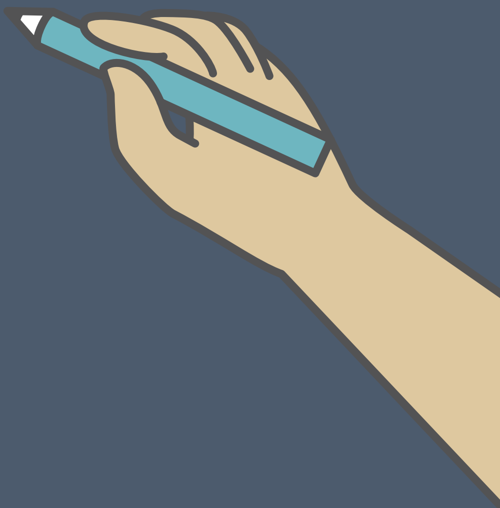
Greater Manchester
Integrated Care
Partnership

Greater Manchester

Post Diagnostic Standards for autistic adults



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GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS in Greater Manchester

Contents

Executive Summary

The Greater Manchester (GM) Post Diagnosis Standards for autistic adults will ensure equity of good quality post diagnostic support across the region, regardless of postcode. The standards set out what is required for neurodivergent people who may be on pre-assessment pathways, the information that autistic people receive about autism and the ongoing support they might need. All localities are being asked to implement post diagnostic support standards listed in this document.

The standards will continue to be reviewed, and in the coming 12-18 months' time there will be an audit undertaken to assess progress in each locality.

Foundation Standards

1 Mapping of provision:

All localities need to map what is available to neurodivergent and autistic adults and their families pre-assessment and post-diagnostically. This enables localities to be transparent and clear about their local offer and will identify gaps for future service development. The suggestion would be for Autism Partnership Boards to instigate this mapping.

2 Local website:

Each locality needs to summarise what support is available for neurodivergent and autistic adults and their families, including services that people can access pre-assessment. Minimum standard is a signposting offer on a web page linking to the local offer and to the GM website. Each locality would have an identified person to review information at least annually and update this information.

3 Diagnostic reports:

Reports should be written to the person and need to be meaningful and affirming; written in strengths-based language and signpost autistic people and their families to ongoing support in areas of need. It should also link the person to websites and materials that promote positive autistic identity. Reports need to evidence that assessments have followed NICE guidance and contain advice about reasonable adjustments. It is also appropriate to have a letter that simply states diagnosis to allow the autistic person to share diagnosis without having to share confidential details.

4 Choice of post diagnosis support:

Localities need to offer a variety of ways of accessing post diagnosis support including one to one sessions, counselling sessions and group work. These should be offered in a variety of formats, including virtual and face to face sessions.

5 Provision is not linear:

Post diagnostic support needs to be available to all autistic adults, regardless of where they are on their diagnostic journey. Many people do not follow a linear journey through a pre-assessment, diagnostic and post diagnostic offer and individuals have a right to the support they need at the time they need it.

6 Involvement of peer mentors:

All post diagnostic offers need to include some paid peer support with autistic peer mentors who are well supported and offered training and development opportunities.

7 Oversight, monitoring and support by commissioners:

Commissioners who outsource the post diagnosis support must ensure there is adequate support and oversight for the post diagnosis support with regular reviews and a method for clinicians on autism diagnostic teams to maintain a close working relationship with the post diagnosis service.

8 Oversight, monitoring and support by local Autism Partnership boards:

Local partnership boards and strategy groups need to keep oversight of the implementation of these standards to ensure there are a wide set of stakeholders including autistic people and their families reviewing the local offer.

Background

The Greater Manchester Autism Consortium (GMAC) is a partnership of the 10 Greater Manchester health and social care localities and the Greater Manchester Health and Social Care partnership. In 2019 the first GM Autism Strategy, **"Making Greater Manchester Autism Friendly"** was published. The new all-age strategy launched in 2022, continues and develops the work of the first strategy, including the provision of post-diagnostic support. This can be found **here.**

GMAC, which is funded by the consortium to steer and implement the GM Autism Strategy, was tasked with developing the GM Autism Standards in relation to diagnosis and post diagnosis. As part of this work, two post diagnostic standards task and finish groups were developed in 2021, including lead clinicians, commissioners, VCSE colleagues and people with lived experience. One task and finish group has developed the standards for children and one has developed the standards for adults.

