 Good practice amongst Health and social care services

Alongside our findings from parents, it is important to highlight some good practice we have become aware of across Norfolk, recognising the efforts some services have made to develop their service to become more autism friendly. These examples demonstrate the difference services can make when staff have an understanding of ASD and the difficulties autistic patients may face when trying to access services.

- **Just One Norfolk**

Cambridgeshire Community Services (CCS) the providers of Norfolk Children and Young People's Health Services are currently developing a website with interactive resources and information to help parents, carers, children and young people improve their health and wellbeing.

The site **Just One Norfolk** will contain different kinds of content for parents, carers and professionals to use, such as video clips, webinars, vlogs, quizzes and webchat. The initial topics covered will be:

- Emotional wellbeing
- Healthy lifestyles
- Minor illnesses and accident prevention
- Development and additional needs
- Staying Safe

Over the coming months they will be looking to develop the site and the range of topics they cover, if you are a parent, grandparent, carer, young person or professional and would like to be involved in development of the website they would love to hear from you.

- **Community Dental Service – Siskin Centre**

We have received positive feedback from families accessing this service who felt the services had worked well with their child and understood their ASD. The community dental service is a specialist service for residents across Norfolk who struggle to use general dentists. There are seven centres across Norfolk excluding Great Yarmouth and Thetford that patients can access and are specifically for:

- Patients with a diagnosed medical, physical or mental health condition which makes accessing NHS dental clinics more difficult.
- Children under 16 with Behavioural management difficulties which makes accessing NHS dental clinics more difficult.
- Patients with long term conditions which can cause confusion and disorientation such as dementia and who may or may not be housebound.

One family recalled being referred to the community dental services as NHS dentists could not cope with her child's ASD and having access to the service this has helped the child to no longer fear having to go to the dentist.

> *"My dentist couldn't cope with my son, who has autism and they referred me to the siskin service. They come from Dereham community hospital and they are just fantastic. They treat my son so well and the staff are very good. They have longer appointments for my son and I can't fault it. As a result my son has no fears of attending the dentist."*

Another described how staff in the service were very understanding of her child's ASD and worked well, despite the services still looking quite clinical.

> *"Our GP referred my children to the Siskin dental clinic. We had our first appointment last month. The dentist was very patient and understanding…especially as my boys didn't want to go into the dentists room…so she let them stand in the door way and looked into their mouth. She didn't get too close and didn't touch their mouth. It was very good she allowed them to be examined like this…as they couldn't cope sitting in the dentist's chair and they couldn't cope with being touched. The only thing I would say is that it would improve the experience if there were toys in the waiting room and in the dentist room…this might have made my boys more calm and less anxious. They found the waiting room and 'waiting ' difficult as there wasn't anything for them to do, apart from a box of tatty books. Also in the dentist's room it was obviously very clinical and therefore made my boys anxious, so again maybe a few toys would make them less anxious in this unfamiliar environment."*

Thorpewood Medical Group – GP Practice

A GP practice based in Norwich has recently undergone some changes to the way they work to try and benefit their autistic patients registered with the GP practice, by trying to develop a more autism friendly approachable service. They have worked with some of their patients including members of the autistic community and their families to understand more about what would improve their experiences of GP services. This was strongly led by the Practice Manager in recent months and is currently something the practice are keen to continue to develop further. All steps they have taken are based on what patients identified would be an improvement.

Using SystmOne as their clinical system they have set up 'alerts' on patients notes (home pages) that will alert the receptionist/medical team that this patient has autism as a diagnosis. These alerts can be amended to have key points medical staff must be aware of or do when communicating with this patient. They keep a register of ASD patients which is monitored and also includes individuals with suspected ASD. They have a quiet waiting room specifically designed for patients with autism with dimmer lighting that they can use if they wish to. Following feedback they have ensured that in all consultation rooms there are always 2 seats available to enable a parent/carer to be a part of the consultation if required and where possible try to use the larger consultation rooms if available for autistic patients. The practice will now text a patient if they are running 20 minutes late prior to the appointment to advise them of this, as families had identified that waiting for an appointment can cause difficulties.

Finally the practice undertook an early implementation of the free NHS wifi roll out amongst practices and have a tablet in the main reception area that can be utilised. This was due to families identifying that ASD patients may need something to keep them occupied when using the service and the tablet can also be used as a way to communicate to medical staff using word processing.

JPUH – Learning disability and autism liaison nurse, ASD training

The JPUH has a Learning disability (LD) and autism liaison nurse who works with patients with ASD and their families for any patient who comes into contact with the hospital for any reason, either through outpatients or through A&E for example. Her role is crucial to enable patients to feel comfortable within the hospital environment in ensuring that they get the care and treatment they need. She works clinically with patients everyday as well as having the responsibility of ensuring staff are trained and aware of ASD to enable reasonable adjustments in patient care.

Last year JPUH had some ASD training in which 100 individuals (parents and staff) accessed an autism reality experience training at their learning disabilities open day held at the hospital (EDP, 2017).

