**NOTTINGHAM’S AUTISM STRATEGY**

**2018-2022**

**Contents**

[1. Introduction 4](#_Toc8401862)

[2. Context 4](#_Toc8401863)

[3. Rationale: Why do we need a strategic framework for autism in Nottingham? 5](#_Toc8401864)

[4. Strategic priorities 7](#_Toc8401865)

[4.1 Understanding Autism 9](#_Toc8401866)

[4.1.1 Priorities for 2018-22 10](#_Toc8401867)

[4.2 Health and being well 10](#_Toc8401868)

[4.2.1 Priorities for 2018-22 12](#_Toc8401869)

[4.3 Housing and home 13](#_Toc8401870)

[4.3.1 Priorities for 2018-22 14](#_Toc8401871)

[4.4 Community presence including education, training and employment 15](#_Toc8401872)

[4.4.1 Priorities for 2018-22 17](#_Toc8401873)

[4.5 Access and autism friendly 19](#_Toc8401874)

[4.5.1 Priorities for 2018-22 19](#_Toc8401875)

[4.6 Cross-cutting themes 20](#_Toc8401876)

[4.6.1 Autism Champions 20](#_Toc8401877)

[5. Co-production and Engagement 21](#_Toc8401878)

[6. Conclusion 21](#_Toc8401879)

[Appendix: Engagement with autistic people to inform the strategy 22](#_Toc8401880)

[References 28](#_Toc8401881)

**Table of Figures**

[Figure 1: A visualisation of the differing needs of autistic people created by Nottingham’s Autism Strategy group 5](#_Toc530380437)

[Figure 2: A visualisation of how the themes of Nottingham’s Autism Strategy interconnect created by Nottingham’s Autism Strategy group 8](#_Toc530380438)

**The terminology used in this strategic framework**

The term autistic people, rather than people with autism, is used throughout 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 organisations such as the National Autistic Society and local organisations including Autistic Nottingham and Autism East Midlands, both of whom are represented on Nottingham’s Autism Strategy Group.

# **Introduction**

This autism strategy 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 is willing to change to enable autistic people to fulfil their potential.

The autism strategy 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.

# **Context**

National data suggests that 1 in 100 people are autistic (Brugha et al, 2012) 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 autistic children, young people and adults in Nottingham. The needs of people on the autism spectrum are as varied as they are. Some autistic people 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 autistic person 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 contact with and as such, it can be challenging to understand whether autistic people have equitable access to, and outcomes from, services. The autism health needs assessment explores the needs of autistic people and can be accessed at<https://www.nottinghaminsight.org.uk/f/aAXSHua>

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 across this spectrum. 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

# **Rationale: Why do we need an autism strategy 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](https://www.gov.uk/government/publications/adult-autism-strategy-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 and
* 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 strategy was developed with a wide range of partners from the statutory and voluntary sectors in Nottingham. Arguably, most importantly, the strategy was developed in partnership with autistic people and agencies that represent their families and carers, both as representatives 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 and
* 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.

# **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 a rolling programme of training and network meetings for these Champions is underway,
* 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 employ and is working to increase this proportion and
* 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 strategy 2018-2022. 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 participate fully 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 contribute fully 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

# **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 the recruitment and retention of autistic people and implementing reasonable adaptations to ensure they thrive in the workplace. 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 autistic people apply for jobs but are unsuccessful in their application. The external focus is on Nottingham as a city and is much more varied. It includes how infrastructure developments can consider the needs of autistic people and actions taken 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 individual 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.

### **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, increasing year-on-year the proportion of staff trained.
* 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 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.

# **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 and health checks that support the population to remain well. The autism strategy group identified supporting health services to more effectively adapt to 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 recorded consistently by health professionals, 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 ensure they are meeting the needs of autistic people.

Local intelligence suggests that both children and adults can have challenges in accessing an autism assessment. In adults, local service providers suggest that some of this challenge relates to variation in referral by GPs. Diagnosis of autism in children in Nottingham does not currently fully meet NICE guidance, which states that it is best practice for diagnosis to be made following a multi‑disciplinary assessment.

In addition, there appears to be variation in autism diagnosis by gender and ethnicity. This variation is explored further in the autism health needs 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 be established that 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 has not been achieved in full and will to continue to be an objective in this strategy.