The membership of the core group of the post diagnostic standards for adults is below:

Dr Anna Dodd (GMMH Districts ASC Clinical Lead) and chair, Sandy Bering (GM ICS MH Lead commissioner), Mari Saeki (Project Lead, GMAC), Hazel Errey (GMAC), Jane Forrest (Autism Support Coordinator, Trafford and GMAC Post Diagnosis project lead), Graham Heywood (Chairman Bolton Adult Autism Support and parent), Omar Matoru (Manchester; Autistic adult), Arlette Miller (Autism Development Lead, Salford Learning Disability team,) Fleur Piacentini (Tameside Autism Team; Autistic adult), Nick Rosenthal (Autistic adult; Autism awareness trainer, Oliver McGowan mandatory training scheme – BILD and NAS project Officer for NW), Rob Wardle (Respect for All), Lynsey Daly (Commissioner, Salford), Fiona Johnson (Service Lead, Bolton), Helen Robson (Autistic Advocate) and Deb Gale (Autism Support Coordinator, Trafford)

There is also an additional group of people who contributed to this work through the wider GM Post Diagnosis Working group, including representatives from the following localities:

Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan as well as Autistic UK, LANC UK, Mersey Care NHS Foundation Trust, NHS England and PossAbilities CIC.

A Note on Language:

In common with the GM Autism strategy "Making Greater Manchester Autism Friendly"; this document 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. We do, however, acknowledge that some people prefer "person with autism". The term autistic people includes autistic children and adults and those with or without a learning disability. We have used the term neurodivergent to describe adults who may be on waiting lists for formal assessment; who may think differently to their neurotypical peers, but who may not have another diagnosis at this point.

What is autism?

Autism is a lifelong developmental condition or difference which affects how people communicate and interact with the world. At least one in 100 people are on the autism spectrum and there are at least 700,000 autistic adults and children in the UK (National Autistic Society).

Andy Smith, an Autistic Advocate, founder and Creative Director of Spectrum Gaming explains autism in the following way:

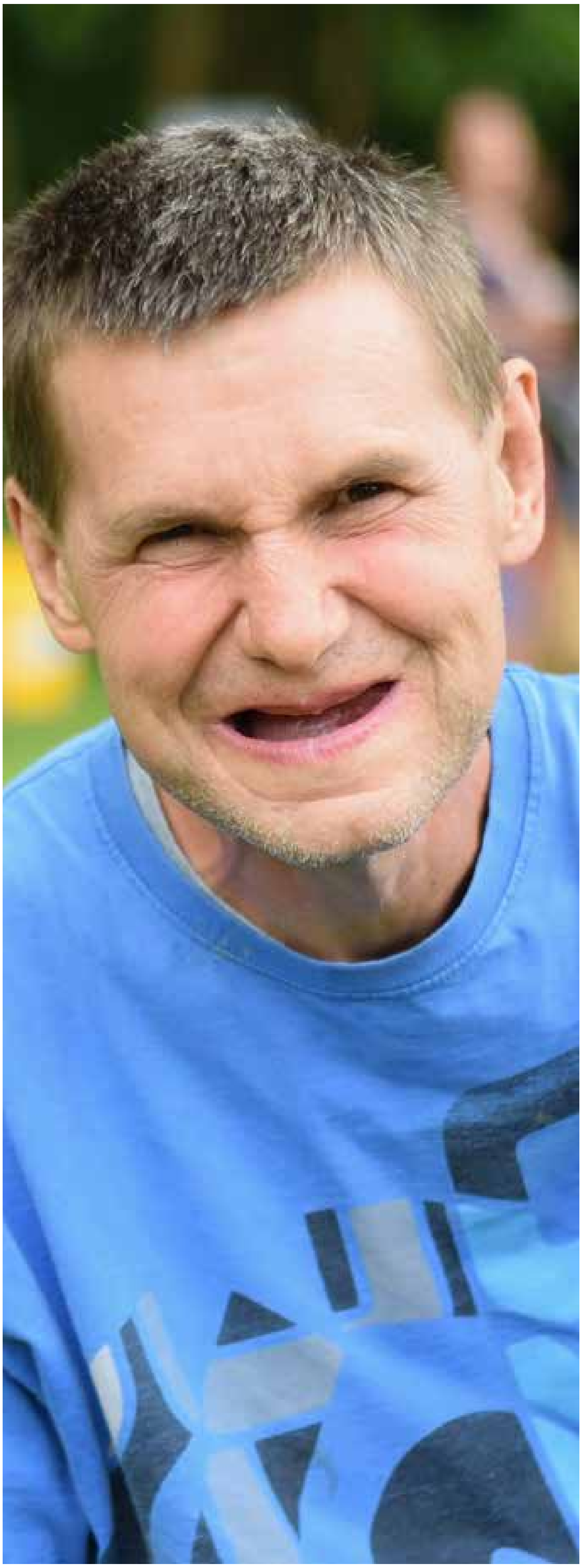
'Just like every other brain type (yes, that includes 'normal' brains too!), the autistic brain has its negatives and things that make life more difficult. But autistic brains also have many positives that others may never have the opportunity to experience. These may include having a logical brain with good attention to detail, the ability to focus deeply, strong memory skills and unique thought processes. Autistic people place less value on small talk and more on openness and honesty. Autistic people may also have lots of knowledge and skills in one specific area.