Eastern Daily Press InBrief | TODAY'S LOCAL NEWS

Virtual reality simulator at Gorleston's James Paget Hospital reveals what it's like to live with autism

PUBLISHED: 18:21 21 June 2017 | UPDATED: 18:21 21 June 2017 | Liz Coates



Autism Reality Experience at James Paget Hospital. Picture : ANTONY KELLY

The virtual experience was launched in January by Essex-based training2care. So far it has been to prisons, schools, airports and health care providers but this was its first visit to a hospital.

Chelsey Cookson, who helped put it together, said the simulator was a powerful tool and that the experience stayed with people.

Rebecca Crossley, learning disability and autism specialist nurse, said: "Nothing can beat this. I have had parents coming out in tears saying 'I did not know what my daughter was going through'."

The Liaison Nurse can help with the following:
Communication advice,
Pre-admission and discharge planning, Desensitisation planning,
Service user education,
Carer support and advice,
Capacity and Consent Advice,
Liaising with GPs, community teams and relevant organisations,
Facilitation of outpatient appointments, Pre-discharge planning,
Accessible information development,
Advice and support on reasonable adjustments for people.

(JUPH, 2018)

The liaison nurse is based at the JPUH five days a week but also goes out into the community working with patients in their homes to enable them to come into the hospital to receive the treatment they need. This was a crucially important aspect working in the community due to patient's heightened anxiety when in a clinical setting. The LD & ASD liaison nurse ensures that every staff member has induction training on ASD and staff have mandatory ASD training yearly. They also have an ASD specific internet page on their system that can support staff if the liaison nurse is not on site.

She also develops and updates all the hospital's policies and procedures regarding ASD & LD and has developed booklets used throughout the hospital highlighting the patents' needs making it person centred. They have items such as a patient passport, hospital communication book and a pre-hospital communications booklet; all utilised to explain patients' needs when attending the service.



The JUPH collects the data of all patients that access the JUPH with ASD from birth to death and read codes are used on the clinical system on patient's notes to make staff aware of patients with ASD. They monitor a populated database of all patients with LD and or ASD

who have been in contact with the hospital since 2011. The liaison nurse is able to see all planned activity across the hospital for LD & ASD patients as well as current patients within the hospital with ASD. It is part of her role to personally work with each patient that comes into the hospital to ensure that reasonable adjustments are received whilst they are using the hospital.

One example she recalled was using a 'theatre journey book' for a patient who has to come into the hospital, including images of staff involved in his care and areas of the hospital. This book was created with the patient as a visual story of the procedure they were to have. It involved a step by step guide of what would happen in their visit to the hospital which helped them to successfully access the service. This is something that could be used elsewhere across other health and social care services to help reduce anxiety and stress.

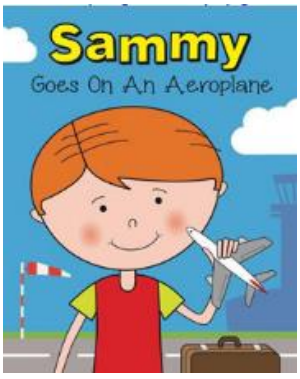
4.5.1 Other good practice within the community

- **Norwich Airport – visualisation tours – ASD friendly**

In developing our awareness of ASD and support available locally, we were made aware of a free service Norwich airport provides specifically for individuals with ASD, physical and/or hidden disabilities. Norwich Airport have been working closely with a range of local and national charities to ensure that individuals have fair access and an enjoyable experience using the airport.

Norwich Airport offers free support and familiarisation visits (a tour) to anyone who may have concerns regarding air travel due to physical or hidden disabilities, such as individuals living with ASD, Dementia, Learning Disabilities or Physical Disabilities. Individuals can contact Norwich airport to discuss their concerns and arrange a familiarisation visit. In these visits individuals and families are taken on a tour of the airport demonstrating the process passengers would follow when using the airport to travel by air. This would include climbing on board an aeroplane if there is one available on the day.

Norwich airport has been working in partnership with Autism Anglia and has signed up to the autism charter to commit to making their services autism friendly. As a result airport staff have undertaken ASD awareness training across all departments of the airport to heighten understanding of ASD and learn to support individuals effectively. During the familiarisation visits individuals and families are given blue wristbands to identify that they have ASD and if families have younger children they also receive a 'Suzie/Sammy goes on an aeroplane' story book to take home.



5. What this means

Undertaking this project has enabled us to gain a valuable insight into the interaction families have had with health and social care services. It has allowed us to develop a deeper understanding of some of the barriers families have when trying to use services as well as identifying what works well to support families in services. This project has certainly revealed the complexity of the journey that many parents have taken across Norfolk, of which many described as a continuous battle to get the help and support their child needs from both health and social care services and education. Typically families were in contact with a whole host of services and at times portrayed the feeling that 'no one was able to help' as a result of being pushed from one service to another. It was evident that many parents were happy to share their experiences resulting in providing fruitful and rich experiences as often these parents have been waiting years to get an outcome from an assessment.

