

**AUTISM STRATEGIC FRAMEWORK FOR
NOTTINGHAM**

2018-2020

DRAFT FOR ENGAGEMENT

Nottingham City Strategic Framework for Autism 2018-2020

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The terminology used in this strategic framework

The term autistic people, rather than people with autism, is used in this strategic framework. This choice of language is deliberate and reflects that many autistic people see their autism as a key feature of their identity rather than as a medical diagnosis. The decision to use the term autistic people reflects the adoption of this term by national and local organisations including the National Autistic Society, Autistic Nottingham and Autism East Midlands, both of whom are represented on Nottingham’s Autism Strategy Group.

1. Introduction

This autism strategic framework encompasses autistic people of all ages who live in Nottingham and their families and carers. Specifically, this strategy recognises the broad spectrum of autism, recognising how the needs of autistic people differ across the life course and that Nottingham needs to change to enable autistic people to fulfil their potential.

The autism strategic framework has been developed within the social model of disability. It recognises that disability is caused by the way society is organised, rather than by autism itself and considers ways of removing barriers that restrict life choices for autistic people. The strategic framework identifies opportunities to remove barriers so autistic people living in Nottingham can be independent and equal, with greater choice and control over their own lives.

2. Context

National data suggests that 1 in 100 people are autistic¹ although not all these people will have received a diagnosis of autism. Current data collection and collation makes it challenging to state accurately the number of children, young people and adults with autism in Nottingham. The needs of people on the autism spectrum are as varied as they are. Some autistic people and have an associated learning disability are non-verbal and have a life-long need for care whilst other autistic people are highly intelligent, analytical and creative. Everyone with autism benefits from the right support, delivered in the right way at the right time by the right people.

Data collection on autism, including the number of people diagnosed with autism, is limited. Many services do not collect information on the number of autistic people they have

¹ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). [Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey](#). Leeds: NHS Information Centre for Health and Social Care

contact with and as such it can be challenging to understand whether autistic people have equitable access to, and outcomes from, services. An exploration of the needs of autistic people can be found in the autism health needs assessment [add link when complete](#).

Figure 1 is a visualisation of the needs of autistic people and how they can be supported to fulfil their potential. It was created by Nottingham’s Autism Strategy group to capture the spectrum of autism and how needs differ; the tiered nature is a rough approximation of the proportion of autistic people in each segment of the pyramid. The group recognise that the visualisation has limitations in describing the broad range of needs of people on the autistic spectrum.



Figure 1: A visualisation of the differing needs of autistic people created by Nottingham’s Autism Strategy group

3. Rationale: Why do we need a strategic framework for autism in Nottingham?

A requirement of the *Autism Act (2009)* is that councils in England should have a strategy for autistic adults led by a named Autism Lead. The Government published new statutory guidance in March 2015, which, in addition to the requirements of the Act, states that local authorities and the NHS:

- Should provide autism awareness training for all staff
- Must provide specialist autism training for key staff, such as GPs and community care assessors
- Cannot refuse a community care assessment for adults with autism based solely on IQ
- Have to develop a clear pathway to diagnosis and assessment for adults with autism
- Need to commission services based on adequate population data.

Nottingham's previous autism strategy, *One Size Fits One: Ensuring Autistic people Live Fulfilling and Rewarding Lives* was an adult only strategy. In line with Nottingham's move to an all-age approach to disability, this strategy will encompass priorities for children, young people, adults, families, and carers.

This strategic framework was developed with a wide range of partners from the statutory and voluntary sectors in Nottingham. Arguably most importantly, the strategic framework was developed in partnership with autistic people and agencies that represent their families and carers both as representative on the autism strategy group and through wider engagement.

This strategic framework will:

- Summarise and coordinate existing activity on autism in Nottingham

- Increase the profile of Nottingham’s work on autism and the needs of autistic people of all ages in the city
- Influence decision-making including commissioning decisions
- Encompass autistic people of all ages ensuring that the needs of one age group, such as children, do not eclipse the needs of another age group.

