

# Norfolk's All Age Autism Strategy 2019-2024

**My Autism, Our Lives, Our Norfolk**



In Partnership with



**Norfolk** County Council



# CONTENTS

---

<b>Foreword and Acknowledgements</b>	Page 3
<b>Section 1: Our Vision</b>	Page 5
<b>Section 2: Background</b>	Page 7
<b>Section 3: Aims</b>	Page 9
<b>Section 4: What we know about Autism Nationally and in Norfolk</b>	Page 11
<b>Section 5: What do Autistic People tell us?</b>	Page 17
<b>Section 6: Our priorities</b>	Page 19
Section 6.1: Working Together	Page 21
Section 6.2: Diagnosis and Support	Page 25
Section 6.3: Autism Awareness	Page 29
Section 6.4: Employment, Education and Training	Page 31
Section 6.5: Understanding Need (Data Collection)	Page 35
Section 6.6: Transitions	Page 37
Section 6.7: Right Place, Right Time, Right Support	Page 39
Section 6.8: Housing	Page 45
Section 6.9: Justice System	Page 47
<b>Section 7: Glossary</b>	Page 49

## FOREWORD

---



The Norfolk All Age Autism Partnership Board (NAPB) is pleased to introduce *My Autism, Our Lives, Our Norfolk*, which sets out our ambition to support children, young people, young adults, adults and older people with autism as well as their families/carers and siblings.

*My Autism, Our Lives, Our Norfolk* is intended for everyone who has an interest in autism: from members of the general public, to politicians.

*My Autism, Our Lives, Our Norfolk*, uses the term autistic people. This is because the autistic members of the NAPB confirmed that they prefer the term autistic people rather than people with autism. The term person with autism implies that autism is an illness or a disorder and it therefore discounts the possibility that autism is just an alternative, but valid, way of being. Autistic person acknowledges an acceptance of autism as part of an individual's identity.

We recognise that autism sits on a spectrum and although autism is not a learning disability or a mental health condition, autistic people may also have these conditions. Equally, they may also have other physical conditions. For the purposes of this strategy we are focusing on principles that should be applied to everyone on the autistic spectrum. For those people with additional needs, this strategy should be read in conjunction with **Norfolk's Learning Disability Partnership Strategy, My Life, My Future, My Ambition 2018–2022**, the **Norfolk and Waveney Mental Health Strategy 2019** and the **Special Educational Needs and Disability (SEND) Strategy** that is currently in development.

*My Autism, Our Lives, Our Norfolk* has been co-produced by Norfolk's first All Age Autism Partnership Board, which includes people with lived experience of autism of all ages, including parents/carers. It also includes people from a wide variety of other organisations, such as individuals working in healthcare, social care, education, voluntary organisations, the police and Healthwatch. Everyone involved with the NAPB is committed to improving the life opportunities of all autistic people living in Norfolk by helping it to become an autism inclusive county.

The NAPB took the decision to develop an all-age strategy, expanding on the national vision to help people with autism reach their full potential and live fulfilling and rewarding lives.

## FOREWORD

---

*My Autism, Our Lives, Our Norfolk* prioritises our responsibilities as set out in the Think Autism Statutory Guidance, in addition to other national priorities in health and social care covering children, young people, young adults, adults and older people. The NAPB jointly identified the first set of priorities, in addition to the other priorities identified by the wider community. As a board we will review the priorities each year and set our action plan, to ensure that we remain aligned with developments locally and nationally.

*My Autism, Our Lives, Our Norfolk* is designed to be used as a working document. This means that individual sections can be removed and used independently, for example as a separate print out.

As a new board, and as this is our first Autism Strategy, we are aware that we are at the start of a long journey. We can only make this a success by listening to a wide range of voices. There are many people living across Norfolk who have not yet had their say about their own experiences of living with autism and what is most important to them. We are therefore committing to continuing our drop-in sessions across Norfolk so that people can hear about the range of work which is already underway. We will also develop more opportunities for people to contribute in other ways that are meaningful to them.

Acknowledgements and special thanks to the following:

- All members of the **NAPB**, past and present, and members of the **general public** who attended the Norfolk Autism Partnership Groups. Both had a major impact on this Strategy by sharing their experience and ideas.
- The Board's **working group members**, for their hard work and dedication to the development of this Strategy and their innovative thinking.

- 1.1 *My Autism, Our Lives, Our Norfolk* begins to set out the Vision for shaping and delivering opportunities for people in Norfolk with Autism and how we intend to achieve this vision, through identifying a series of key priorities and actions.

**Our Vision: All autistic people, their parents/carers are accepted, understood and treated as equal members of the community. That there is a greater awareness and understanding of autism by people that live and work in Norfolk. That this understanding will enable autistic people to have the same opportunities as everyone else to live a fulfilling and rewarding life and achieve their life's ambitions.**

- 1.2 *My Autism, Our Lives, Our Norfolk* aims to raise public and professional awareness of autism and will help autistic people to be accepted, understood and treated fairly within their communities.
- 1.3 Through the implementation of *My Autism, Our Lives, Our Norfolk*, more people will have the opportunity to be diagnosed and access support if they need it.
- 1.4 *My Autism, Our Lives, Our Norfolk* focuses on early intervention, getting the right support, at the right time in the right place by the right person. It focuses on identifying issues and resolving challenges as quickly as possible in a sensitive, practical and appropriate way before problems escalate.
- 1.5 *My Autism, Our Lives, Our Norfolk* will develop an approach to create an **Autism Inclusive and Accessible Norfolk**. We will not only seek to provide the right support, at the right time by the right provider, we will also work with the wider community itself. We will, with your support, raise awareness and enable opportunities for autistic citizens of Norfolk to access universal, community services including health services. While social care and diagnosis is important, it is equally vital to allow people to have the opportunity to live a rich, fulfilling life.
- 1.6 *My Autism, Our Lives, Our Norfolk* pledges a new commitment to being person-centred and autism aware in everything we do, with a focus on promoting opportunities and positive personal outcomes.
- 1.7 *My Autism, Our Lives, Our Norfolk* focuses on enabling autistic children, young people, young adults, adults and older people to identify and achieve goals

important to them and improve their quality of life through accessing a wide range of community resources and services across Norfolk.

- 1.8 *My Autism, Our Lives, Our Norfolk* focuses on promoting inclusion through raising awareness and reasonable adjustments. It focuses on resolving challenges in the most practicable way that is right for the person and as quick as possible, so problems do not get worse. Working together so we can prevent things from going wrong earlier and to achieve equitable outcomes.

## 2.1 Autism Definition

2.1.1 For *My Autism, Our Lives, Our Norfolk*, autism is defined as:

*A lifelong condition that affects how a person communicates with and relates to other people. It also affects how a person makes sense of the world around them.*

Source: National Autistic Society

2.1.2 Autism is a lifelong neurological condition: people are born with it, do not grow out of it and it cannot be cured. It is a spectrum condition which means it presents differently in every autistic person. This is summed up in author Dr Stephen Shore's much-quoted comment - "If you've met one person with autism, you've met one person with autism".

2.1.3 Whilst autistic people share the same underlying differences which affect how they think, communicate with and relate to other people, they each have a range of strengths as well as different needs.

2.1.4 Autism is not a learning disability or a mental illness. Autistic people can, however, have additional needs including learning disabilities and health conditions just like anyone else. Autistic people with additional needs are far less equipped to deal with their condition and may require more support than non-autistic people. Autism is a lifelong condition and individuals will have unique needs. Some people can live independently while others require specialist care.

Please see additional reading for more information about autism and how it affects people's lives.

## 2.2 Why does Norfolk need an Autism Strategy?

2.2.1 *My Autism, Our Lives, Our Norfolk* responds to the NAPB and the autism community's request to have in place a clear plan that sets out our shared vision, our principles and the intended outcomes we wish to achieve for all autistic people and their families/carers living in Norfolk.

