

MAKING GREATER MANCHESTER AUTISM FRIENDLY

2019-2022



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FOREWORD from Mayor of Greater Manchester, Andy Burnham

I am delighted to introduce the first ever Greater Manchester autism strategy.

This strategy has been developed in partnership with autistic people, their families and practitioners. It is informed by questionnaires, surveys and series of engagement events where we asked people what needs to change to make Greater Manchester autism friendly.

Since the ground-breaking Autism Act 2009, and the publication of the first national strategy for autism, which I brought forward as Secretary of State for Health, progress has been made in improving support for autistic adults.

In line with the strategy, most local authorities now have a dedicated adult diagnosis service and a designated lead for the development of adult autism services. As a result, autistic people are increasingly engaged in planning and designing services.

In Greater Manchester our ten local authorities, and more recently our Clinical Commissioning Groups and the Greater Manchester Health and Social Care Partnership, have been working together to improve services and support for autistic people.

But we are only at the beginning of this journey.

I still hear from many autistic people and their families who say that things have not changed enough. There are still gaps in provision, delays in diagnosis and difficulties accessing services.

Too many autistic people are not being supported to reach their full potential.

So it is fitting that 10 years on from the Autism Act, we are now presenting a strategy to make Greater Manchester the country's first autism friendly city region.

This means making Greater Manchester a place where you can get a timely diagnosis, meet professionals with a good understanding of autism, find services, organisations and employers that make reasonable adjustments when required, and where people can feel safe, have aspirations and fulfil their potential.

It is now down to all of us to make this change happen.

OUR VISION

To work towards making Greater Manchester an autism friendly place to live. This means a place where you can get a timely diagnosis with support, meet professionals with a good understanding of autism, find services, organisations and employers that make reasonable adjustments when required, where people can feel safe, have aspirations and fulfil their potential, and become a full member of the local community.



INTRODUCTION

The first Greater Manchester autism strategy has been commissioned by the Greater Manchester Autism Consortium (GMAC) - a partnership of adult services from the 10 local authorities in Greater Manchester, the 10 Clinical Commissioning groups (CCG) and the Greater Manchester Health and Social Care Partnership. The work has been coordinated by the Greater Manchester Autism Consortium project, run by the National Autistic Society.

Reflecting the remit of the Autism Act 2009, the strategy focuses on autistic adults, but also includes young autistic people in transition. However, during the course of the development of the strategy, it has become increasingly clear that in order to achieve our vision, we will need to expand the strategy to all ages in the future. This would require buy-in, engagement and funding from children’s and education services across the region.

By 2021, the GMAC project will therefore work with children’s services across the region to draw up a proposal for extension of the strategy to all ages.

The content of the strategy is based on information gathered during a stocktaking exercise via a region-wide questionnaire in April 2018, and a series of events between December 2017 and May 2018 as well as a survey filled in by over 150 people.

This strategy covers all autistic people and their families within Greater Manchester including those with a learning disability, those without a learning disability and also those with other co-occurring conditions such as a mental health problem or physical health problems. We will link closely with the Greater Manchester learning disability strategy and the mental health and wellbeing strategy as some of the areas not covered within this strategy are covered by these two strategies.

We acknowledge that the priorities identified in this strategy may not cover every area that needs improvement, but we hope that this is the first of many strategies and is just the starting point for Greater Manchester.

From our work, it has become clear that to make Greater Manchester autism friendly, we would need to work across four key areas:

Access	This is about making sure that public services for autistic people are accessible and that appropriate reasonable adjustments are made in mainstream settings (i.e. services that are not specialist for people on the autism spectrum or with learning disabilities but aimed at the general population) and that staff in these settings are trained. This includes housing and general council services.
Community	To make sure that autistic people and their families are able to take part in their communities, be active citizens and access the help to which they are entitled, accessible information available needs to be available. As well autistic people and their families should be active participants in the planning of local services. This strand also looks at addressing additional barriers faced by certain groups including those in the criminal justice system, older adults, women, Black, Asian and Minority Ethnic (BAME) communities and Lesbian, Gay, Bisexual, Transgender, Queer and Others (LGBTQ+) communities.
Health and support	This includes ensuring access to diagnosis and post diagnostic support across the region, making sure that health and care have the right information on local need and are planning the right services locally as well as making sure health and care staff have appropriate levels of training in line with the Autism Act.
Employment and transition	This includes employment and transition into adulthood for autistic people and family members.