4. Strategic priorities

The final implementation plan from Nottingham’s last autism strategy, 2014-2017, highlights progress that includes:

- Commissioning and delivery of an autism awareness programme open to partners across the city.
- The recruitment of Autism Champions is underway and training for these Champions has been commissioned.
- A clear pathway for the diagnosis of Asperger’s in adults is in place.
- Nottingham City Council (NCC) has implemented a system to better capture the number of autistic people in its employment and is working to increase the proportion of autistic people employed by NCC.
- DVDs have been produced for and by autistic people to support their access to a range of services.

In contrast, some actions were only achieved in part, and so have informed the areas of focus for the new strategic framework 2018-2020. The Autism Strategy Group has created a visual, figure 2, to describe the interconnecting areas of focus in the new strategic framework. Namely:

- Understanding autism
- Health and being well
- Housing and home
- Community presence including education, training and employment
- Access and autism friendly

This symbolic representation of the strategy also integrates a hierarchy of needs which is fundamentally underpinned by an increased understanding of autism.

Community presence, in the context of this strategic framework, is about recognising the right of autistic people to fully participate in the community they live in including education, employment, volunteering and social opportunities. It recognises that some autistic people will need to make gradual steps towards employment. For example, an autistic person who feels unable to leave home and is socially isolated could be supported to attend a meeting in a local library; a seemingly small but significant step in community presence.

The strategic framework aims to influence education, training, business and leisure services to remove barriers that restrict autistic people's community presence, supporting and enabling autistic people to fully contribute to Nottingham's communities.

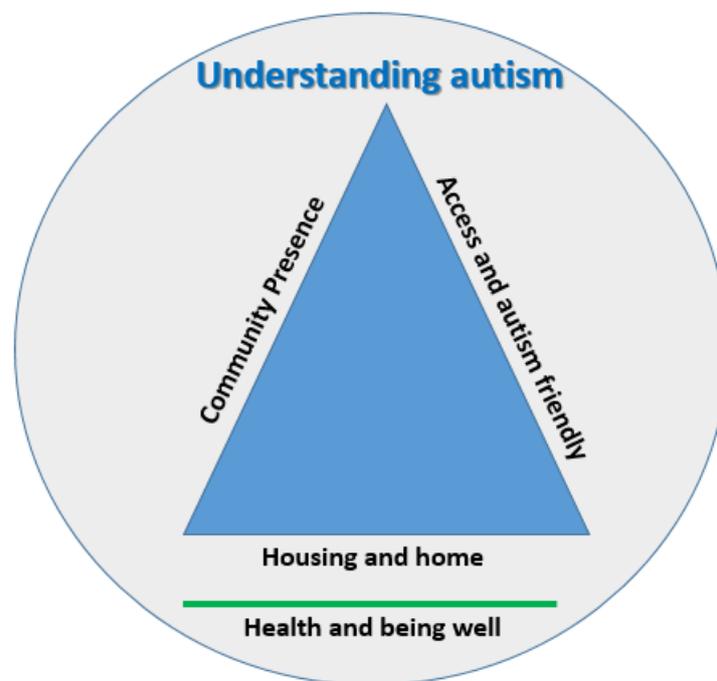


Figure 2: A visualisation of how the themes of Nottingham's Autism Strategy interconnect created by Nottingham's Autism Strategy group

The group also identified crosscutting themes including:

- Autism friendly including increase access and challenging stigma
- Identification and diagnosis of autism
- Transition between services including education, health and social care.
- The role of Autism Champions
- Early interventions and interventions at the right time

- Care and support

4.1 Understanding Autism

Increasing understanding of autism, including through formal training, underpins every area of focus in this strategic framework as without adequate understanding of autism all other actions to improve the lives of autistic people in Nottingham is limited. Arguably, increasing understanding of autism is particularly important for those working on the frontline.

Increasing understanding of autism has both an internal and external focus. Within organisations, the internal focus is on recruitment, retention and reasonable adaptations. In order to do this it is important that organisations understand how many autistic people are in their employ. In the future, this could be expanded to how many people apply for jobs but are unsuccessful in their application. The external focus, on Nottingham as a city, is much more varied and includes how infrastructure developments can consider the needs of autistic people and actions to make more Nottingham more autism friendly.