2.2.2 The national guidance *Implementing and Rewarding Lives 2020* requires local councils and their partners to have in place plans in relation to the provision of service to people with autism as they transition from childhood to adulthood. Additionally, there needs to be local planning and leadership in relation to the provision of services for Adults with Autism.

2.2.3 *My Autism, Our Lives, Our Norfolk* responds to the national challenge by government, NHS Long Term Plans for autism and key national guidance and

legislation to meet our statutory responsibilities. Please see additional reading for more information about the key pieces of legislation.

- 2.2.4 *My Autism, Our Lives, Our Norfolk* answers the local response to the *National 2018 Autism Self-Assessment* which informs the key priorities and plans for Norfolk.
- 2.2.5 *My Autism, Our Lives, Our Norfolk* is based on the priorities of the Norfolk Health and Wellbeing Board through the vision of a single sustainable system prioritising prevention, tackling inequalities in communities and integrating ways of working.
- 2.2.6 *My Autism, Our Lives, Our Norfolk* responds to the recommendations of Healthwatch Norfolk report *Access to health and social care services for Norfolk families with Autism* (October 2018)<sup>1</sup> through ensuring leadership, delivering co-production and monitoring services.
- 2.2.7 *My Autism, Our Lives, Our Norfolk* priorities and recommendations include the consultation of the Needs assessment for adults and children with autism in Norfolk (March 2019). The needs assessment considers the prevalence and need of autistic people of all ages living in Norfolk. Please see additional reading for Needs assessment for adults and children with autism in Norfolk (March 2019).
- 2.2.8 *My Autism, Our Lives, Our Norfolk* provides a point of reference for all future papers, plans and policies when considering the needs of all people with autism, including those with other needs such as mental health issues, learning disabilities and physical health problems.

---

<sup>1</sup> Steph Tuvey, *Access to health and social care services for Norfolk families with Autism*, <https://www.healthwatchnorfolk.co.uk/reports/published-reports/>, accessed March 2019



The key aims of this strategy are:

- Enabling autistic people and their families/carers to have timely access to and specific support from public and voluntary services (including health, social care, criminal justice system, employment, education, housing and public transport) which is accessible, integrated and focused on outcomes that improve their lives.
- Increasing awareness and understanding of autism.
- Ensuring Norfolk County Council and local NHS bodies will meet their legal duties and how the autism community can help them do it.

We will use these aims to inform our Norfolk Autism Plan, which will set out what needs to be done and what services are needed to improve the lives of autistic people and their families/carers living in Norfolk. The following eight key priorities will underpin the aims and priorities for our actions and outline what we are going to do:

- 3.1 Increasing the awareness and acceptance of autism in the wider community by, among other aims, overseeing the development of a multi-agency work workforce plan.
- 3.2 Influencing and monitoring the development of clear and consistent pathways for diagnosis for assessment of needs at all ages, including offers of support for autistic people and their families/carers following diagnosis.
- 3.3 Influencing and enabling access to all relevant services, including the development of clear, consistent services and support for young autistic people making the transition to adulthood. To also influence and monitor the development of clear, consistent services and support for autistic people making other transitions, including, for example, to later life.
- 3.4 To influence and monitor the development of advocacy services to support autistic people to access health and social care along with other services.
- 3.5 To ensure the right support is available at the right time by working with key partners to enable better access to, and better experiences of, education, training and work. To aid this, we aim to influence and monitor the development of clear and consistent support for autistic people.
- 3.6 To enable autistic people to be an equal part of the wider community, including social inclusion, housing support and keeping them safe.
- 3.7 To involve the families/carers of autistic people and to influence and enable the development of support for them.

- 3.8 To influence and monitor the strategic planning and operational delivery of services for autistic people.

The NAPB will monitor the delivery of the Autism Plan and what progress is made against the *My Autism, Our Lives, Our Norfolk* objectives and identified outcomes. It will review the plan on an annual basis and update the priorities for the year ahead over the 5 years of the strategy.

## What we know Nationally

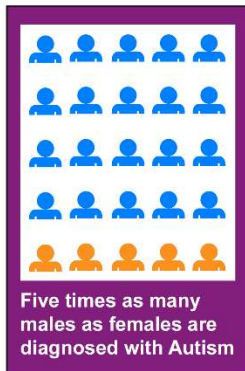
A BRIEF GUIDE TO

# AUTISM IN THE UK

Around 1.1% of the population  
in the UK are living with Autism



## THAT'S AROUND 700,000 PEOPLE!



### OF ADULTS WITH AUTISM

Say they are not getting the help they  
need from social services and that with  
more support they would feel less isolated

**1 in 3**  
Develop mental  
health difficulties  
due to a lack of  
support

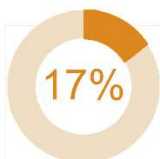


## AROUND 100,000 CHILDREN IN THE UK HAVE AUTISM



OF CHILDREN WITH AUTISM ATTEND MAINSTREAM SCHOOLS

But 69% of parents feel their child is in the wrong setting



OF CHILDREN WITH AUTISM HAVE BEEN EXCLUDED FROM SCHOOL

Of these, 48% have ben excluded three times or more

SECTION 4: WHAT WE KNOW ABOUT  
AUTISM NATIONALLY AND IN NORFOLK

---

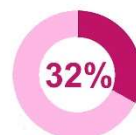
Although Autistic people may need support, when this is given at the right time and in the right way, this can make an enormous difference to people's lives



**Autism doesn't just affect children  
Autistic children grow up to be Autistic adults**



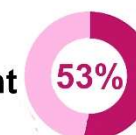
Of Autistic Adults are in full-time paid employment



Are in any paid work



Of Autistic adults receive employment support



Say they want it



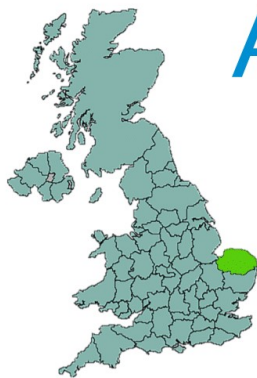
Say that they are not getting the help they need from social services  
The same percentage also stated that with more support they would feel less isolated

Suicide rates for people with Autism are far higher than the national average



SECTION 4: WHAT WE KNOW ABOUT  
AUTISM NATIONALLY AND IN NORFOLK

## What we know Locally



# Autism in Norfolk

1.1% of the Norfolk population are Autistic, mirroring the UK average

That's nearly **10,000** people!

Of these 2,500 are aged 0-19, 5000 are adults aged 16-64 and 2000 are older people (65+)

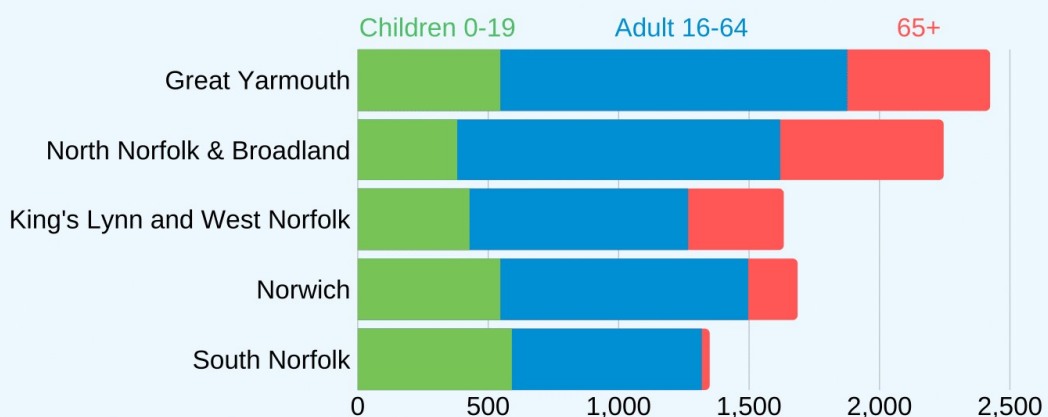
These figures are likely underestimated. Before June 2018 Norfolk hadn't consistently recorded autism statistics.