### **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. This will include communicating with autistic people to inform them why service providers collect information on the number of autistic service users.
* Primary care commissioners and providers will work together to improve the uptake of GP annual health checks for people with learning disabilities (LD) and autism 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 that meets NICE guidance.
* Acute Learning Disability Liaison Nurses and Primary Care Learning Disability Liaison Nurses services[[1]](#footnote-1) within Nottingham City will be encouraged to identify ‘Autism Champions’ within their services who can link with the network of Autism Champions across the city.
* Preventative health services such as screening will consider how services need to be adapted to meet the needs of autistic people.
* Nottingham City CCG will consider further training that highlights potential under‑diagnosis of autism in girls, women and black and minority ethnic (BME) communities for colleagues who might identify and/or refer to autism diagnostic services.

# **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 their social care record identified them as autistic. Autistic people make up 3.1% of the 6,098 citizens who received social care services in this period.

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* (NHS England 2015a) agenda. *Building the Right Support* (2015) (NHS England 2016) and *Building the Right Home* (2016) (NHS England 2015b) 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.

### **Priorities for 2018-22**

**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 understand better 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. A cluster model of support for adults with learning needs and autism within communities could be an appropriate model.
* 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

# **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 participate fully 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 contribute fully to Nottingham’s communities.

###

Current data collection and collation makes it challenging to identify accurately 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’ 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 Nottingham[[2]](#footnote-2), 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 work (National Autistic Society 2016). Applying this research would suggest that in Nottingham:

* 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 autistic employees, further work is needed across the partnership and this will be reflected in the objectives of the new strategy.

### **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.
* Autism awareness training for educational settings will be expanded and schools encouraged to use, Autism Education Trust resources.
* All activity, will promote co-production with autistic children, young people and their families.
* Agencies will work together to enable more effective sharing of information at key points of transition, including between early years settings, schools and colleges.

To ensure that autistic people have opportunity to **transition** successfully from school to college and college to work, organisations 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.

Organisations 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. Specifically by:

* Working with employers to increase supported internships and work experience placements for autistic young adults.
* Promoting the *Disability Confident* standard[[3]](#footnote-3)
* 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 to become members of the Autism Champions Network.
* 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, organisations 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.

**Autism and Employment statistical insight** will be improved in order 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. An evaluation of the range of information available currently, such as employment levels of people registered with the diagnostic service will support the building of a comprehensive picture.

# **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 an ‘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.

### **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.

## **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.

### **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.
* Identify an Autism Champion on the Health and Wellbeing Board.
* 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.
* Request that organisations, such as those on the Health and Wellbeing Board, pledge the number of Autism Champions they will recruit each year, ensuring a spread across different job roles.

# **Co-production and Engagement**

This strategic framework was developed in partnership with autistic people and their families and carers. Autistic people are represented on the Autism Strategy Group by self‑advocates and voluntary and community sector (VCS) groups who work with autistic children, adults and their families. 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 and the views shared in 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 is in the appendix.

# **Conclusion**

This autism strategy encompasses autistic people of all ages who live in Nottingham and their families and carers and recognises the broad spectrum of autism. The focus is on how Nottingham can change to enable autistic people to fulfil their potential, removing barriers so autistic people can be independent and equal, with greater choice and control over their own lives. The role of organisations and individuals in driving this change is noted throughout the strategy and is the focus of the accompanying action plan. The plan is ambitious and will only be achieved by the collective efforts of the statutory and voluntary sectors and in co-production with autistic people and their families.

# **Appendix: Engagement with autistic people to inform the strategy**

Discussions with autistic people and their carers in Nottingham City, via focus groups and 1:1 meetings, have reported a number of challenges affecting them and members of the public. These include:

**Difficulties in accessing healthcare services.**

There is a lack of understanding of autism amongst healthcare professionals. It is often assumed to be a learning disability and there is general confusion over the needs of autistic people. Autistic traits that are not stereotypical are often missed and reasonable adjustments are not put in place.

There is difficulty in communicating effectively with all partners who support autistic people (e.g. sending letters to carers regarding an autistic person’s appointment or arranging for consent to share autistic person’s information with carers and/or other organisations who support them).