The last autism strategy had objectives to:

- Raise awareness of the 'Equality Duty' and 'Reasonable Adjustments' to ensure services are accessible among employers by Jobcentre Plus, the SPLAT Partnership Board and voluntary/community organisations.
- Establish and implement an Autism Training Programme for Nottingham city incorporating voluntary/community private and public sector and the Criminal Justice System.

The strategy group members have consistently highlighted the 'Equality Duty' to their organisations and raised awareness of how 'Reasonable Adjustments' can support autistic people into employment and support those in employment. For example, Nottingham City Council has adapted recruitment processes for autistic people and used 'job carving' as one way of adapting job roles to better meet the needs of autistic people.

An 'autism awareness' training programme has been established by Nottingham City Council which is open to colleagues across Nottingham. The programme includes a web-based introduction to autism and face-to-face autism awareness sessions delivered by trainers who not only have in-depth knowledge of autism but also are able to supplement this knowledge with lived experience.

4.1.1 Priorities for 2018-22

Autism awareness training

- Nottingham City Council will work with partners to identify funding to continue to offer face-to-face autism awareness and autism champions training to the workforce to supplement online training.
- Nottingham City Council will monitor who takes up the offer of training to ensure all services areas are accessing training particularly those that have citizen-facing roles.
- All partners, specifically organisations who deliver services directly to citizens, will identify what autism awareness training is provided and who takes up the offer of training.
- Nottingham City Council's Autism Team will continue to run a range of training by the Autism Education Trust (AET) to increase the skills of teaching and support staff including 'Making Sense of Autism', 'Good Autism Practice' and 'Leading Good Autism Practice'.

Workforce

- Human Resources departments in Nottingham City Council and partners will explore, with Trade Unions support, how to increase the proportion of the workforce that identify themselves as autistic.
- Partners will consider how to assess whether managers feel confident to support autistic employees including supporting 'reasonable adjustments' as identified in the Equality Act 2010.

4.2 Health and being well

Autism is a life-long neuro-difference that can make it more challenging for autistic people to access health services including preventative services, such as screening, that aim to support the population to remain well. The autism strategy group identified supporting health services to adapt to better meet the needs of autistic people as an area of focus.

The number of health records that identify people as being autistic is likely to be an under-representation of the 'true' number of autistic people in Nottingham as autism is not consistently recorded by health, like many other services.

As autism is not consistently recorded it is challenging to assess whether autistic people have equality of access to, and equality of outcomes from, health services. Limited availability of this information also means that, at a local level, we are unable to establish how many autistic people also have a learning disability, a mental health problem or other diagnoses such as ADHD. Without data that establishes how many autistic people are using which services, specifically when compared to the neuro-typical population, commissioners are limited in their ability to review services to ensuring their meeting the needs of autistic people.

Local intelligence suggests that both children and adults can have challenges in being assessed for autism. In adults, some of this challenge appears to be related to variation in referral by GPs. Diagnosis of autism in children in Nottingham does not currently meet NICE guidance which states that best practice is that diagnosis is made following a multi-disciplinary assessment.

The last autism strategy had objectives to:

- Set targets and monitor the impact of incentivised quality payment scheme for community forensic teams. It was recognised that there was a need for a specific service, and a new team was commissioned to provide a community forensic service for people with a learning disability and/or Autism.

- A clear and concise diagnosis and assessment pathway is clearly communicated and known by professionals, autistic people and Carers. An assessment pathway is in place although local intelligence suggests not all professionals are aware of the pathway and therefore unable to support citizens to access it.
- Improve knowledge of the numbers of autistic people using health services. This objective hasn't been achieved in full and will continue to be an objective in this strategy.