The number of people with autism is expected to rise



By 2035 there will be 5200 people aged 16-64 and 2800 aged 65+ with autism

## Where does our autistic population live?



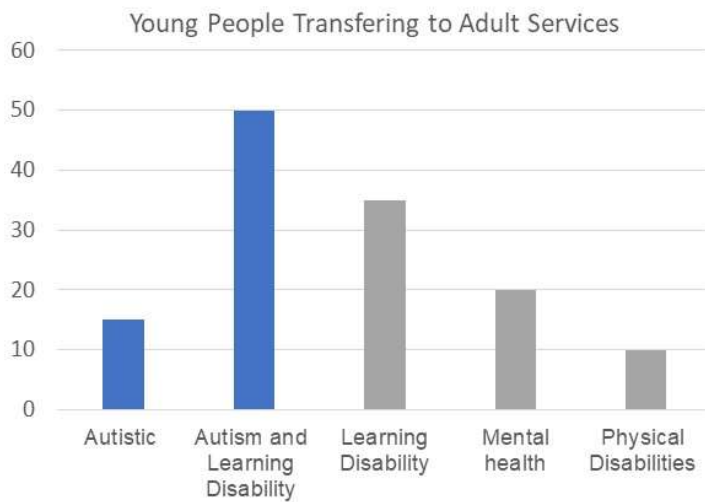
## Children with Autism

There are...

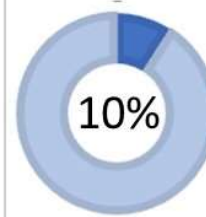


Of these, 90 have Education Health and Care Plans (EHCPs). There were 46 in 2017 but the number is expected to drop to 70 in 2020. The number of EHCPs in Norfolk has risen by 230% since 2015.

## SECTION 4: WHAT WE KNOW ABOUT AUTISM NATIONALLY AND IN NORFOLK



**1400** young children with an EHCP have **Autism Spectrum disorder (ASD)** as the primary need (5<sup>th</sup> highest category)



ASD accounts for 10% of all children with an EHCP



Around **130** young people transfer to Adult Services each year. Of which **15** are autistic without a learning disability or mental health issue, 85 have a learning disability with around **50** recorded as autistic, 20 have mental health issues, 10 have physical disabilities .

### Adult Diagnosis Service

In the year to the end of March 2018, how many people received a diagnosis of an autistic spectrum condition?

**24** ✓

For adult diagnosis, the average wait between referral and assessment is

**45 weeks**



**212** ⌚

people have been referred for an assessment but have yet to receive a diagnosis.



4 in 10 autistic people in Norfolk are likely to have a mental health problem too

The NHS Long Term Plan focuses on the prevention of inappropriate use of secure hospital settings.

In Norfolk, the number of adults with a learning disability and autism in a secure setting 2016-2019 is **17**. This is **10%** of the inpatient population. Admissions are expected to fall as community support improves.

## SECTION 4: WHAT WE KNOW ABOUT AUTISM NATIONALLY AND IN NORFOLK



problems.

Local data reported in December 2018 through the National Autism Self-Assessment tell us that **587** autistic adults were assessed and met the social care eligibility criteria. Of these, **415** had autism and learning disabilities while **70** had autism and were in receipt of treatment for mental health

### Employment

Data includes service users with an open service on 19.03.2019 with a reported health condition of Autism, Asperger's or both.

	Employed (Paid) - 16 or more hours per week	Employed (Paid) - less than 16 hours per week	Not Recorded	Self-Employed (Paid) - less than 16 hours per week	Unemployed - No hours listed	Voluntary	Grand Total
Autism	3	5	2	1	415	18	444
Asperger's	6	3	0	0	119	2	130
Both	0	0	0	0	2	0	2
Grand Total	9	8	2	1	536	20	576



Autism Asperger's Both Grand Total

% of Grand Total employed: 2.03% 6.87% 0.00% 3.12%

The wider **Norfolk community** is promoting and raising awareness of autism. From *My Autism, Our Lives, Our Norfolk* the following examples were identified:



Castle Mall, Hawkin's Bazaar The Entertainer, The Tea Junction and Norwich Travel are turning off music from 9-10am on Saturdays. They hope to help people with autism cope with shopping in a more comfortable environment.

Norwich International Airport is autism friendly, in line with the Civil Aviation Authority (CAA) guidelines setting out how airports should support people with hidden disabilities, including autistic people.

The ODEON and Vue have specially adapted Autism Friendly Screenings of new releases, which they host one Sunday morning each month. Picture House - Cinema City also regularly run Autism Friendly Screen clubs.

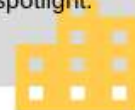
During the Christmas period, the Norwich Ice Rink introduced a new quiet session for people with disabilities, including autistic people.



Many supermarkets have engaged in quiet hours on a regular basis to make their stores inclusive for all.



Autism Anglia work with many providers to deliver autism friendly environments, including Norwich Airport and Gressenhall Farm Museum. Other providers are becoming more aware of autism due to national spotlight.



SECTION 4: WHAT WE KNOW ABOUT  
AUTISM NATIONALLY AND IN NORFOLK

---

THIS PAGE IS LEFT INTENTIONALLY BLANK



## SECTION 5: WHAT DO AUTISTIC PEOPLE TELL US?

---

Autistic people and their families/carers have told us how important it is for all agencies that work with them to cooperate with each other and with autistic people, their families/carers to implement the aims of *My Autism, Our Lives, Our Norfolk*

The outcomes autistic people want to achieve are covered within the vision, Section 1 but also described below:



People with Autism tell us:

**5.1 Life Skills:** Autistic people, their parents/carers have shared the importance of obtaining life skills that are necessary and desirable for full participation in everyday life. These skills do not always come naturally to autistic people and reasonable adjustments can support autistic people to develop them at a pace that is right for them.

Parents/carers have shared concerns about autistic children, young people and young adult's ability to cope during current transitions without appropriate support. They note particularly that some become withdrawn and may develop explosive behaviour as teenagers and young adults.

**5.2 Education Volunteering and Training:** Many children, young people and young adults find school and adults education difficult as it is challenging to get the right support in place. We also know that not enough autistic people are able to find or maintain work.

## SECTION 5: WHAT DO AUTISTIC PEOPLE TELL US?

---

- 5.3 Right Support, Right Time, Right Place:** Autistic people and their families/carers need timely intervention and to know where to go for support. Greater understanding of the condition and early intervention to put into place person centred strategies is very effective and prevents escalation of need.

Autistic people need advocacy services but are unable to easily access them in Norfolk.

Autistic people and their families/carers have told us it is difficult to navigate different services, understand their criteria and finally access the service. They have also told us understanding of autism varies significantly across services and support.

- 5.4 Treated with equality and respect:** Autistic people and their families/carers would like to access mainstream and statutory services with 'reasonable adjustments' made to ensure that support is 'autism friendly'.

- 5.5 Timely diagnosis:** Autistic people and their families/carers need primary care to make timely referrals through clear and transparent pathways. Autistic people and their families/carers can wait too long for an assessment and as a result diagnosis does not always lead to further support.

Autistic people and their families/carers tell us there needs to be more information about people who are autistic in Norfolk.

- 5.6 Right place to Live:** Autistic people and their families/carers have spoken about the difficulties they have finding the right accommodation to meet their needs, but which also enables independent living. There needs to be better partnership working between providers, families/carers and wider partners that include the council.

- 5.7 Secure, Safe and Positive:** Autistic people need to feel safe and to experience positive responses to build secure and trusting relationships over a period of time. Autistic people have also shared the importance of understanding autism within the youth and criminal justice system.

We will link our key priorities to our action plan to ensure the outcomes are clearly identified.