Further investigations have found that many of the findings of this project resonate with another inquiry document published by The Westminster commission on Autism (2016). It is entitled "A spectrum of obstacles: an inquiry into healthcare for autistic people" with this publication supporting our findings in these areas:

- Health and social care professionals do not always understand autism and lack training.
- Autistic people can find it difficult to tell a medical professional what is wrong or how they are feeling.
- Often services do not make reasonable adjustments particularly in GP practices.
- Some families feel socially isolated.
- GP practices do not record a list of autistic patients.

At this point it is important to highlight some key messages that have emerged throughout the project.

5.1 Health and social care services

Unfortunately many of the experiences families received were directed around the things that had not gone well when accessing services, regularly resulting in families being unhappy about the services they had accessed. The majority of families recalled the fight they have had to undertake in order to support their child to enable them to access services, help and support to meet there needs. For many this has been a continuous battle that has developed over many years with the feeling that little progression has been made and implemented to support them as a family. This has been apparent due to many services being overstretched and 'unable to support' a child with ASD. Often parents recounted my doors to services being closed and unsure of where to get alternative support.

One big area of concern to families was the lack of understanding and awareness of ASD across all health and social care services. Families expressed how they felt that many professionals did not have an understanding of how to work with their child and the affect ASD can have on the way the child interprets the world around them. Parents suggested that more awareness was urgently needed across all services, learning how to support children to attend medical appointments effectively and make reasonable adjustments to the clinical environment. This may come down to introducing basic training throughout all services, this could perhaps be undertaken through online methods or using other means to reach all professionals. In the context of Norfolk this may be where the development of the autism strategy and the AAPB could look to influence and explore this.

Parents highlighted the frustrations they experienced being bounced from service to service and professional after professional. They openly described the ongoing toll this took on their whole family who were all equally affected. Many families spoke of them having to 'jump through many hoops' to qualify for services and support and that if their child did not meet the set and established criteria then there was no service for them and they were just left on their own. Similarly they described the expectancy to be able to receive help and support after a diagnosis of ASD was confirmed and described the despair it caused feeling they were just dropped from services and left to cope with a developing child on their own, with little advice and information given at that time. This may suggest the need to realign parents' expectations with regards to services post diagnosis and part of this may be achieved if more information and advice were given at the start of the diagnostic pathway (outline the process and what to expect). This is something NHS ASD diagnostic services need to consider to improve their services.

Some parents found it difficult to get their voices heard and suggested that they did not feel listened to by professionals. In their view, they may be one of the individuals best placed to know and understand what is and is not usual for their child. Some parents felt that they were just one of many families they were processing in relation to the ASD diagnostic service. Services should want to be working alongside parents empowering them to support their child and have their say.

5.2 ASD Diagnostic services

It is important to realise that many families accessing ASD diagnostic services in Norfolk have experienced years of waiting to access and then receive a diagnosis. As a result many parents have felt let down by this service due to the effect the lack of support has had on their child and typically their education too.

One crucial missing element from NHS diagnostic services conveyed by the majority of parents was communication. Parents described the unjust scenario they faced daily due to a lack of communication and not knowing where they stood in long waits to access a diagnosis. This influenced parents' expectations and led

to a feeling that they had been forgotten or that services 'were not doing anything'. This was due to the lack of ongoing communication throughout the pathway meaning that parents often received little information or updates as to how long they would be waiting. NHS ASD diagnostic services should look to give more updates and open communication with families using and waiting to access the pathway. It would appear appropriate to ensure that further developments are coproduced by working with some parents to make significant changes to the newly designed pathway at NCHC and at the JPUH.

Parents were clear that NHS diagnostic services did not explain the process and what is involved in the journey they were about to undertake. This links directly to parent's request that more access to information and advice was needed. Parents highlighted that you are on a pathway but don't know where you are going or headed and how long this will take. There is a lot of evidence families and schools have to gather for a child's assessment and having an awareness of what is involved in the assessment process can only be beneficial for parents.

This was particularly imperative when parents are questioned by their child about what would happen as they often recalled being unable to answer. Therefore, in line with the recent service changes since December 2017, the NCHC diagnostic service should look to address this and implement 'process/pathway awareness'. Even with the launch of NCHC's services for children and young people website (ASD diagnostic service) there is still no clear description of the pathway, so families know what they can expect.

One existing factor that needs improvement is the long waiting times families undergo when trying to access an ASD diagnosis in Norfolk. Many understand that services are under pressure and stretched but they recalled the reality of what this meant for the child and their family. Parents felt it was vital that early intervention took place and delays in accessing help subsequently resulted in delays to appropriate education or children missing education. As a result many parents believed the current waiting times they had experienced were unacceptable and that action needed to be taken to actively improve this for the future.

5.3 Support for families

On the whole, many families highlighted the lack of support they received from health and social care services and felt that ongoing contact was central to help support a growing and developing child, living with ASD. Families suggested that it can be difficult to 'get back into the system' when things change and they need some health and social care input. It was evident that many families valued understanding from other parents going through the same process or feelings. With this in mind, many found the value in parent support groups as they felt that groups were rarely judgmental. Parents also valued online support as another method of providing advice and information, many used parent support groups'

social media pages to communicate to one another and ask questions. Therefore this could be something that services could learn from and look to develop into their current methods of supporting parents, particularly with regard to parenting programmes held across the county. These could be held in webinars enabling more parents to complete the programme and to learn in their own home, particularly in light of the recent poor uptake of these courses from NCHCs services.