Terminology

This strategy uses Identity-First language (i.e. “autistic people” rather than “people with autism”) as this was the stated preference of many of the autistic group of stakeholders who engaged with this work. This also aligns with research based on the response of over 3,000 people, led by the National Autistic Society (<https://www.autism.org.uk/about/what-is/describing.aspx>). We do, however, acknowledge that some people prefer the term person with autism. The term autistic also covers those who identify as having Asperger Syndrome.

Glossary of Terms used in this report:

Term	Expanded Version	Meaning (if applicable)
ADASS	Association of Directors of Adult Social Services	ADASS is the association of directors of adult social services in England. We are a charity and the association aims to further the interests of people in need of social care by promoting high standards of social care services and influencing the development of social care legislation and policy.
ASD	Autistic Spectrum Disorder	Autism spectrum disorder (ASD) is the name for a range of similar conditions, including Asperger syndrome, that affect a person’s social interaction, communication, interests and behaviour.
BAME	Black, Asian and Minority Ethnic	used to refer to members of non-white communities in the UK.
CCG	Clinical Commissioning Group	Clinical Commissioning Groups are responsible for implementing the commissioning roles as set out in the Health and Social Care Act 2012.
EHCP	Education, Health and Care Plan	An EHC plan is a legal document that describes a child or young person’s special educational, health and social care needs.
GM	Greater Manchester	A city region consisting of ten localities: Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan.
GMAC	Greater Manchester Autism Consortium	The Greater Manchester Autism Consortium’s Project provides information, advice and support to individuals, family members, carers and professionals about all issues relating to autism - children and adults.
GMCA	Greater Manchester Combined Authority	The GMCA is made up of the ten Greater Manchester councils and Mayor, who work with other local services, businesses, communities and other partners to improve the city-region.
GMHSC Partnership	Greater Manchester Health and Social Care Partnership	The Partnership was formed to oversee the devolution of health and social care services. They aim is to achieve the biggest, fastest improvement to the health and wellbeing of Greater Manchester.

Term	Expanded Version	Meaning (if applicable)
GP	General Practitioner	A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital.
JSNA	Joint Strategic Needs Assessment	Joint Strategic Needs Assessment is a core function of health and wellbeing boards. To be fit for purpose, JSNAs should support strategy and commissioning by providing “an objective analysis of local, current and future needs for adults and children, assembling a wide range of quantitative and qualitative data, including user views”
LD	Learning Disability	A learning disability is defined by the Department of Health as a “significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood”.
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and Others	LGBTQ+ stands for lesbian, gay, bisexual, transgender, questioning and “plus,” which represents other sexual identities including pansexual, asexual and omnisexual.
NAS	National Autistic Society	The National Autistic Society is a British charity for autistic people. The purpose of the organisation is to improve the lives of autistic people in the UK.
NHS	National Health Service	The National Health Service (NHS) is the publicly funded national healthcare system in the United Kingdom.
NICE	National Institute of Health and Care Excellence	Provide the NHS, and those who rely on it for their care, with an increasing range of advice on effective, good value healthcare.
SAF	Self-Assessment Framework	A questionnaire commissioned by Public Health England (PHE) to allow PHE, local authorities and their partners to monitor their progress in implementing the Autism Strategy.
SEN	Special Educational Need	Special Educational Needs (SEN) is a legal term. It describes the needs of a child who has a difficulty or disability which makes learning harder for them than for other children their age.

CONTEXT

As a result of the Autism Act 2009, there are clear duties and expectations on local authorities and the NHS to plan and commission appropriate services for autistic adults and their families.