- Priority 1: Working Together** - We will continue to engage through co-production.
- Priority 2: Diagnosis and Support** - We will have clear, transparent and timely pathways for diagnosis and support for children, young children, young adults, adults and older people with autism spectrum disorder.
- Priority 3: Autism Awareness** - We will identify gaps in knowledge and understanding. We will make available high quality basic awareness training and specialist face to face autism training to raise awareness and understanding regarding the complexity of autism.
- Priority 4: Education, employment and training** - We will work with providers of education, employment and training opportunities to ensure the needs of autistic people are in place and supported appropriately.
- Priority 5: Understanding Needs** - We will improve our data collection, which will be used to inform future planning, priorities and the commissioning of services.
- Priority 6: Transitions** - We will promote a seamless progression through life transition. Children to young people, young people to young adult, young adults to adulthood, adulthood to older people.
- Priority 7: Right Service, Right Time, Right Place** - We will identify and put in place appropriate support at the earliest opportunity. This will include access to appropriate advocacy services and reducing the use of restrictive environments such as long stay hospitals.
- Priority 8: Housing** - We will offer and promote a range of accommodation options for autistic people based on their individual needs.
- Priority 9: Justice System** – We will work with the police and wider justice system to make sure they are aware of how to engage with autistic victims and perpetrators of crime to improve the experiences of autistic people when they come into contact with the criminal justice system and the reduce the risk of offending and harm. We want to improve autism practice across every area of the criminal justice system with the aim to identifying the specific issues faced by autistic people.

THIS PAGE IS LEFT INTENTIONALLY BLANK

We will continue to work together through co-production and wider engagement.

## What we know Nationally

The **Care Act 2014** is one of the first pieces of legislation to specifically include the concept of co-production in its statutory guidance.

*Co-production is a key concept in the development of public services. It has the potential to make an important contribution to all of the big challenges that face social care services. Co-production can support: the implementation of the Care Act 2014; cost-effective services; improved user and carer experience of services; increased community capacity; outcome-focused and preventative services; [and] integration.*

Social Care Institute for Excellence, *Co-production in social care: what it is and how to do it* (2015)<sup>2</sup>.

The use of co-production to achieve desirable outcomes is a constant theme in both the Care Act legislation and its accompanying statutory guidance. The guidance particularly identifies its importance when considering commissioning and market shaping, stating that they should be a 'shared endeavour' with 'commissioners working alongside people with care and support needs, carers, family members, care providers, representative of care workers, relevant voluntary, user and other support organisation and the public to find shared and agreed solutions.'<sup>3</sup>

## What we know now in Norfolk

It is important that the outcomes achieved are meaningful to autistic people living in Norfolk and makes a difference to their lives now and in the future.

Families/carers highlighted the need for them 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 as they believed they often knew their child best.

As a new board we are aware that we are at the start of a long journey. We can only make this a success by listening to many voices. There are many people living across Norfolk who have not yet had their say about their own experiences about living with autism and what is most important to them.

---

<sup>2</sup> SCIE, *Co-production in social care*, 'Introduction',

<https://www.scie.org.uk/publications/guides/guide51/introduction.asp> (accessed March 2019)

<sup>3</sup> Department of Health & Social Care, *Care and support statutory guidance*, 4.51,

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> (accessed March 2019)

## What is important to people

*I want to be listened to and treated with respect.*

*I want my views to be considered when decisions are made.*

## What we want to do as a partnership

- The Norfolk Autism Partnership Board is committing to continuing our drop-in sessions across Norfolk so that people can hear about the range of work underway. Alongside this, we will develop more opportunities for people to contribute to the priorities in different ways that are meaningful for them.
- We will involve autistic adults, their families/carers and autism representative groups when commissioning or planning training. This will include comments on and contributions to training material, asking them to talk to staff about autism and how it affects them, and to be a part of providing and delivering the training itself.<sup>4</sup>
- The NAPB will meet four times a year and provide updates to the Norfolk Autism Partnership Group. It will distribute relevant communications, for example the Autism Newsletter.
- Information about the work of the NAPB will be posted on the Autism webpages on the Norfolk County Council website with links on other partners websites, as well as meeting dates and other relevant information. Enquiries can be made via the Norfolk Autism Central email address [autism@norfolk.gov.uk](mailto:autism@norfolk.gov.uk)
- The NAPB will align *My Autism, Our Lives, Our Norfolk* to national and local policy as it changes and develops, over the 5 years of the strategy.
- The NAPB has responsibility to ensure that recommendations are achieved in the development of *My Autism, Our Lives, Our Norfolk* and to ensure that all service contracts are regularly monitored.

---

<sup>4</sup> This links to Priority 4, [Section 6.4]

- The NAPB has responsibility to ensure the implementation of the Autism Plan. It will continue to monitor implementation.
- The NAPB will invite the leaders of statutory agencies and other professionals to provide updates on how their service continues to develop to meet the requirements of the Autism Act, other relevant legislation, and the objectives set out in *My Autism, Our Lives, Our Norfolk*.
- The work of the NAPB will be overseen by the relevant organisation's governance and assurance processes, as well as the Norfolk Health and Wellbeing Board.
- Ensure that people involved in, waiting for or who have accessed the child and adult diagnosis pre- and post-support services inform the commissioning body of further diagnosis and support services.

THIS PAGE IS LEFT INTENTIONALLY BLANK



We will develop clear, transparent and timely pathways for diagnosis and support for children, young children, young adults, adults and older people to receive an assessment for autism. We will consider the diagnosis as part of a pathway that includes accessing pre- and post-diagnostic support which is right for the person.

## What we know Nationally

The **Department of Health** states that many autistic people are likely to go undiagnosed or be misdiagnosed with other conditions; this is particularly a problem among autistic adults. Waiting times for a diagnosis are too long across the country and across all ages groups. Combined, these facts can make life extremely challenging for young people, who can become stuck making the transition between children and adult services.

That there is a gender gap between the diagnosis of autism in men and women is becoming increasingly recognised. Studies have shown that the ratio of men to women with autism may be anywhere between 2:1 or 16:1, although the reasons for this are still hotly debated.<sup>5</sup> Some suspect that this might be due to an under-recognition of autism in women.

The **NHS Long Term Plan 2019** has identified the need to reduce waiting times for a diagnosis for 'specialist services' for children and young people. **National Institute for Health and Social Care Clinical Excellence (NICE) Guidelines for autism spectrum disorder in under 19s** recommends that a diagnostic assessment should be undertaken by an autism team within 3 months of a referral.<sup>6</sup> This team can access a range of specialists to inform their diagnosis and will be inclusive of education and social care where appropriate. Where the young person is transitioning to adulthood, it should be considered that a joint diagnosis assessment to be undertaken. The **NICE Quality Standard on Autism** (2014) also states that everyone who undergoes an assessment for autism should also be assessed for any co-existing physical and mental health problems.

**Think Autism 2014** identified 'getting a diagnosis' as number thirteen in its Priority Challenges for Action. While clinical commissioning group (CCG) commissioners were expected to take the lead, they would work in partnership with the local authority to provide a joined-up approach. **Think Autism 2016**, meanwhile, recognises how challenging it can be for people with autism to have support adapted to their needs when they also have a co-existing mental health problem, a learning disability or display challenging behaviour.

---

<sup>5</sup> National Autistic Society, *Gender and autism*, <https://www.autism.org.uk/about/what-is/gender.aspx> (accessed March 2019)

<sup>6</sup> <https://www.nice.org.uk/guidance/cg128/chapter/Recommendations>, Recommendations 1.5.1 (accessed March 2019)

## What we know now in Norfolk

**Healthwatch Norfolk: Access to health and social care services for Norfolk families with Autism (October 2018)** reported a lack of clear and transparent pathways for those who refer into the service and those who access the service; issues regarding young people becoming adults and transitioning into adult services; too long waiting times; and limited pre- and post-diagnosis support. In addition, it details the difficulties autistic people and their families/carers faced when accessing services, often due to a lack of awareness surrounding autism.

Families/carers revealed that they were often offered a place on a parent support programme too late, which suggests that timely access needs to be improved. Some parents suggested that these programmes were not always accessible, either due to the times at which they were running or their locations. Others suggested that parents should be actively involved in shaping these programmes. The use of digital platforms and webinars could enable more parents to access them.