Families called for more support for the siblings to enable them to understand and thrive within the home environment, as they believed quite strongly that it can have an impact on the wider family unit and currently the support is just not there. When local ASD diagnostic services are procured again in March 2019 this may need wider consideration as to how they can best support families undertaking the pathway towards a diagnosis and openly listen to parents feedback about the service. On the whole, families recalled the impact an understanding school could have on supporting their child and their education. Parents believed that more supportive schools that listened to parents' concerns and acted on them were needed across the county. More specialist schools that are placed to meet children's needs with ASD were also needed in parents' views on education.

When attending health and social care services, families stated there needed to be more understanding of ASD in respect of services making reasonable adjustments, to the appointments and environment surrounding them. It was felt that services needed to become more autism friendly, with particular consideration for the waiting areas autistic patients would be using. Parents said they needed more support and understanding from services particularly when children are waiting for appointments that are often delayed. In respect of NCHC ASD diagnostic service, this may be something that parents could work with services to influence including development of the buildings these services are based in. Parents could work with the service providers to develop appropriate environments for children during the upcoming renovations process at NCHC.

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7. Appendix

7.1 Organisations involved

This list includes voluntary sector services, parent support groups and statutory bodies.

1	ASD Helping Hands
2	Autism Anglia
3	Family Action
4	Family Voice
5	Slice of advice
6	Sunbeams Play
7	West Norfolk National Autistic Society

7.2 Family case study

This family had been referred for an ASD diagnosis, using the NCHC pathway in Norfolk. They had received little written communication from the service throughout their wait for a diagnosis after their initial paediatrician appointment was in May 2015 and they were still waiting for diagnosis in November 2017.

May 2015
- The family had their first appointment with a Paediatrician.

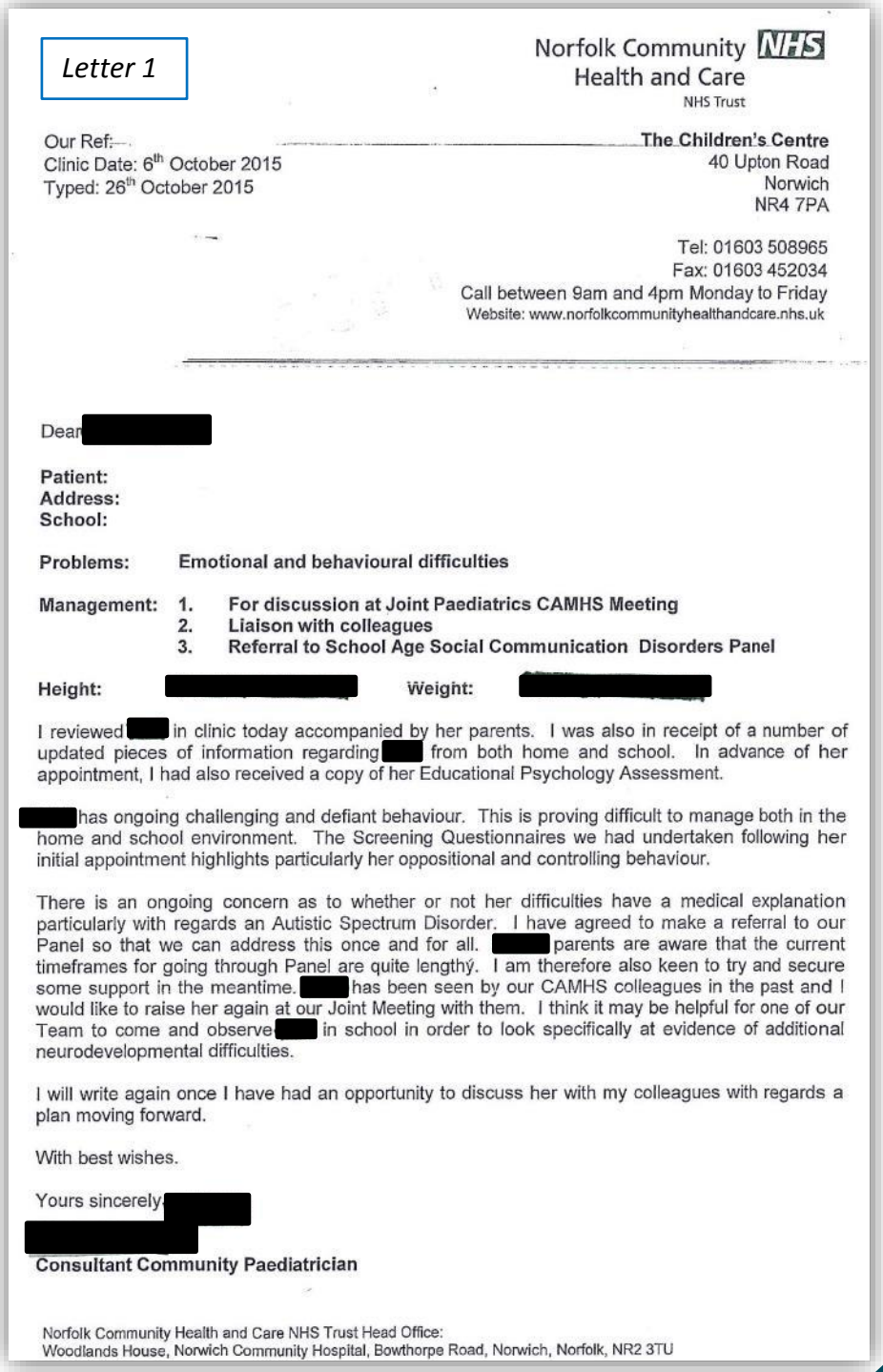
October 2015
- The family received a letter (letter 1) as a follow up from the initial meeting stating the paediatrician had seen the child.