At the core of this, there is a duty on every local area to have:

- A pathway to diagnosis for adults
- A named joint commissioner/senior manager to lead commissioning of care and support services for autistic adults
- A meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders (including autistic adults) locally to set the direction of services
- A means of collecting data and information on the needs of the local autistic population and inclusion of this information in the Joint Strategic Needs Assessment (JSNA)
- A joint commissioning plan for services for autistic adults based on the JSNA
- A plan to make sure that staff across health and care have training in autism, appropriate to their roles
- Specific training in place for community care assessors

There are additional duties and expectations as a result of the Act, which are incorporated throughout this strategy. **However, every local authority area in Greater Manchester must ensure that at the very least they are Autism Act compliant, meaning that the above is in place by end of March 2019, when the strategy starts.**

The devolution of health and social care within Greater Manchester gives us opportunities to look at how these core elements of the Autism Act, as well as the wider duties and expectations of

“Every local authority area in Greater Manchester must ensure that at the very least they are Autism Act compliant.”

the act can be delivered through joint working, as referenced in the Partnership plan “Taking Charge”.

It is also important to note that this strategy will link up with other programmes of work being taken forward at Greater Manchester level. Notably, this includes the Greater Manchester work on Building the Right Support and any successor programme, the Greater Manchester learning disability strategy, the mental health and wellbeing strategy, the suicide prevention strategy and the housing strategy. It will also seek to link with the delivery of the work and health programme in the region.

PRINCIPLES AND VALUES

In developing the strategy, we have been mindful of the following principles for delivering services and support in Greater Manchester as set out in Our People, Our Place:

- A place where all children are given the best start in life and young people grow up inspired to exceed expectations.
- A place where people are proud to live, with a decent home, a fulfilling job, and stress-free journeys the norm. But if you need a helping hand, you’ll get it.
- A place of ideas and invention, with a modern and productive economy that draws in investment, visitors and talent.
- A place where people live healthy lives and older people are valued.
- A place where all voices are heard and where, working together, we can shape our future.

Building on the final principle, it is important to note that partnership working will be fundamental to the success of the strategy. In developing, implementing and reviewing the strategy we will work in partnership with all stakeholders from decision makers to people with lived experience.

The strategy is based on evidence of need of autistic people and their families. We will continue to gather evidence of need and of what works. The strategy will need to be seen as a living document and we will keep it and the action plan under regular review to ensure we are making best use of resources to achieve the outcomes we seek.

We are also committed to principles of equality, recognising that there may be additional barriers to accessing support and help for some autistic people and their families. This is why we are committed to identifying and addressing the barriers to support and participation experienced by specific groups such as older people, people from BAME communities, women and those who are LGBTQ+.



STRATEGY

Access

This strand is about making sure that public services for autistic people are accessible and that appropriate reasonable adjustments are made in mainstream settings (i.e. services that are not specialist for people with autism or learning disabilities but aimed at the general population) and that staff in these settings are trained. This will include housing and general council services.

Vision

To ensure that mainstream services and facilities in the community are welcoming to autistic people and their families and that those services work towards achieving a Greater Manchester Autism Friendly Award to demonstrate their commitment to making changes so autistic people feel included and welcome.

How do we get there?

1. In the previous self-assessments of progress in implementing the Autism Act and in the recent stocktake of services, making appropriate reasonable adjustments to their mainstream services was identified by local authorities across Greater Manchester as a key challenge.

As a result, the GMAC project worked alongside autistic people, family members and professionals on the development of reasonable adjustment guides for different settings. These included guides for GP surgeries, Jobcentre Plus, housing offices and general council services. As well as promoting these guides (available from December 2018), we will develop new reasonable adjustment guides on public transport, other primary care settings and mental health and also develop plans around training that might be available within Greater Manchester.

Each local area will be expected to take these guides to their partnership boards and develop a plan for dissemination.

2. The group working on the reasonable adjustment guides identified that not only do organisations and services need to understand what reasonable adjustments are, but autistic people should be supported to explain what they need clearly in a variety of settings. Working with autistic adults and family members, we will develop a personalised reasonable adjustment profile or passport that autistic people can use in different settings and ensure that this is recognised by public services across the region.
3. Building on this work we will develop, alongside the Mayor's office, a Greater Manchester kite mark for public spaces, facilities and mainstream services to demonstrate their work to become autism friendly. The National Autistic Society has experience in this area through its Autism Friendly Award. We will build on this experience and work with autistic adults across Greater Manchester to identify facilities they want to become autism friendly, and with additional funding, we'll roll out a kite mark in key areas across the region.