The diagnosis rate is much lower for girls and women than boys and men. Our local perspective mirrors the national understanding that autism presents differently in girls and women as they are more able to mask their autistic traits. Everyone masks, but if you are autistic this can be more of an effort and physically draining, causing anxiety and depression that can result in “social burnout”. Due to consistent masking in various environments, such as school or work, burnout or melt downs often happen in a place where people feel most safe. This can have a significant impact on their relationship with those closest to them, for example family/carers.

## What is important to people

*A diagnosis is about understanding the condition and putting in place strategies to manage life events.*

*Autism is often the first thing considered if you have boy and the last thing when you have a girl.*

## What we want to do as a partnership

- The NAPB will ensure leadership is provided to coordinate more awareness of ASD diagnostic services, the process and procedures involved, and openly share this with families/carers when accessing the service.
- Neurodevelopmental diagnosis pathways to be reviewed alongside autism diagnosis pathways.
- Ensure the appropriate identification and management of demand avoidance to prevent an escalation to pathological demand avoidance. Ensure appropriate assessment and guidance is in place.
- As part of any future modelling and support pathways scope out and include access to appropriate psychological support and make reasonable adjustments to mental health and emotional wellbeing services.
- Reduce the current waiting lists for an assessment in line with NICE guidance to 18 weeks for children, young people.
- To develop diagnostic pathways in line with NICE guidance. This will include access to multidisciplinary assessment of needs that can support the development of skills and opportunities to promote independence, as well as improved health and wellbeing outcomes.
- Pre-diagnosis screening to be developed to identify immediate needs or risks that can be supported and that may prevent them from increasing. Where appropriate, this will include support to parents/carers.
- Ensure support to navigate the health and social care system so that all autistic people get the right support from the service that is best placed to meet their additional needs. This service will consider the specific nature of their autism, the impact it has on their life and how this can interact with other disabilities or conditions they may have. This will be considered during the assessment process of autism as identified within the NICE Guidelines.
- To influence and support the development of a local register for monitoring and support to maintain positive health and wellbeing, including access to primary care. Primary care will be made aware of all diagnoses of autism made.
- Improve the recording and reporting in both children's and adult ASD pathways of diagnosis and support. An ASD partnership dashboard which excludes

personal identifiable information will be made available as part of the local datasets and reporting.

- Improve links with the liaison and diversion teams, police and mental health services and those at risk of accessing community justice system and homeless services.
- Continual review and monitoring of the ASD pathways.
- Reduce waiting times in line with NICE guidelines and Quality Standards.
- Ensure consistency in waiting areas, particularly in providing a quiet space.<sup>7</sup>
- Produce letters that provide more information about how long an appointment will last, what will go on during the time and, where possible, a photo of the people involved in order to manage anxieties.<sup>8</sup>
- Work to make sure appointments can be offered outside of school hours or at weekends to manage routines and a right to an education.<sup>9</sup>
- The adult diagnosis service must ensure it works for older people who report obstacles to receiving a diagnosis, such as problems in being identified, not being able to provide a developmental history and additional health problems.
- All professionals within the diagnosis pathway must ensure it takes into consider people who are able to mask their autism and listen to the experiences of family/carers.

---

<sup>7</sup> This links to Priority 7. [see section 6.7]

<sup>8</sup> This links to Priority 7. [see section 6.7]

<sup>9</sup> This links to Priority 7. [see section 6.7]]

We will identify gaps in knowledge and understanding. We will make available high quality basic awareness training and specialist face to face autism training, to raise awareness and understanding of the complexity how autism plays a part in individuals lives.

## What we know Nationally

Local Authorities should ensure that any person carrying out a needs assessment under the **Care Act 2014** has the knowledge, skills, appropriate training and competency to carry out the assessment in question. Where the assessor does not have experience in the condition, the local authority must ensure that a person with that expertise is consulted.

**Think Autism 2014** highlighted the importance of giving staff training on autism across all public services, as well as recommending improved training for staff in health and social care, welfare, employment, education, transport, the police and criminal justice.

The **2015 Statutory Guidance** recommends that staff training for local authorities, NHS Trusts and NHS Foundation Trusts includes autism focussed awareness training alongside more general equality and diversity training in programmes for all staff working in health and care. This recommendation was built upon in the **NHS Long Term Plan 2019**. The plan highlighted its intention to ensure that the entire NHS workforce will be autism aware to improve people's access to health services and reduce the risk of health inequalities.

## What we know now in Norfolk

We recognise that there has been limited training for assessors to undertake assessments in a manner that recognises the specific approaches that can support autistic adults.

Many parents highlighted the general lack of awareness and understanding of ASD from professionals. Some autistic adults felt dismissed and some parents recalled instances where professionals had not known how best to work with their child during appointments. The difficulties autistic people and their families/carers faced when accessing services was often due to a lack of awareness of autism. It was felt that more training was required for professionals who may meet an autistic patient.

## What is important to people

*When different people turn up from the team I can't cope and just shut down.*

*Waiting areas are not suitable. Sensory overload is a problem and there's no consistency to manage expectations.*

## What we want to do as a partnership

- Ensure basic autism awareness training is delivered to all staff working in health and social care in line with existing equality and diversity training.
- Ensure basic awareness training enables staff to identify potential signs of autism and to understand how to make reasonable adjustments in their behaviour, communication and service towards people who have a diagnosis of autism or who display these characteristics.
- Deliver specialist autism training in line with NICE guidance for key staff who are likely to have contact with adults with autism.
- Ensure both general awareness and specialist autism training is provided on an ongoing basis and that new staff, or staff whose roles change, are given the opportunity to update their autism training and knowledge.
- Raise community awareness of autism.
- The NAPB will lead the way in providing training across all universal health and social care services.
- Develop a multi-agency workforce development training plan to achieve an autism capable, confident and skilled workforce.
- Promote the use of the National Autistic Society Hospital Passport, with autistic people in Norfolk and hospital staff, to achieve good in and outpatient health outcomes.
- To ensure Primary Care as the gatekeepers to diagnosis service, have adequate training and a good understanding of the diagnosis pathways that have been developed in the area.<sup>10</sup>

<sup>10</sup> This links to Priority 2, [see Section 6.2]

We will work with providers of education, employment and training opportunities to ensure the needs of autistic people are in place and supported appropriately.

## What we know Nationally

The **NHS Long Term Plan**, the **Equality Act 2010**, **Think Autism 2014**, the **Care Act 2014** and the **Care and Families Act 2014** all recognise the principles of developing skills, independence and working to the best of an individual's ability. They aim to enable access to and sustain education, training and employment opportunities that include the enhancement of skills to allow people to feel empowered to be as independent as possible.

The **NHS Long Term Plan 2019**, communicates the intention to offer more opportunities for people with a learning disability and for people with autism. This includes the provision of supported internship opportunities targeted at people with a learning disability and/or autism will increase by 2023/24

**Care and Families Act 2014** gives special regard to the SEND code of practice for people aged 0-25 years. It requires preparation for adulthood from the earliest years.

**The Equality Act 2010** reminds employers of their responsibilities to make reasonable adjustments in the workplace to support people with disabilities, including autistic people, to obtain and sustain employment opportunities.

## What we know now in Norfolk

The number of autistic people in employment is unknown as many people that are diagnosed with autism do not disclose their diagnosis. However, the number of people with autism and additional needs such as a learning disability entering employment is known to be low, at approximately only 5% of the learning disability population.

The links with the local Department for Work and Pensions (DWP), the Chamber of Commerce and local businesses could be improved to encourage the employment of autistic young people and adults as well as the benefits this can bring.

Some autistic people, their parents/carers feel they have been let down by the SEND and Education, Health and Care Plan (EHCP) process that is currently under review. They understand the challenges the local authority face but feel there needs to be radical changes in the relationship between the local authority and schools to ensure autistic children and young people receive support aligned to their individual education, health and social care needs.