Post diagnosis support has been reduced. Past prevision of 8 weeks of counselling and wrap around support addressing a wide range of needs appears to be no longer available to autistic people.

Difficulties in obtaining autism diagnosis in primary care at all stages in a person’s life due to concerns by professionals of labelling or because they do not see it as important or due to the fact that there is no specific treatment.

Autistic people often dislike the ‘high functioning’ diagnostic label but feel those with less obvious autistic traits are forced to ‘put it on’ to get the support they require.

Poor access to appropriate mental health services such as Improving Access to Psychological Therapies (IAPT). Programmes tend to focus on Cognitive Behavioural Therapy (CBT) techniques which is not necessarily helpful when fixed autistic traits and modifiable behaviours are not differentiated from one another.

**Autistic people from BME communities.**

There appears to be a lack of understanding or ‘blindness’ amongst professionals to autistic traits in BME groups, dismissing them as cultural rather than autistic.

**Workplace and educational settings.**

*“It’s one thing that services and businesses don’t know about autism but listen to us when we try help you understand.”*

Workplaces often do not make reasonable adjustments for their employers who have autism.There is a general lack of understanding amongst colleagues who perceive the autistic person as being rude (despite no customer complaints being made). Autistic people are often not viewed as an asset to a team.

Language used in some workplaces makes it difficult for autistic people working there. For example, a well-known catering establishment has two types of bacon on their menu (breakfast meal and in their burgers). The establishment often uses the statement ‘we’re out of bacon’ in the morning, which can be confusing for autistic staff who then tell all customers that there is no bacon available throughout the day.

There are examples where colleges and universities are not listening to adjustment requests of their autistic students. Colleges and universities often have stereotypical ideas of autism and do not acknowledge the wide variation amongst autistic people, leading to ‘all or nothing’ adjustments. For example, offering someone to read lecture slides for an autistic people (an adjustment commonly used for other disabilities) is not necessarily appropriate for autistic students because it is often not the reading but the language contained within the slides that can cause difficulties.

There are instances where nurseries/primary/secondary schools have not identified the autistic traits of their students leading to their behaviour being viewed as ‘disruptive’ and ‘bad’, at times leading to alternative provisions being put in place and/or exclusion.

**Criminal justice system.**

Cases have been highlighted where a lack of understanding of autism in the criminal justice system has led to the unnecessary suffering of autistic people detained in custody. For example, spending the night in a custody suite which is unfamiliar can lead to fear, anger and agitation which if not dealt with effectively can escalate and lead to further charges and labelling of the individual as ‘bad’.

Poor adjustments made for autistic people navigating the social care and criminal justice system e.g. attending multi-disciplinary safeguarding meetings, which include a number of strangers asking question can increase displays agitation and aggression which would not have occurred if 1:1 meetings had taken place instead.

**Community presence.**

There is persistent negative causal language within society that, whilst not aimed at autistic people, is still offensive to them e.g. ‘*that’s so….retarded, spastic’*.

The opportunities to socialise for young autistic adults is limited, particularly for those ‘higher functioning’. There are few people in mainstream social and sports clubs who understand autism. This can lead to feelings of isolation and loneliness amongst autistic people.

Portrayal of autistic people in the media is often negative. For example, the English television quiz personality [Anne Hegerty](https://www.autism.org.uk/get-involved/membership/magazine/current-issue/anne-hegerty.aspx) was one of the first examples of someone with autism who was intelligent and high functioning and who received a positive high profile.

Media programmes often portray the ‘unbelievable’ aspects of autism in programmes like [The Undateables](https://www.channel4.com/programmes/the-undateables) i.e. how can someone be autistic and good looking.

Community training that does not meaningfully involve autistic people isn’t always correct or effective and does not always portray autism very well. There are cases where training has been presented by people (including parents or carers of autistic people) who misunderstand or portray only one type of autism. The training often misses the autistic culture and group identity of autistic people when courses are run by people who aren’t autistic.

**Support for the carers of autistic people.**

There is a lack of specialist placements/short breaks/day services for autistic people which not only benefit their wellbeing but also give carers some protected time to focus on their own needs.

Discussions with clinicians from Nottinghamshire Healthcare Foundation Trust have highlighted a number of issues facing autistic people in Nottingham.