4.2.1 Priorities for 2018-22

Recording of autism and service provision

- Organisations that provide health services will work towards overcoming operational and/or system barriers that prevent them accurately recording the number of autistic people using their services.
- Primary care commissions and providers will work together to improve the uptake of GP annual health checks for people with LD and ASD including continued liaison with the Primary Care LD Liaison Nurses and wider communication with GPs.
- Nottingham City CCG will work with General Practice to identify options to record Autism/Asperger's as part of Annual Health Checks for people with learning disabilities and the GP Practice Learning Disability registers. Autistic people receiving an Annual Health Check will have a health action plan that identifies needs related to their autism as well as their learning disability.
- Once data recording of autistic people using health services is more accurate and robust, Nottingham City CCG will review service provision for citizens with Autism/Asperger's.
- Commissioners will review the autism diagnostic pathway for children and consider the steps needed to move to multi-disciplinary assessment.
- Acute Primary Care Liaison Nurses and Primary Care Liaison Nurses services² within Nottingham City will be encouraged to identify 'Autism Champions' within their services who can link with network of Autism Champions across the city.

² The Primary Care Learning Disabilities Liaison Nurses offer advice, education and liaison to GP Practices, patients, carers and Primary Care Services. The main focus of the team is to educate and advise stakeholders around detecting unmet health needs, making reasonable adjustments to practice, and preventing unnecessary hospital admissions. The team will provide advice and short-term intervention for those people with a learning disability (LD), and those with joint LD/Autism diagnoses, requiring support to access Primary Care services.

4.3 Housing and home

Many autistic people live with their family, partner or friends or live independently within their community. Other autistic people will need additional support from statutory services including Social Care, for some this may be intensive support included adapted environments, to live in their local community. In September 2018, 189 adults with Autism/Autistic Spectrum Disorder/Asperger's had this diagnosis identified either as their primary support need or indicated on their social care record. This was 3.1% of the 6,098 citizens who received social care services.

Nationally and locally, efforts to ensure people with learning disabilities and/or autism can live in their community, close to home, with the right support is led by 'Transforming Care' agenda³. [Building the Right Support \(2015\)](#)⁴ and [Building the Right Home \(2016\)](#)⁵ focus on the community support and housing plans elements of the Transforming Care agenda.

The last autism strategy had an objective to gain further information on the types of housing options autistic people would prefer. An 'Accommodation Broker' has been in post two years for to source suitable housing providers and provision for citizens with learning disabilities and/or autism, accessible information to support choice is being developed and housing providers are engaged with the *Transforming Care* agenda to increase community placements.

4.3.1 Priorities for 2018-22

The Acute Learning Disabilities Liaison Nurses assist hospital services at Nottingham University Hospitals NHS Trust and Circle Nottingham NHS Treatment Centre to effectively meet the healthcare needs of people with a learning disability and joint LD/Autism diagnoses, respond appropriately to the additional needs which some individuals may present, and assist individuals, their carers and supporters to achieve a positive experiences and effective outcomes at hospital. The team will assess individual's care needs and advise on specific requirements including behavioural management, communication techniques and reasonable adjustments.

³ Building the Right Support (2015) <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

⁴ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

⁵ <https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf>

Housing strategy and housing providers

- We will encourage housing providers including private landlords to complete autism awareness training and, where appropriate, to identify Autism Champions.
- We will explore the option to work with those building new homes and delivering housing options to better understand what housing adaptations may support autistic people.
- The Housing and Social Care forum will work in partnership to consider a broader range of supported living options.
- Housing partners will work with the adult social care strategy, Better Outcomes, Better Lives, to ensure synergy between the strategies. For example, developing a protocol to support adults leaving supported accommodation and those wanting to be part of *Shared Lives* but whose current accommodation is lacking and considering a cluster model of support for adults with learning needs within communities.
- As an increasing number of autistic people reach old age, partners will work together to consider the implications for independent living, residential and homecare.

Nottinghamshire Transforming Care Partnership

- Nottinghamshire Transforming Care Partnership (TCP) will work together to facilitate access to housing with security of tenure or home ownership for all people with learning disabilities and/or autism who display challenging behaviour where this supports the least restrictive option and enables the person to feel safe and secure.
- Nottinghamshire TCP will ensure a variety of housing options are available to meet the needs of people at different stages in their journey, including:
 - Short term accommodation to prevent hospital admission or facilitate timely discharge
 - Transitional accommodation which promotes independence where people may find transition from long term hospital to supported living too big a step in one go. and the opportunity for compatibility assessment where people are preparing to live in shared accommodation
 - Bespoke robust housing options for people who challenge their physical environment
 - Access to general needs housing for people whose interests are not best served by access to specialist or clustered housing
 - *Shared Lives* placements, for both long and short term
 - Move on options for people whose support needs have reduced over time and who no longer need specialist accommodation

4.4 Community presence including education, training and employment

Community presence, in the context of this strategic framework, is about recognising the right of autistic people to fully participate in the community they live in including education, employment, volunteering and social opportunities. This strategy aims to influence education, training, employers and business to remove barriers that restrict community presence, supporting and enabling Autistic people to fully contribute to Nottingham's communities.