In the meanwhile, we will also work with the Greater Manchester Disabled People's Panel to ensure autism is included in this work.

Through our stakeholder events we are aware that transport is often a barrier to accessing support. Working with the Mayor's office and Transport for Greater Manchester, GMAC will raise the issue of concessionary bus passes for autistic people across Greater Manchester to address the need for a consistent approach.

4. The last Autism Self- Assessment Framework (SAF) identified that most of the areas in Greater Manchester struggled to engage housing in partnership boards or consider them in the training delivered. The stocktake reflected this too and several areas identified that they would like help in this area.

To develop a regional and local approach to housing for autistic people, we will establish a strategy implementation group on housing with a variety of stakeholders by April 2019 to report its progress by April 2020. This will be a joint group with those leading on the learning disability strategy.

Part of the purpose of this group will also be to consider training needs for this sector.



Community

To make sure that autistic people and their families are able to take part in their communities actively participate in the local community and access the help to which they are entitled, this strand is about making sure that there is accessible information available and autistic people and their families participate in the planning of local services. This strand also looks at addressing additional barriers faced by certain groups including those in the criminal justice system, older adults, women, (BAME) communities and LGBTQ+ communities.

Vision

Autistic people and family members can access timely, updated relevant information and support about every stage of life, and to reduce the barriers to accessing support in their community.

How do we get there?

1. The stakeholder events, stocktake and survey have shown clearly that autistic people and family members struggle to access the information they need about what is available and what care and support they are entitled to. GMAC have built up a website with information on different services and support available in each local council area. Each council should review the information we have about their area on an annual basis and feed back on what needs to be added or amended. GMAC will also develop some information that can be shared with autistic adults and family members about the services they are entitled to by April 2019. Each locality should develop a plan for disseminating this information by April 2020. GMAC will also identify and share good models for sharing information and promote these to the localities at a good practice sharing event in each of the three years of the strategy.

2. The stocktake, the last SAF returns and the stakeholder events showed that localities are struggling to engage with criminal justice services to develop training and clear pathways for autistic adults.
3. We will establish a strategy implementation group on the criminal justice system with a variety of stakeholders to consider areas of joint working in relation to data, reasonable adjustments and training. By 2021 we will have identified some joint working plans that may involve a business case.
4. The last SAF and the stakeholder events and survey identified that the consortium needs to do more work to engage with communities that are severely under-represented in terms of diagnosis and access to support.

We will set up an engagement plan with community organisations working with BAME communities, LGBTQ+ communities, older adults and women for autistic adults and family members in order to try to understand what those barriers are and to encourage people from those communities to access support and services. **After a period of scoping we will develop a plan for each of those groups to increase engagement (future business case likely).**

Health and Support

This includes ensuring access to diagnosis and post-diagnostic support in every area, making sure that health and care have the right information on local need and are planning the right services locally and making sure health and care staff have appropriate levels of training in line with the Autism Act.

Vision

That autistic people and their families across Greater Manchester have timely, local, high quality access to diagnosis and post diagnostic support, social care support and information given to them by well trained professionals within well planned services that understand and can anticipate the level of need.

How do we get there?

1. Page 2 sets out the key duties and expectations on local authorities and the NHS to plan and commission appropriate services for autistic adults and their families. We will make sure that every partnership board in the 10 localities has a summary of these key duties and they will be expected to set out their next steps in each of these areas by April 2019. Below we set out some specific areas of work that will help support localities in making sure they are meeting these duties.
- 2) Diagnostic pathways vary considerably across Greater Manchester. In December 2017, the Partnership collated information on the diagnostic assessment process in every area. It found in some areas there is a specialist multi-disciplinary team that meet National Institute of Health and Care Excellence (NICE) guidance and in others diagnosis is carried out by single professionals.