The key to happiness for everyone is to focus on your positives, and then either working on or making adjustments for the difficulties that you experience. But the world is made for the majority, and we are expected to be like the majority too because people can't see our brains are wired differently. So autistic people are often expected to conform to a world that is not made for them, meaning we don't get much opportunity to show your true strengths or prove your potential.

Another big difficulty autistic people face is that most people are afraid of difference. If you have an interest that is different from most, you may be judged for it. If you react to your sensory differences or are feeling anxious, people often lack empathy and put you through difficult experiences that you are not ready for. If you talk, act or behave in a different way, people may misunderstand or mistreat you because they don't understand.

Even without these environmental barriers, autism has its difficulties. But we aspire to live in a world where there is a level playing field and where autistic people have the best possible chance of thriving.'

(Andy Smith, 2022)



Existing guidance on diagnosis and post diagnosis

The NICE Guidelines 'Autism spectrum disorder in adults: diagnosis and management: Clinical Guidance (CG142)' include the following background information:

> 'A significant proportion of autistic adults across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, autistic people are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.... Even if they manage to obtain a diagnosis they may receive no follow-up support because of the absence of appropriate services or an agreed **care pathway.**'

The NICE Guidelines recommend establishing a local care pathway for autistic adults, which includes post diagnostic support.

The importance of all professionals & services involved having knowledge and understanding of autism is highlighted.

They also make references to "psychosocial support" and the importance of this.

NICE Quality Standard 5 named access to Psychosocial interventions a quality marker for diagnostic services.

The Department of Health and SC guidance on commissioning services for autistic people mentioned that each area needed to consider what post diagnostic support is commissioned locally.

Other reports on the need for post diagnosis support

The University of York study on **Specialist Autism Teams (SHAPE)** concluded that access to post diagnostic support which they called psychosocial education, positively impacted immediate and long-term adjustment.

The Autistica Autism Support Plan

Cites the SHAPE Study on the efficacy of psychoeducation programmes -

Recent findings from the SHAPE study suggest that psychoeducation programmes used by some specialist autism diagnostic services can improve the mental health outcomes of recently diagnosed autistic adults. A follow-up study commissioned by NHS England is consulting with autistic adults and professionals on the core elements of an optimised psychoeducation programme. Trialling a manualised version of that new programme would help ensure that high-quality psychoeducation is available to autistic adults no matter where they live.

The Westminster Commission on Autism's report, **'Support Surrounding Diagnosis: An Inquiry into Pre- and Post- Support for the Autism Diagnosis Pathway'** found that

> 'Individuals and families need better support both before and after the diagnostic process' and also that, 'There is also a strong desire for peer-support, for the autistic community themselves to support those exploring an autistic identity.'
>
> The report also highlights the need for 'A single, accessible source of information' throughout the autism diagnosis pathway.

The Sheffield Autism Research Lab report **"A knowledge exchange project to explore what autistic adults want from support after diagnosis"** published in October 2022 has listed 153 ideas for what those interviewed wanted information on including emotional and psychological support, person centred support, practical support, support in relationships and support to understand autism.

The NHS England work on commissioning guidance is to be published soon and which will likely break down support pathways to 5 inter-related service elements that should be in place across the country. These match previous published NHSE Deep Dive and Autistica model service descriptions - including references to:

- Identification, surveillance and referral
- Screening and Triage
- Pre-assessment support
- Diagnostic assessment
- Post assessment support

These GM Standards focus on the pre and post assessment/diagnostic support - But the commissioning principles for the other elements likely to be published by NHSE have been given due consideration in the writing of this report.