Current data collection and collation makes it challenging to accurately identify the number of autistic children and young people in Nottingham's schools and colleges. However, children and young people with 'high-level needs' are more easily identified as they are more likely to have participated in statutory processes such as education and health care plans (EHCP). Local intelligence, from school census, suggests that the number of autistic children requiring 'high-level needs funding'⁶ is increasing year-on-year. This increase in numbers requires careful planning to ensure that there are sufficient, suitable secondary school places.

Supporting transition is particularly important for autistic pupils whether that is from early years' settings to primary schools or secondary schools to college and remains a priority in Nottingham.

Supporting more autistic people into employment requires a partnership approach including work with schools and colleges. There are approximately 227,108 adults of working age in Nottingham⁷, 2271 of whom are on the autistic spectrum (assuming 1 in 100 citizens are autistic). The National Autistic Society state that 16% of autistic people are in full-time work⁸. Applying this research would suggest that in Nottingham:

⁶ Add definition of HLN funding

⁷ Based on mid-year population estimates

⁸ The National Autistic Society <http://www.autism.org.uk/get-involved/media-centre/news/2016-10-27-employment-gap.aspx>

- 363 autistic people are in full-time work
- 727 autistic people are in some paid work
- 1544 autistic people are unemployed.

In July 2018, of the 351 clients 'open' to the Nottingham City Asperger Service, 63 were in employment.

Work is underway with the Department of Work and Pensions (DWP) to more accurately identify the number of autistic people claiming out of work benefits so they can be better supported into employment.

The last autism strategy had objectives to:

- Enable access to mainstream services by providing a suite of Information and Advice available at Nottingham City services and locations including Service centres. Nine instructional DVDs were produced by and for Autistic People. These include real life situations and Autistic Citizens have been involved with all elements including writing the scripts and appearing in the films. There is also an accompanying booklet.
- Provide transitions support to enable access to work placements, apprenticeships and volunteering. This work is ongoing and be reflected in the objectives of the new strategy.
- Ensure Nottingham City Council's and CCG employment initiatives are able to accommodate and include autistic people. Whilst Nottingham City have introduced data collation in order to capture better information about its employees further work is needed across the partnership and this will be reflected in the objectives of the new strategy.

4.4.1 Priorities for 2018-22

To ensure that autistic people are able to flourish and contribute, achieving their potential **within education**, Nottingham City Council will continue to provide autism awareness

training for teachers and other school staff and encourage schools to use Autism Education Trust resources.

We will expand provision of autism awareness training for educational settings and encourage them to use Autism Education Trust resources.

In all our activity, we will promote co-production with autistic children, young people and their families.

To ensure that autistic people have opportunity to **transition** successfully from school to college and college to work, we will:

- Work together to raise the work aspirations and career confidence of young Autistic people. For example, through an Autism friendly careers inspiration project.
- Create new supported internships for autistic young adults with local employers.
- Connect diagnostic and healthcare services with employment services including DWP.

We will work together to ensure that employers in Nottingham are supported to **effectively recruit and retain** more Autistic people in appropriate jobs by challenging stigmas and attitudes towards employing autistic people and promoting the positive benefits of a workforce that includes autistic people. We will achieve this by:

- Working with employers to increase supported internships and work experience placements for autistic young adults.
- Promoting the 'Disability Confident' standard⁹
- Supporting employers to understand good practice in relation to reasonable adjustments for Autistic people, including awareness of the support that DWP's Access to Work scheme can provide.
- Engaging employers as members of the Autism Champions Network.

⁹ Add brief explanation

- Including case studies of autistic people within careers campaigns in order to challenge stigmas and change attitudes.