## What is important to people

*To be listened to and get the support my child needs, not having to fight every little step!*

*Money needs to be spent differently – the system isn't working.*

## What we want to do as a partnership

- Understand what is and is not working within the special education needs process, education and health care plans for autistic children and young people. This will allow us to make recommendations and implement improvements.
- Review access to existing skills, training and employment support for people with additional mental health and learning disability needs. Ensure that they can make the required reasonable adjustments for those who also have a diagnosis of autism.
- Link with the DWP to ensure people have access to the right support and reasonable adjustments they need to seek employment opportunities. This will include links with local DWP accessibility advocates.
- Develop an employment workstream to improve employment opportunities, linking to welfare rights, the DWP and employment specific projects underway in Norfolk.
- For those receiving support from Norfolk County Council, continue to deliver employment and volunteering opportunities through local Employment Co-ordinators.
- Connect with local businesses, promoting opportunities for employment and considering how to support employers to make reasonable adjustments in the work place.
- Review the local individual service funds provision to ensure they have received awareness and training on autism and are able to support in their employment responsibilities.



- Nationally, raise the issue of local authority responsibilities versus school delivery.
- Continue to influence the build of an additional special school for ASD in Norfolk with current evidence base suggesting this would be in the North of the county

THIS PAGE IS LEFT INTENTIONALLY BLANK

We will improve our data collection, which will be used to inform future planning, the development of priorities and the commissioning of services.

## What we know Nationally

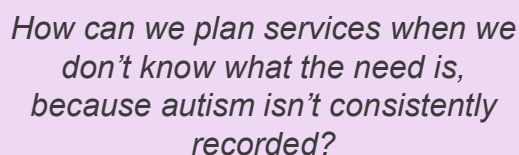
**Think Autism 2014** suggests that to plan and commission services effectively, the local authority and their Health and Wellbeing Board, CCGs and other partners need to have access to as comprehensive data on local numbers of autistic people and their needs as possible.

## What we know now in Norfolk

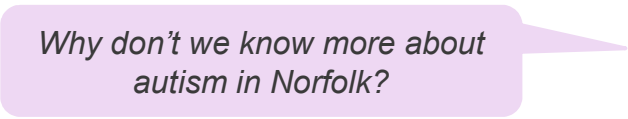
The local response to the *National 2018 Autism Self-Assessment* tells us that data collection remains a priority. Data is collected on those people known to access adult social care, but more work needs to be done to demonstrate accurate and consistent recording. This must be across the entire partnership and not just within the local authority.

The recognition of autistic people remains a challenge as there is currently no single place where all relevant information is kept. We are working together in Norfolk to develop a single dataset to inform those people accessing services across the county.

## What is important to people



*How can we plan services when we don't know what the need is, because autism isn't consistently recorded?*



*Why don't we know more about autism in Norfolk?*

## What we want to do as a partnership

- Work together to oversee the development of a central point of information that informs planning across the partnership.
- Contribute to the council's Market Position Statement.

- Where permission is granted, take further action to collect data on people with autism accessing other services.
- Where permission is granted, to progress work with local primary care service of those people registered with autism.
- Improve recording of autism and sharing of information across local authorities and the police.
- Identify the age profile and range of support needs for people living with autism in Norfolk to predict how numbers and needs will change over time. This data will include numbers of children and young people, those of working age and over 65s.
- The NAPB will ensure the review of the autism needs assessment is included in the commissioning joint strategic needs assessment and market positioning statements produced by Norfolk County Council.

We will promote a seamless progression through life transition: children to young people, young people to adulthood, adulthood to later life.

## What we know Nationally

The **Children and Families Act 2014** states that a young person's EHCP can continue up to the age of 25 if the council thinks they still need that help. This help may include supporting a young person with autism, whether they have a learning disability or not, to access college or job training if that is what they need and want.

The **Care Act 2016** is designed to work in partnership with the Children and Families Act 2014, with specific legislation applying to children aged up to 25 years and other young people with SEN and disabilities. In combination, the two Acts enable local authorities to prepare children and young people for adulthood from the earliest possible stage, including their transition to adult services.

The national **SEND Code of Practice: 0 to 25 years, Chapter 8 on Preparation for Adulthood**, requires supporting young people to plan for adulthood, including employment. If a young person is being trained as an apprentice, they can get help through an EHCP as well. The focus will be on supporting a young person that can work to be as independent as possible and have better life opportunities and not to become registered as Not in Education, Employment or Training.

The **Children and Families Act 2014** places the responsibility on educational establishments, local authorities and health organisations to consider how best to support children and young people with special educational needs and disabilities to access education, putting appropriate support in place to maximise their opportunities. It extends its responsibilities up to age of 25 years to better support young people, including accessing opportunities in further education, training and employment as they enter adulthood.

Where additional health and care support is required to best enable such opportunities, an EHCP can be devised alongside adult services.

## What we know now in Norfolk

We recognise transition periods are very difficult times for autistic people. Improvements are required so that autistic people of all ages feel sufficiently supported as they progress through the life journey, all whilst treated with dignity, equality and respect.

## What is important to people

*I need support now, because I worry about what will happen to me when mum gets older.*

*I'd like support, so it's not always left up to mum.*

## What we want to do as a partnership

- A Norfolk Preparing for Adult Life Team is in the process of development across adult and children's social care. They will also work with health teams to consider what needs must be considered when planning for continued educational support up to the age of 25 years and for those young people leaving care up to the age of 25 years.
- The NAPB will ensure local housing strategies and plans are developed and examine how those strategies and plans deal with adults with autism.
- The NAPB will link with the Norfolk Older People's Strategic Partnership to ensure special consideration is taken when planning for the transition into older age of autistic people, particularly given the attendant risk of other health issues developing in later life. This is especially a concern in cases when family members may not be able to support an older autistic adult. Invitations to the NAPG will be extended to the Norfolk Older People's Forum.
- Ensure access to appropriate support for parents/carers (and siblings involved), who have decided to have their children and young people accommodated.

We will provide effective and enabling care and support.

## What we know Nationally

**Think Autism 2014** includes 15 Priority Challenges for Action, which states that every day public services that autistic people frequently encounter will know how to make reasonable adjustments to aid inclusion and acceptance.

**Autism Statutory Guidance 2015** refers to the requirement for NHS Provider Services, in particular those involving mental health, to apply reasonable adjustments in order for autistic people to receive the right support. Including Child and Adolescent Mental Health Service (CAMHS) so that fewer children, young people and young adults with a learning disability, autism, or both, access inpatient hospital settings inappropriately or for long periods. The guidance calls for the end of the use of out-of-area placements, whenever possible and suitable.

The **Care Act 2014** focuses on the delivery of wellbeing outcomes to prevent needs from escalating. Information and advice should be given to help resolve issues early and prevent them from getting worse. A carer for an autistic person can receive a carers assessment and assessed support.

**The NHS Health Child Programme** identifies the recommendation pathways to access support for parents, infants, children and young people to receive the right health care and support. This includes access to specialist paediatric services to determine additional needs, such as ADHD and autism, when they are identified by primary care.

The **Children and Families Act 2016** equally communicates the need for a joined-up assessment inclusive of health needs through an Education, Health and Care Plan for children and young people with SEN and/or a disability.

The **Equality Act 2010** aims to make society fairer for people with a known disability or those who are perceived to have a disability. Expanding from the work place, the Act includes access to community service providers and places the responsibility on providers to minimise the risk of exclusion or discrimination through reasonable adjustments and provision of appropriate information wherever possible.

**Think Autism 2014** and **Statutory Guidance 2015** promote the idea that all autistic people live a fulfilling and rewarding life as equal members of their community, supported through wider awareness of autism and reasonable adjustments to access employment and any other life opportunities. It includes 15 Priority Challenges for Action, one of which has a specific focus on being an equal part of the local community.

It specifically encourages the strengthening of opportunities for autistic people to be actively engaged and included, and that anyone who works with an autistic person is aware and accepting of their condition.

**Building the Right Support 2016** communicates the absolute need to provide the right type of support in the community that can meet the needs of people, no matter their age or whether they have a learning disability. It insists that both health and social care commissioning need to work together to determine the needs of the population as a whole to ensure the right support can be provided locally. This will prevent needs from escalating and resulting in inappropriate hospital placements and/or placements outside of the local area.