**Post-diagnostic support for autistic children and adults in Nottingham.**

There is a perception that, currently, a diagnosis of autism is seen as the end point. However, for most individuals this is often the beginning of their journey. Increasing the capacity of the Asperger’s service for adults, who are experiencing increasing demand in the city, would be one way to achieve this.

**Provision of services for autistic people and ADHD in the city.**

Approximately 20% of autistic people seen by the Asperger’s service also have ADHD. However, there is currently no shared care protocol or pathway for prescribing.

**Support for autistic people with restricted food disorders in the city.**

TheAsperger’s service have identified increasing numbers of autistic people who have a restricted food disorder and need more specialist support.

Discussions with representatives from Autism East Midlands have drawn attention to additional needs of autistic people in Nottingham.

**Support for parents of autistic children and/or adults.** Ensuring that those who love and care for autistic people are aware of the services at their disposal and have the ability to take a break and receive the support and rest they deserve.

**Support for teenagers and young adults with Asperger’s.** Due to perceived lower levels of need they do not meet statutory service thresholds but are largely reliant on their families (i.e. socially isolated, not in education, employment or training). Improving the numbers of employers in Nottingham who are autism confident may be one way to achieve this aim.

**Support for autistic parents.** A diagnosis of autism does not stop someone from being a good parent. However, some specialist information, advice and support would be beneficial. Providing online and/or face to face support for autistic parents in Nottingham could be one way to achieve this aim.

Discussions with representatives from the Department of Work and Pensions (DWP) has identified the following issue facing autistic people in Nottingham.

 **Support for autistic people to access the correct benefits and, where possible, employment, education and training.** Working with DWP to ensure that autistic people are in the correct Employment and Support Allowance group and in contact with the right services and offering, the [Nottinghamshire iWork programme](https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/service.page?id=alPkFeWBFvY) currently operating in the county to citizens in Nottingham city, could be two ways to achieve this aim.

Discussions with representatives from the Low Secure Community Forensics & Local Partnerships Speech and Language Therapy team have identified the need for:

**Increased understanding and awareness of autism in adult mental health services.** The team have observed inappropriate mental health hospital admissions of autistic people. A patient’s presentations is sometimes incorrectly identified as being due to an acute mental health need when in fact their presentation is likely to be related to their autism.

In other cases, autistic people who do have mental health needs do not receive reasonable adjustments and mental health staff understanding of autism is not adequate. This can result in diagnostic overshadowing (with the focus being on mental health diagnoses rather than autism). It can also negatively affect autistic people’s access to verbally mediated treatments and involvement in care planning.

Discussions with representatives from Nottingham City POhWER have elucidated the following need.

* Systems that allow autistic people to return to the community quickly after a hospital admission (e.g. more community placements).
* Skilled, knowledgeable, confident, trained support staff who can work in an appropriate environment to meet the needs of people with autism who have multiple complex needs.
* More bespoke packages of care that are tailored to the individual in order to prevent ‘placement breakdowns’.

# **References**

1. BRUGHA, T., et al., 2012. Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey [online]. Leeds: NHS Information Centre for Health and Social Care, Community and Mental Health Team. Available at: < <https://digital.nhs.uk/data-and-information/publications/statistical/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey>> [Accessed 2019].
2. NHS ENGLAND., 2015a. Building the right support [online]. London: NHS England. Available at < <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>> [Accessed 2019].
3. NHS ENGLAND., 2016. Building the Right Home [online]. London: NHS England. Available at <<https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf>> [Accessed 2019].
4. NHS ENGLAND., 2015b. Transforming care for people with learning disabilities: Next steps [online]. London: NHS England. Available at <<https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>> [Accessed 2019].
5. NATIONAL AUTISTIC SOCIETY., 2016. Government must tackle the autism employment gap [online]. London: National Autistic Society. Available at <<http://www.autism.org.uk/get-involved/media-centre/news/2016-10-27-employment-gap.aspx>> [Accessed 2019].
1. 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.

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. [↑](#footnote-ref-1)
2. Based on mid-year population estimates [↑](#footnote-ref-2)
3. Disability Confident is a government scheme designed to encourage employers to recruit and retain disabled people and those with health conditions. [↑](#footnote-ref-3)