To ensure that Autistic people are encouraged to **find and retain work**, including through accessible support, we will:

- Facilitate regular Autism and Employment focus groups that give Autistic people the opportunity to give mutual support in relation to employment.
- Offer Autistic people tailored, individual support to gain and retain employment.
- Increase understanding of Autism and the more tailored services needed within Jobcentres.

We will improve **Autism and Employment statistical insight** to provide local benchmarks, such as the number of autistic people receiving employment support allowance. Current DWP systems do not provide any means of gathering meaningful information on the number of autistic people accessing DWP support. We will evaluate the range of information available currently, such as employment levels of people registered with the diagnostic service, and in the future to build as comprehensive picture as possible.

4.5 Access and autism friendly

'Autism Friendly' is challenging to define and prescribed 'Autism Friendly' criteria can be hard, and costly, to implement. This strategy adopts a broader concept of 'Autism Friendly' that includes:

- Increased understanding of autism including through the support of Autism Champions.
- Considering the needs of autistic people in new and remodelled buildings and environments.
- Encouraging and supporting public facing organisations and businesses to make small adaptations such as having an 'autism hour' where music is off, lights are dimmed, a quiet space is available and staff are aware of the needs of, and welcoming to, autistic people.
- Recognising the challenges some autistic people have in accessing public transport and the support they may need to access public transport including and 'accompanier'.

The last strategy had objectives to:

- Provide autism training and awareness to include adapting processes, design for potential sensitivities e.g. lighting and layout of space, information. In addition to referencing adapting processes and design in the autism awareness training, this is seen as a key role of our Autism Champions.
- Develop a "Charter/Quality Mark" for organisations that are autism friendly in Nottingham city. This objective was superseded by our work to make Nottingham Autism Friendly and remains a priority for the current strategy.

4.5.1 Priorities for 2018-22

- Increased understanding of autism across Nottingham including through the Autism Champions role.

- Work together to empower Autism Champions to make small changes to environments that make a big difference autistic people such as having a quiet space for those feeling overwhelmed and reducing ambiguity in correspondence.
- Explore how Autism Champions can influence new buildings such as Nottingham College and the city centre library and remodelled environments such as the Broadmarsh centre.
- In recognition of the challenges that some autistic people have with public transport explore access to concessionary bus passes including adding an accompanier for those autistic people that struggle to access their community without support.
- Use local networks, including free advertising space, to promote understanding of autistic people.

4.6 Cross-cutting themes

Many autistic people experience societal barriers that limit their ability to participate fully in their communities in Nottingham. For example, struggling to use public buildings due to bright lights and/or intrusive noise. In addition, autistic people can experience indirect discrimination in that organisations apply practices uniformly which have a detrimental effect on autistic people.

4.6.1 Autism Champions

Many areas across England have implemented the role of 'Autism Champion' although the role is not nationally defined. In Nottingham, we see the Champion role as key in influencing their own work environment to become more autism friendly, promoting autism awareness training to colleagues and other reputable sources of further information, challenging stigma and supporting colleagues with autism in their work area.

Developing the role of the Autism Champions was identified as a priority in the last strategy and remains a priority for 2018-22. We will:

- Establish a network of Autism Champions across Nottingham with a particular focus on areas that are more likely to have contact with autistic people.

- Ensure that Autism Champions are offered additional training to fulfil their role as part of regular network meetings where Champions can learn from and support each other.
- Work within organisational policies to enable Autism Champions to have dedicated time to fulfil their role including attending network meetings.

5. Co-production and Engagement

This strategic framework was developed in partnership with autistic people and their families and carers. Autistic people were represented on the Autism Strategy Group by self-advocates and voluntary and community sector (VCS) groups who work with autistic people. Some members of the Autism Strategy Group sought the views of autistic people through focus groups on specific topics such as employment and the learning from these focus groups fed into the development of this strategic framework.

In addition, engagement events took place with autistic people and their families and carers including those self-advocating and those represented by professionals and VCS groups. [A summary of this engagement can be found in **appendix xx**.](#)

6. Conclusion

A summary of the strategic framework will be completed following local engagement

7. Action plan

To be developed when engagement has taken place.