March 2016
- The family received a letter (letter 2) saying the child had been referred to the ASD panel and the referral date was confirmed as 10th March 2016.

September 2016
- The family received a third letter (letter 3) to say the referral had been discussed at the panel and added to the waiting list for a full diagnostic assessment.

October 2016
- The family received a final letter (letter 4) inviting the parents to positive behaviour workshops at a range of venues.

November 2017
- The family were still waiting in the waiting list for an ASD diagnosis and met with Healthwatch to share their story.



Letter 1

Norfolk Community Health and Care NHS Trust

Our Ref:
Clinic Date: 6th October 2015
Typed: 26th October 2015

The Children's Centre
40 Upton Road
Norwich
NR4 7PA

Tel: 01603 508965
Fax: 01603 452034
Call between 9am and 4pm Monday to Friday
Website: www.norfolkcommunityhealthandcare.nhs.uk

Dear [redacted]

Patient:
Address:
School:

Problems: **Emotional and behavioural difficulties**

Management:
1. **For discussion at Joint Paediatrics CAMHS Meeting**
2. **Liaison with colleagues**
3. **Referral to School Age Social Communication Disorders Panel**

Height: [redacted] **Weight:** [redacted]

I reviewed [redacted] in clinic today accompanied by her parents. I was also in receipt of a number of updated pieces of information regarding [redacted] from both home and school. In advance of her appointment, I had also received a copy of her Educational Psychology Assessment.

[redacted] has ongoing challenging and defiant behaviour. This is proving difficult to manage both in the home and school environment. The Screening Questionnaires we had undertaken following her initial appointment highlights particularly her oppositional and controlling behaviour.

There is an ongoing concern as to whether or not her difficulties have a medical explanation particularly with regards an Autistic Spectrum Disorder. I have agreed to make a referral to our Panel so that we can address this once and for all. [redacted] parents are aware that the current timeframes for going through Panel are quite lengthy. I am therefore also keen to try and secure some support in the meantime. [redacted] has been seen by our CAMHS colleagues in the past and I would like to raise her again at our Joint Meeting with them. I think it may be helpful for one of our Team to come and observe [redacted] in school in order to look specifically at evidence of additional neurodevelopmental difficulties.

I will write again once I have had an opportunity to discuss her with my colleagues with regards a plan moving forward.

With best wishes.

Yours sincerely,

[redacted]

Consultant Community Paediatrician

Norfolk Community Health and Care NHS Trust Head Office:
Woodlands House, Norwich Community Hospital, Bowthorpe Road, Norwich, Norfolk, NR2 3TU

Letter 2

Norfolk Community Health and Care NHS Trust

Parent/Guardian of

ASD Pathway Co-ordinator
Room 33
St James
Exton's Road
King's Lynn
PE30 5NU

Date: 17 March 2016

Tel: 01553 668606
Fax: 01553 668669

Dear parent/guardian

[redacted] has been referred to the School-age Social Communication Panel – Central Team by [redacted] Consultant Community Paediatrician for assessment into a possible Social Communication Disorder such as autism. The referral date has been recorded as 10.03.16.

The first step is for the Panel to discuss your referral in depth, and decide whether or not a full assessment is required. The Panel aim to complete this step within 20 weeks.

If your child's referral is accepted we will let you know and your child's name will be added to our assessment waiting list. Currently, owing to high numbers of cases being accepted for assessment the time from referral date to completing the diagnostic assessment can be up to 12-18 months.

Should you child's referral not be accepted for further assessment we will contact your Paediatrician to advise.

In the meantime if there are any significant changes for your child and you have any concerns please contact your GP or Consultant Community Paediatrician to discuss further.

We regret the length of this assessment process, but it is needed in order to ensure, for you and your child, the quality of the diagnostic work carried out by our staff.

Yours sincerely

[redacted]

On behalf of
School-age Social Communication Panel – Central Team

Cc:
GP – [redacted]

Letter 3

Norfolk Community Health and Care NHS Trust

Parent/Guardian of
[redacted]

ASD Pathway Co-Ordinator, St James Clinic
Room 33
Extons Road
King's Lynn
Norfolk
PE30 5NU

Tel: 01553 668606

08 September 2016

Dear Parent/Guardian

As you know your child has been referred to the School-age Social Communication Panel – Central Team for assessment into a possible Social Communication Disorder such as Autistic Spectrum Disorder. The referral was discussed at our team meeting on 07.09.16 and [redacted] has now been put on our waiting list for assessment. We will be in contact with you as soon as we are able to start the assessment.