**The NHS Long Term Plan 2019** identifies the need to raise awareness across the NHS so that Autistic people can better access their local health services, with particular focus on the need for autistic children and young people to access key services such as dentistry. It also identifies the need to be aware of autism to effectively engage with individuals to identify and meet their needs appropriately. For those individuals with more complex needs, the NHS will work with partners, including the local authority, to provide greater access to care in the community. For those who need it, this may include specialist forensic and multidisciplinary crisis support for children and young people.

## What we know now in Norfolk

Currently autistic people accessing primary care for support report a mixed experience; some patients have a positive relationship with primary care, while others feel unable to access them due to a lack of understanding and/or that reasonable adjustments have not been made.

Autistic people have communicated that access to support in managing their emotional wellbeing and mental health is a challenge. However, once they can access specialist mental health services they may, if identified as autistic, experience some reasonable adjustments. This is due to an approach called the Green Light Tool Kit, which promotes consideration of the additional needs of people with autism, including those with a learning disability, when they are accessing inpatient mental health services.

Some autistic adults accessing acute hospital services for their physical needs may receive help from a liaison nurse who can support the general hospital to staff think about the reasonable adjustments they require while staying as an in-patient. This support is not always consistent, and while it has been used by autistic people it appears intended for people that have an additional learning disability.

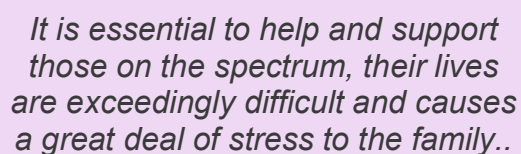


It is understood that there are limited amounts of targeted services, support or understanding of the needs of older autistic people. Many of these individuals are currently being cared for by ageing parents, as provision for older autistic people in the commercial residential sector is virtually non-existent and understanding of autism is therefore limited.

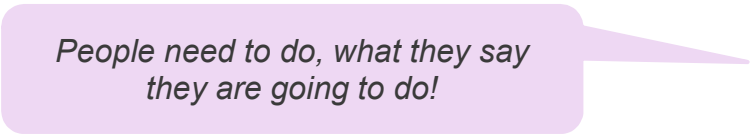
There has been an expectation that people with autism access current models of care, which may mean that some individuals receive support from a learning disability or mental health team that is not always appropriate to their needs.

Some children and young people with autism displaying challenging behaviour at home, school and in other environments may need a crisis medication review. An autism crisis service that provides a person centred, time limited intervention programme, with a step-down package to prevent readmission and which focuses on the reintegration of children and young people with their families/carers and communities, could prevent admission to Tier 4 services and/or 52-week residential placements.

## What is important to people



*It is essential to help and support those on the spectrum, their lives are exceedingly difficult and causes a great deal of stress to the family..*



*People need to do, what they say they are going to do!*

## What we want to do as a partnership

- Linked to priority 6.4, we will work in partnership with health providers and commissioners to provide autism specific training for staff at different levels, including general awareness and more in-depth training for assessors of health and social care.
- Linked to priority 6.5, we will use data to inform the future provision of health services across Norfolk to prevent needs from escalating. This will include working with providers to ensure the right community support is available.

- Linked to priority 6.1, on reviewing the diagnostic pathways we will also review the pre-diagnosis support and ensure that people's needs are identified early so they can be addressed appropriately before they escalate. People who are waiting for a diagnosis will be screened to ensure that they are not at risk of harm, vulnerable or that their wellbeing outcomes are at risk. Following diagnosis these people will be advised and, where required, provided appropriate support in managing their wellbeing. This could include assessments of their dietary and nutritional needs as well as their mental wellbeing.
- Autistic Children, parents and siblings offered a whole family approach and appropriate support as part of the Early Help Offer.
- We will explore the demand and supply for those pre-school children who don't have dysphagia but may have sensory and psychological difficulties that would benefit from a feeding clinic and a higher level of support to assess their needs and provide advice within the home.

We will explore the demand and supply for those children and young people (aged 5-16 years) being assessed or diagnosed with autism who have difficulty in their eating and drinking due to sensory and psychological difficulties.

These approaches aim to prevent children and young people with sensory issues that do not meet criteria for support or have a service to address their needs. Furthermore, its purpose is to reduce demand on NHS prescribed supplements and vitamins throughout life and in addition the escalation of health needs later life due to sensory issues.

- We will ensure the right information on accessing support is on the Norfolk Directory and Local Offer alongside information on reasonable adjustments and other approaches to accessing wider community services.
- We will work closely with Norfolk Healthwatch as a member of Norfolk's Autism partnership.
- We will work with the CCGs' to develop links and better awareness of autism among dentists and oral health professionals.
- Ensure that Autism is recognised in the developing Mental Health Strategy and any future service model for adults. This will include reasonable adjustments to access primary care wellbeing services.

- Ensure that autism is included in the review of CAMHs services and any future service models.
- Ensure that autism is recognised in the development of the future LD specialist integrated service model.
- We will review the pathways of support, including accessing health support, so that all autistic people get the right support that is best placed to meet their additional needs. This support will consider the specific impact that their autism has on their lives and how it can interact with any other disabilities or conditions they may have.
- We will make sure that people can access the right information and advice in a way that is meaningful to them at the first point of contact, to resolve issues as early as possible and prevent needs from escalating.
- A new approach to delivering the assessments and case management of people who do not require mental health or learning disability services are being considered to meet the needs of people with autism. Workers will receive specific training to undertake their assessments and promote every opportunity to enable service users to live an independent and fulfilling life. They will also work alongside other services, such as healthcare providers, to support people to navigate through the 'system' and enable them to receive the right support at the right time, reducing the risk of escalating needs.
- Review advocacy services for adults, ensuring they have proper knowledge and awareness of autism. We will ensure that people receive support to fully participate in their assessment through a range of reasonable adjustments, including identifying what is most important to the individual undergoing the process.
- Work with the council to develop community hubs open to the public to ensure autistic people can access them through facilities such as changing places, safe places and quiet rooms.
- Work with the autism community and community providers to enable greater access to mainstream community services.
- Work with transport providers to raise awareness of autism.
- Roll out Independent Travel Training for autistic people.

- Encourage the use of smartphone apps such as *Brain in Hand* and other autism specific programs that provide reminders of strategies, recognise the escalation of stress and anxiety and provide deep breathing exercises for de-escalation.
- We will link with community resources to maximise opportunities to support autistic people of all ages in the local community. We will particularly focus on including the voluntary sector, as currently there are very few Norfolk-based agencies charity or voluntary sector accessible or targeted on autism.
- Work with the police to make sure that they are aware on how to engage with autistic victims and perpetrators of offences to reduce risk of offending and harm. Work to reduce contact with the Criminal Justice System in general.
- As opportunities arise, involve parents in the redesign of services, buildings and waiting areas used by autistic people.
- NAPB to monitor the delivery of parent support programmes to ensure parents involvement in the design and implementation to ensure they are accessible for all, for example by considering the impact of digital platforms.
- Work with the access points including the Integrated Care Partnership wellbeing hubs.
- Provide advice on how to make the first contact between an autistic person and a service user is appropriate and accessible to ensure that people's needs can be addressed at the earliest point in time
- The government announced on the 29<sup>th</sup> July 2018 that the Blue Badge scheme is to be extended to hidden disabilities, including autism and mental health conditions. We will work with the blue badge scheme to ensure the criteria considers the needs of autistic people and their families and takes into account their needs for certainty and safety.

We will offer and promote a range of accommodation options for people with autism based on their individual needs.

Autistic people and their families/carers have spoken about the difficulties finding the right accommodation to meet their needs, which also enables them to live independently. They want to live free from fear, we have considered their shared experiences of vulnerability due to hate crime and victimisation.

## What we know Nationally

The **Care Act 2014** states that housing is a priority for all individuals, inclusive of autistic people. Having the right accommodation is fundamental to people's wellbeing and is therefore a protective factor. It encourages working together across housing providers and housing related support to ensure that people's accommodation meets their needs and supports their ability to live their life as independently as possible.