To ensure that across the region, in line with the Autism Act, autistic adults can access a quality diagnostic assessment in a timely way, we will develop a clear service specification for diagnostic services, which all areas will meet by April 2021.

- 3) We also know from looking across autism services nationally that where autistic people have a better experience of services locally it's because there is an autism specific team in their area. Where these teams have been particularly successful, they have involved diagnosis, post-diagnostic support and a social care or local facilitator who helps to identify other agencies locally who need support to be upskilled to better support autistic people. These teams will usually only take on a very small number of direct case co-ordination work, for those who cannot be supported elsewhere. These teams are usually NHS led.

Research by the National Audit Office in 2009 showed these teams to be highly cost effective. In Greater Manchester, the Trafford Extended Service is an example of such a team and meets most of the green standards in the new Greater Manchester standard on diagnosis.

We will work alongside health services across Greater Manchester with a view to securing coverage from this type of team across the region by 2021.
- 4) On post diagnostic support (which we have defined as the support available within the first year of the diagnosis and related to understanding the diagnosis), the differences between each area are even greater than for diagnosis. Some areas offer no post-diagnostic support unless specifically requested and others offer a comprehensive package.

By 2020 we will bring together good practice across the region, and beyond, to show Greater Manchester CCGs what is achievable and at what cost. **We will use this information to develop a business case by the end of 2020 for the development of services that could be offered across Greater Manchester as part of a post-diagnostic 'offer' for the region.**

5. While, as a result of the Autism Act, there are clear duties on health and care to deliver training in autism to staff at all levels, we know from the stocktake that most of the 10 areas do not have a strategy on delivering autism training locally. Training for specific groups such as social care assessors varies greatly across Greater Manchester and most of the 10 areas do not have access to regular training.

Local authorities, CCGs and NHS Foundation Trusts must make sure that they are complying with the requirements on training as set out in the Autism Act. The GMAC project will provide information on those requirements to autism leads and partnership boards to help them to review compliance.

To support better training in autism across the region, we will also use the new competency framework currently being developed by Health Education England, to develop a Greater Manchester training plan for health and care

services. This will include clear expectations on localities to ensure that they are meeting statutory duties, but also identify where delivery of training may be appropriate in partnership across locality areas.

6. We know that local areas are struggling to collect accurate data on the needs of their local autistic population. This means that they aren't able to plan effectively, based on local needs.

In line with the Autism Act statutory guidance, there is some data that local councils should already be collecting. We will identify this, share with autism leads and ask them to report back on how they will ensure they are collecting this data by April 2019.

We will also identify good practice in data collection on autism within local councils and share this with autism leads and partnership boards.

In addition, from April 2018, NHS trusts have been required to collect data on diagnosis waiting times as well as the services they provide to autistic people. There are also moves to develop a national GP autism register. This is currently a recommendation by NICE to NHS England, following a pilot in number of CCG areas in England.

We will work with the localities to ensure that the region uses the information from NICE's pilot to introduce a GP autism register by the end of 2020 and that protocols are established so that anonymised data from NHS Trusts, and the register, can be shared with local councils.

- 7) Within Greater Manchester, there are a number of specialist posts that support the implementation of the local autism strategy. These posts vary but most of the posts support the partnership boards, deliver training and as highlighted under point 3 above are often embedded into the post-diagnostic offer and support. Evidence from the SAF returns show that such posts help secure local implementation of the strategy. We will share with localities business cases for these types of roles and job descriptions.
- 8) There is a significant unmet need for autistic adults not eligible for social care support, who may need some help in their day to day lives to prevent social isolation and the development of mental health problems.

There are a number of local small community groups and support groups who provide some of this support. We will work with local Greater Manchester community groups such as the council for voluntary services to develop a network of these groups and support them to build up their capacity, identify where they could work together and where they could access funding. This group, alongside other key stakeholders including the GMAC Advisory Group, will also help to identify key priorities, projects or support that aim to counter social isolation within Greater Manchester and gaps in the post-diagnostic offer available (including where those diagnosed were not offered post diagnostic support at the time). This will include work to increase resilience with autistic adults.