Yours sincerely

[redacted]

On behalf of
School-age Social Communication Panel – Central Team

Letter 4

Norfolk Community Health and Care NHS Trust

Parent/Guardian of

ASD Pathway Co-Ordinator, St James Clinic
Room 33
Extons Road
King's Lynn
Norfolk
PE30 5NU

Tel: 01553 668606

20 October 2016

Dear Parent/Guardian

As you know your child is currently on our waiting list for assessment with the Social Communication Panel. As you are aware it may be some time before we are able to start our assessments. We are holding some Positive Behaviour Workshops for parents to offer advice and support while you are waiting for assessment (please see leaflet for more details). We would like to invite you to attend a workshop. This will run consecutively over a three week period for 2 hours one morning a week. It is important that you are able to attend all 3 sessions, wherever possible, as the sessions are closely linked.

We are offering a choice of venues and dates. **As places are limited on each workshop it will be important that you contact us to book a place as soon as possible by calling 01553 668606.** Depending on demand we may not be able to offer you your preferred venue/date but we will offer you an alternative.

Workshops will be taking place **from 10.00 – 12 noon** on the following:

Venue – Bowthorpe Surestart Childrens Centre, Humbleyard, Clover Hill, Norwich NR5 9BN
Thursdays 1st, 8th & 15th December 2016

Venue – Childrens Centre, Breckland District Resource Base, London Road, Dereham NR19 1AS
Wednesdays 11th, 18th & 25th January 2017

Venue – Childrens Centre, 40 Upton Road, Norwich NR4 7PA
Thursdays 2nd, 9th & 23rd February 2017

May

Venue – Surestart Childrens Centre, Kingsway, Thetford, IP24 3DY
Wednesdays 1st, 8th & 15th March 2017

(Please note these workshops are not for your child to attend).
If you have any queries please do not hesitate to contact us.

Yours sincerely

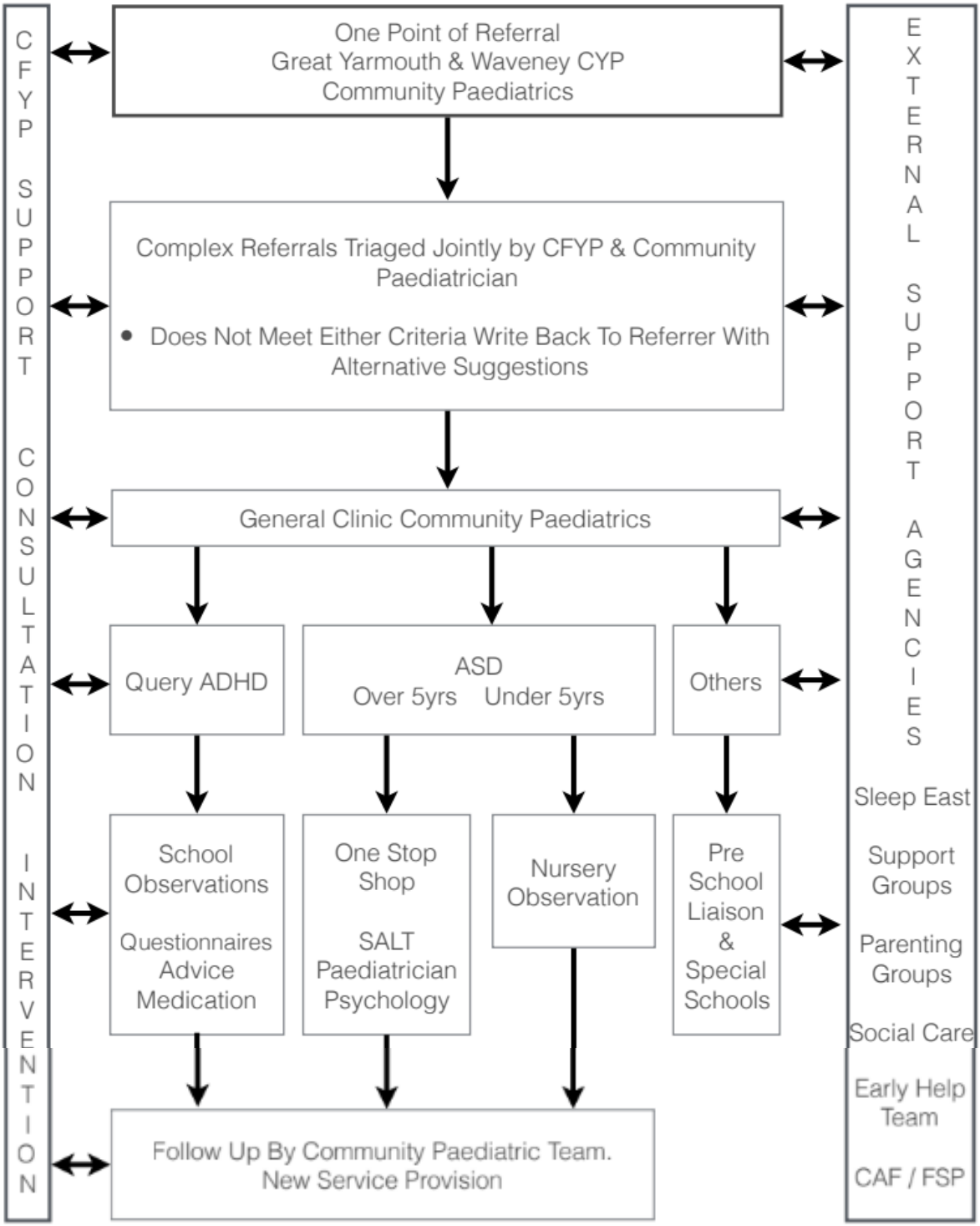
ASD Pathway Co-ordinator
Enc: PBS Workshop Leaflet