Transition planning should cover all relevant areas of service provision, including housing and employment support.

**Adult Autism Strategy 2015** considers that housing can play a vital role in autistic people to maintain good health, independence and improve their quality of life.

On considering the needs of autistic people when planning how care and support needs of autistic adults are to be met, the local authority should consider how autism impacts on all local housing strategies and plans.

## What we know now in Norfolk

There is limited accommodation specifically designed for autistic people in Norfolk, although some plans are in place to develop accommodation options for people with learning disabilities and autism, more specialist accommodation is required for those people with multiple, complex needs. Some individuals require more bespoke packages of care which consider their home environment, or to support a transition from hospital and specialist placements to new accommodation. It can be difficult to find residential care that is able to cater for both autism and additional needs.

The use of everyday technology can make a positive impact on the living environment of autistic people; for example, prompting technology and ambient lighting provide clear benefits. The review of the use of the technology policy at Norfolk County Council is underway and will include both assistive technology and universal technology.

## What is important to people

*I want my own space, my own things and a place where I feel safe.*

*I want a choice of where I live and the activities I do.*

## What we want to do as a partnership

- Work with housing officers to consider how autistic people and their family members and/or carers can quickly access the right support and advice in a meaningful way to resolve problems before they escalate. This will prevent debt accumulating uncontrollably or accommodation from being lost.
- Develop a housing and accommodation plan for autism, working with district councils', local housing providers, and private landlords to support autistic people to access the right accommodation for them.
- Work with housing providers to consider how reasonable adjustments to existing accommodation could maintain existing accommodation, for example sound proofing where excessive noise is becoming a specific challenge due to sensory, anxiety-based or noise related issue.
- Work with housing developers and providers to be considerate of sensory and autism needs in the design and development of new accommodation, particularly for those people with more complex needs.
- Work with housing providers to enable people to buy their own accommodation, including properties with shared ownership, without risking any support they receive.
- Ensure that a review of current inpatient placements is carried out and that anyone found to be inappropriately placed in a hospital setting is moved to community-based support.
- Ensure all placement's where a vulnerable autistic person is placed, are regularly monitored with the autistic person seen.

We will work with the police and wider justice system to make sure they are aware of how to engage with autistic victims and perpetrators of crime to improve the experiences of autistic people when they come into contact with the criminal justice system and the reduce the risk of offending and harm. We want to improve autism practice across every area of the criminal justice system with the aim to identifying the specific issues faced by autistic people.

## What we know Nationally

**Think Autism 2014** highlights that autistic people need access to support when encountering the Criminal Justice system, whether they are a victim, witness or are suspected of committing a crime. Local Authorities will work with prisons and other local authorities to ensure that individuals in custody with care and support needs receive continuity of care when moving to another custodial setting or where they are being released from prison and back into the community.

The **Bradley report 2009** and **Care Not Custody** coalition report (Prison Reform Trust 2018) consider the development of effective liaison and diversion arrangements and improved health and justice outcomes for people with mental health conditions, learning disabilities, autism and other needs caught up in the criminal justice system. In addition, the **Ministry of Justice and Department of Health** are to encourage greater use of the Community Sentence Treatment Requirement, including the Mental Health Treatment Requirement (MHTR) where appropriate.

The **NHS Long Term Plan 2019**, intends to increase investment in intensive, crisis and forensic community support, to enable more people with autism and or a learning disability to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services, including specialist multidisciplinary service and crisis care, which could align with the wider community mental health services.

The **Care Act Statutory Guidance 2016, (14.83)** refers to Criminal offences and adult safeguarding, in which everyone is entitled to the protection of the law and access to justice.

## What we know now in Norfolk

The police are members of the NAPB and are working to develop greater awareness of autism across the force and the wider criminal justice system. The police have put in place an Autism Alert Card. Autistic people can apply for a card which they carry on them, if stopped by the police they can hand the card to the officer that explains to them what they need to do. We realise more work needs to be done to make sure people who are at risk of offending or at risk of becoming a victim do not fall through

any gaps between organisations and pathways, all autistic people are appropriately supported and advised. We will continue to work with the police, the criminal justice system, liaison and diversion teams, youth offending and the children and adult safeguarding boards to raise awareness of autism to do this.

## What is important to people

*Prison feels safe. I need somewhere to feel safe when I leave, to prevent me from wanting to go back.*

*I want support that meets my needs to keep me safe and helps me understand the consequences of actions.*

## What we want to do as a partnership

- Work with the Norfolk Community Safety Partnership and the Norfolk Local Criminal Justice Board to bring different agencies together and develop a plan to support *My Autism, Our Lives, Our Norfolk*.
- Ensure the criminal justice system (including liaison and diversion services) refer autistic people to appropriate health and care support to divert them from offending and prevent them from re-offending.
- Ensure reasonable adjustments are in place to enable individuals to effectively engage in the Youth and Criminal Justice System. When engaging with issues surrounding informed consent, ensure workers in the Youth and Criminal Justice System have correctly considered the autistic person's ability to make decisions and predict consequences.
- For adults in prison or other forms of detention, assess the care and support available to them and ensure that it meets their needs.
- Work with prison services to ensure individuals with care and support needs in custody have continuity of care when moving to another custodial setting, or when they are being released from prison and back into the community.
- Ensure that in commissioning health services for autistic people in prison and other forms of detention prisoners can access an autism diagnosis in a timely way. Ensure that healthcare, including mental health support, considers the needs of people with autism.



**ASD:** Acronym for Autism Spectrum Disorder. Autism Spectrum Disorder, and the related diagnosis **Autism Spectrum Condition (ASC)**, are typically used by doctors to describe what ordinary people tend to simply call autism. One can have the condition without it also being a disorder, as an official diagnosis of ASD is usually only made when a person's condition has deteriorated to the point that it is significantly damaging them. The disorder's impact upon a person's life can also fluctuate over time, so that at times when they can live without significant distress they can be said to move from a disorder to a condition.

**Asperger's Syndrome:** is considered a type of autism. The term has now been dropped from the current DSM-5 (the American diagnostic 'bible' – see below), replaced by the term 'high-functioning autism'. This has proved controversial, as many people who identify as having Asperger's find this replacement term offensive.

**CAMHS:** Child and Adolescent Mental Health Service.

**DSM-5:** The *Diagnostic and Statistical Manual of Mental Disorders (fifth edition)*. Published in 2013, this is the latest a classification of mental health conditions, diseases and disabilities published by the American Psychiatric Association. The DSM is revised, and new editions are put out, every few years as knowledge grows. In the United States the DSM is the universal authority for psychiatric diagnoses. Treatment recommendations are often determined by DSM classifications, so a new version has significant practical importance.

**ICD-11:** The *International Statistical Classification of Diseases and Related Health Problems* (eleventh edition). Published in 2018, this is the diagnostic classification standard used by the World Health Organisation for all its clinical and research purposes. It lists more than 14,400 different diseases and health conditions. Generally, where DSM leads, ICD follows. Although many doctors in the UK and Europe use the ICD classification, others also use the DSM.

**EHCP:** Education, Health and Care Plans. These replaced Statements of Special Educational Needs and Learning Disability Assessments in September 2014.

**Healthwatch:** is a UK statutory agency whose job is to monitor NHS services on behalf of the public and make its findings public.

**JSNA:** The Joint Strategic Needs Assessment. This is an annual survey carried out by Public Health Departments, using information from both local councils and the local NHS.

**NAPB:** The Norfolk All Age Partnership Board.

**NICE:** The National Institute for Health and Care Excellence. NICE provides national guidance and advice to improve health and social care. They regularly publish important guidelines on a wide variety of topics.

**NHS:** National Health Service.

**SAF:** The *Self-Assessment Framework*, a questionnaire council must complete to describe how well they are performing against government-set targets for autism services.

**SEND:** Special Educational Needs and/or Disabilities. Usually used in the context of children and young people up to the age of 25.