During 2020-2021 **the group will develop a business case on Greater Manchester wide services or support that would address some of those gaps.**

We will also look at the feasibility of establishing National Autistic Society Branches in Greater Manchester. National Autistic Society research has shown that 81% of people involved in their local branch felt less isolated as a result.

9. Autistic people and their families tell us that mainstream health services do not always meet their needs. In particular, they feel that appropriate reasonable adjustments are not made within health settings. In the October 2017 GMAC service specification there was a target to develop plans for Autism Friendly hospitals. **This will require further investments and we will gather the evidence to develop a business case for this during the life of this strategy.**

In the meantime, we will write reasonable adjustment guides for acute hospital settings as well as adding to the reasonable adjustment guides we have already developed on GP surgeries to extend this guide to other primary and secondary health care settings

10. GMAC have developed carers' resilience programmes and parent seminars and we will increase capacity for these programmes in a variety of ways, including running "train the trainer" sessions and supporting parents to fundraise to run them.

Photo by Paul Husband



Employment and transition

Includes employment and transition into adulthood for autistic people and family members

Vision

All autistic people and their family members are given the right information to prepare for adulthood and that those autistic adults who are able to work can access the support they need to find and maintain work, including from employers who understand them.

What do we need to do?

1. There are clear statutory duties that all local areas should be complying with already regarding transition. We will circulate a check list to each partnership board for them to check their compliance against statutory duties.

2. The stocktake, stakeholder events and survey identified that there is a gap in information and support for parents with respect to transition to adulthood.

We will promote the resource “Growing up with autism in Greater Manchester”, previously developed by GMAC. We will also gather examples of good practice around transition and preparation for adulthood and hold an event to share this practice with commissioners and practitioners across the region.

Localities will be expected to take the resources to the autism partnership boards and children’s boards, as well as information from the good practice event and develop a plan for using the resources or building on the good practice to improve transition processes in their area.

3. We have also developed a transition workshop programme for parents which localities can use. A roll out of the workshops across Greater Manchester will require additional funds.

4. We will reconstitute the autism and transition group that developed the “Growing up with autism” materials and invite extra stakeholders to start to identify other gaps in transition across Greater Manchester. This group will be the strategy implementation group on transition and will consider what other resources could be developed to support better transition and how the previously developed resources could be better utilised across GM.

5. In Greater Manchester, we want to lead the way on transition for young people on the autism spectrum and ensure planning for those who don’t have an Education, Health and Care Plan (EHCP) still happens. We will use the resources outlined above to develop a framework for a transition review for 14-year-old autistic young people on Special Educational Need (SEN) support. This framework will be developed with localities via the strategy implementation group on transition and be ready to roll out from September 2020.

6. GMAC will work with children’s services across the region to draw up a proposal for extension of the strategy to all ages.

7. The stocktake and stakeholder events reinforced the importance of employment on the wellbeing of autistic adults. To reach employers in the region, we will work with the mayor’s office on the Greater Manchester Employer’s charter and ensure that autistic people will be included in this.

8. The stocktake, the Learning Disability Strategy Sub Group on supported employment and stakeholder events identified how much variance there is across Greater Manchester in the provision of employment support was for autistic adults More widely, autistic people have identified the need for support in finding, staying in work and progressing at work.

A strategy implementation group on employment will be established by April 2019. The group will develop a plan for improving the support available across Greater Manchester and this will be a joint group with those leading on the learning disability strategy. This will include looking at developing standards for employment support (to complement the standards that the learning disability sub group are developing for supported employment), working with Jobcentre Plus, ensuring employment is part of local autism strategies, identifying actions around self-employment and looking at preparation for work. **A business case will be developed if we identify common gaps across Greater Manchester by this group.**



NEXT STEPS

Now the strategy has been signed off at the GM Health and Care Board (25 January 2019) we will convene the implementation groups and start work on the engagement plan. Membership will be drawn from autistic people and family members, relevant professionals, support organisations and commissioners. The groups will report back to the Greater Manchester Autism Strategy delivery group on a quarterly basis.

The strategy and in particular the action plan will be updated quarterly to reflect latest developments.

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Greater Manchester Autism
Consortium Project
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