Norfolk Community Health and Care NHS Trust Head Office: Woodlands House, Norwich Community Hospital, Bowthorpe Road, Norwich, Norfolk, NR2 3TU

7.3 JPUH Diagnosis service

James Paget University Hospitals NHS
NHS Foundation Trust

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



7.4 Parent Questionnaire

healthwatch Norfolk

Are you a parent/carer of a child/young person (0-18) with ASD or suspected ASD in Norfolk?

Healthwatch Norfolk is the independent consumer champion for anyone in Norfolk who uses health and social care services. As a registered charity our role is to help you have your say about the way that health and social care services are planned and delivered in Norfolk. Your feedback is really important to us for helping us improve local services across Norfolk. For more information please visit: www.healthwatchnorfolk.co.uk

Experiences of Health & Social Care services for children with ASD

Autism represents one of our three key priorities for our work this year. We are looking to understand more about families' experiences of health and social care services supporting their child's needs. We also want to hear of families' journey through the local Autistic Spectrum Disorder (ASD) diagnosis services across Norfolk. We know that ASD can affect many individuals and families, which can often define what services both them and their child may need and come into contact with. We also know that having access to the right help and support at the right time can really make a difference to families.

We want to hear from parents and carers of children/young people (0-18 years old) with ASD or suspected ASD in Norfolk. This includes families who have concerns their child may have ASD, those waiting for a diagnosis and those whose child has a diagnosis. We want to understand your experiences of; general health and social care services, ASD diagnosis services and getting support.

If you have any questions, please contact **Steph Tuvey**, Healthwatch Norfolk Assistant Project Manager, as follows: **Freephone**: 0808 168 9669
Email: steph.tuvey@healthwatchnorfolk.co.uk

Parents/carers/families perspectives, your feedback

All responses will be anonymous. We will publish all feedback we collect about specific services on our public facing website, and all the information you provide in this project will be shared with local decision makers who are responsible for planning and delivering services locally. You will not be named at any point and we will take great care to make sure that individuals cannot be identified by any comments they make. All information will be stored securely and will be destroyed at the end of the project, once the final report has been published. Please note that by completing the survey you are giving your consent to share your experiences and take part in the project. Once we receive your completed survey it may not be possible for it to be withdrawn.

Please read the following bullet points and confirm if you wish to participate:

- I understand the purpose of this project.
- I understand participation is voluntary.
- I understand all responses will be anonymous.
- I understand my experiences may be used in future reports, publications, articles or presentations by Healthwatch Norfolk.
- I understand that I can withdraw from this project at any time during completion. However, once Healthwatch Norfolk receive my completed survey it may not be possible for it be be withdrawn.

Do you wish to participate in this project, by completing this survey?

☐ Yes *Please continue to the survey, question 1.*
☐ No *Thank you for your time, please dispose of this survey.*

healthwatch Norfolk

1a) Do you have any children 18 and under who have ASD/suspected ASD?

- ☐ Yes — *Please continue to question b.*
- ☐ No — **Please read the statement at the bottom of the page.*

b) How old is your child/children with ASD? .....

c) What is the first half of your postcode? .....
(I.e. NR18...this is used to understand what ASD diagnosis pathway you used/are using.)

Using Health & Social care services for your child/children with ASD

2) Thinking about your child and their needs, please tell us about one recent experience of using health and social care services for your child in the last 2 years?

For example, using any of these services: *Community services, Dentist, GP, Hospital, Mental Health, Opticians, Pharmacy, Social Care and Urgent Care.*

Name of the service: *I.e. Norfolk and Norwich hospital- paediatric/children's service*

.....

.....

What overall rating would you give this service? *Please select one*

☆ Very Poor ☆ Poor ☆ Neither good nor poor ☆ Good ☆ Very Good

Please tell us about your experience...

When did this happen? *Please select one*

☐ In the last 4 weeks ☐ In the last 6 months ☐ In the last year ☐ Over a year ago ☐ Not sure

**Thank you for your time. This survey is for parents/carers of children aged 18 & under with ASD or suspected ASD. If you would like to leave a review about any health and social care services, you can do so at our website: www.healthwatchnorfolk.co.uk*

3) Thinking about your child's/children's needs, when you have used health and social care services, what has worked well?

4) Thinking about your child's/children's needs, what barriers, if any, do you face when using health and social care services?

5) Thinking about your child's/children's needs, what would improve your/their experiences of health and social care services?

ASD diagnosis services

6) Does your child/children have an ASD diagnosis?

- ☐ Yes, my child was diagnosed by the NHS.
- ☐ Yes, my child was diagnosed privately.
- ☐ No, my child does not have a diagnosis. **Please read the statement below.*

7) How old was your child/children when they referred for an ASD Diagnosis?

.....

8) How long did you wait for an ASD diagnosis for your child/children?

☐ 3-6 months	☐ 1-2 years	☐ 3-4 years	☐ I'm still waiting	☐ N/A
☐ 6-12 months	☐ 2-3 years	☐ 4-5 years	☐ Not sure	

9) Please tell us more about your experiences of ASD diagnosis services in Norfolk.

Please comment on the areas you have used and experienced on the ASD diagnosis pathway within the last 5 years *(I.e. GP referral, community paediatrician assessment, delivery of ASD assessment and outcome etc.)*. We understand that undertaking this pathway can be a long process, so if you are currently using the diagnosis service but have been waiting for longer than 2 years we would also like to hear from you. *If you need more space to share your experience, please continue on the back of the last page of the survey.*

What is your overall rating of ASD diagnosis services? *Please select and circle one*

☆ N/A ☆ Very Poor ☆ Poor ☆ Neither good nor poor ☆ Good ☆ Very Good

Please explain your rating...

When did this happen (year)?

*When answering No, if your child has been through an ASD diagnosis pathway but was identified as not having ASD, please continue to reflect on the service you received despite the outcome.

Accessing Support

10) What support have you accessed/tried to access in Norfolk?
Please select all that apply

☐ Cygnet course	☐ Early bird course	☐ Norfolk Steps
☐ Parent support group	☐ Sensory Support	☐ Voluntary sector support *(I.e. ASD helping hands, Autism Anglia etc.)*
☐ N/A		
☐ Something else? Please say...		

11) How well did the support you accessed meet yours and your child's needs?
Please rate the support you have used below.

Support used	Very Poor	Poor	Neither good nor poor	Good	Very good	N/A
Cygnet course	☐	☐	☐	☐	☐	☐
Early bird course	☐	☐	☐	☐	☐	☐
Norfolk Steps	☐	☐	☐	☐	☐	☐
Parent support group	☐	☐	☐	☐	☐	☐
Sensory Support	☐	☐	☐	☐	☐	☐
Voluntary sector support	☐	☐	☐	☐	☐	☐
Something else	☐	☐	☐	☐	☐	☐
Anything else to say?						

12) What service do you value the most from the support you've received and why?

13) What further support do you feel you need to help you and your child/children?

About You

Thank you for sharing your experiences with us. We would now like to ask some further questions about you, on the following pages. **You do NOT have to answer these questions if you do not want to** but any information you give us will help us to make sure that we are representing local people effectively. Your personal information will remain confidential.

What was your age on your last birthday?

.....

What is your gender?

Please select one option that best describes your gender...

- ☐ Male
- ☐ Female
- ☐ Prefer not to disclose

Is your gender identity the same as the gender you were assigned at birth?

- ☐ Yes
- ☐ No
- ☐ Prefer not to disclose

What is your sexual orientation?

Please select one option that best describes your sexual orientation...

- ☐ Bisexual
- ☐ Gay or lesbian
- ☐ Heterosexual or straight
- ☐ Prefer not to say
- ☐ Other (please describe):

.....

What is your religion?

Please select one option that best describes your religion...

- ☐ No religion
- ☐ Christian (all denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Prefer not to disclose
- ☐ Any other religion (please describe):

.....

Do you agree or disagree that you can influence decisions affecting your local health and care services?

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

Do you have any physical or mental health conditions or illnesses lasting, or expected to last for 12 months or more?

- ☐ Yes
- ☐ No
- ☐ Prefer not to disclose

Does your condition(s) reduce your ability to carry out day-to-day activities?
Please select one option...

- ☐ Yes, a lot
- ☐ Yes, a little
- ☐ No
- ☐ Disagree
- ☐ Prefer not to say

Do any of these conditions or illnesses affect you in any of the following areas?
Please select all areas that apply to you...

- ☐ Vision
- ☐ Hearing
- ☐ Mobility
- ☐ Dexterity
- ☐ Learning
- ☐ Memory
- ☐ Mental health
- ☐ Stamina/breathing/fatigue
- ☐ Socially or behaviourally
- ☐ Other (please describe):

.....

What is your ethnic group? Choose one section from A to E, then tick one box which best describes your ethnic group or background:

A. White

- ☐ English/Welsh/Scottish/ Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other white background

B. Mixed/Multiple

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/Multiple background

C. Asian/Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian/Asian British background

D. Black/African/Caribbean/Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/Caribbean/ Black British background

E. Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group
- ☐ Prefer not to say
- ☐ If other, please describe:

.....

Thank you

You have now completed this survey. Thank you very much for your time. Your feedback is important and will help us to make local services more responsive to you and your child's needs. **Please do not forget to send Healthwatch Norfolk your completed survey using the freepost envelope provided.**