Purpose of the GM standards

Since the devolution in Greater Manchester, the region has been trying to work closely to ensure that common standards are created in a number of areas of work. Whilst there are national guidelines, such as NICE guidelines, there are no local guidelines.

The purpose of this work is to set standards for the commissioning and provision of the Autism post diagnostic offer across the GM region. It also hopes to clarify the offers currently available in Greater Manchester

Current Picture

Services across GM remain fragmented with an inconsistent service offer to autistic people. Some areas do not offer post diagnostic support at all, or a very minimal offer of 1-2 sessions. Also, not all autistic people are ready, or able, to take in the information offered in a post diagnostic workshop (where it is available) at the time of diagnosis and, in some areas, there is no option to opt back in to this offer, or repeat it, or for that offer to be made available to wider family members.

Overall, autistic adults are less likely to receive post diagnostic support for themselves than the parents/carers of autistic children. The type and amount of post-diagnostic support on offer to autistic adults varies greatly across different GM local areas.

A recent survey undertaken for the steering group also highlighted there may be a gap in some areas between what service providers described as their post diagnostic offer and

what autistic people felt they had been offered or received. The survey also highlighted how information and access to support often came after diagnosis, but there was very little support for those awaiting assessment. People are now often waiting up to three years for a diagnostic assessment to start; this means that in practice, autistic people do not have the targeted support when they need it. This is turn is likely to have a negative impact on the quality of life and mental health.

The working group has acknowledged that as the survey was undertaken in 2021, standard offers in various areas had been pared back due to Covid restrictions. This has resulted in more group work taking place online, opening up opportunities for a more hybrid provision of services which include face to face and online initiatives. Some areas have been able to move their offer online more easily than others, reflecting that there needs to be better shared learning across GM and leading to the possibility of shared post diagnostic support resources that could be accessed across the region online.

Each area needs a clear way to signpost people to appropriate local support ideally via a variety of means including websites, social media and in person support.

The number of people seeking diagnosis is rising year on year. Some of this increase may be due to backlog following Covid, although this does not account for the increase overall. This continual increase in numbers also makes it hard to predict and understand the scope of demand for post-diagnostic support.

The working group strongly feel that post diagnostic support could be offered by community or VCSE services and delivered by non- clinicians. We do, however, feel that there needs to be a strong connection with the diagnosing clinicians and also strong support, communication and oversight by local commissioners.

Key Principles

The steering group for this project identified a number of key principles that were to be applied to the development and delivery of the standards; including:

1. Provision is not linear:

These standards recognise that interventions need to be available to all autistic adults, regardless of where they are on their diagnostic journey. Many people do not follow a linear journey through a pre-asessment, diagnostic and post diagnostic offer and individuals have a right to the support they need at the time they need it. Offer of post diagnostic workshops should be left open if an autistic adult is not ready to access them immediately at the point of diagnosis. Information needs to be available pre and post formal diagnosis to support and empower autistic adults. If a person had a diagnosis many years before but did not receive any post diagnostic support they should be able to access the offers.

2. One size does not fit all:

Support and interventions need to be individualised and person-centred in order to meet each autistic person's needs. However, there can be an overall framework guiding this work as this can be useful to maintain a key direction/aim for the work.

3. Strengths-based model:

Interventions and support need to be provided on a strengths-based model; acknowledging realistic challenges the neurodiverse community may face whilst highlighting positive aspects of neurodiversity and committing to using strengths-based and identity first language.

4. Evidence base:

The standards set out to incorporate interventions that are evidence based and reflect good practice as outlined in NICE guidance (references at the end of this document These standards include guidance on collating and reviewing outcome data to drive forward improvement and enhance quality of life for autistic adults.

5. Peer Support Networks:

Alongside evidence- based interventions, the standards will include guidance regarding the need for clear peer support and local peer networks. Payment of peer mentors within all post diagnostic support sessions/roles is essential & should be commissioned along with a system to ensure the safe payments of peer mentors. Peer mentors must be provided with support & supervision.

6. Voice of Autistic Adults:

Co-production of local and GM developments must be integral to the standards. Any post diagnostic offer, including training offers should include the voice of autistic adults. Post Diagnostic teams should warmly welcome/actively recruit people with lived experience i.e. autistic adults &/or people who have a person close to them who is autistic.

7. Audit and Review:

The standards should be audited to help commissioners review gaps in local provision and inform service development and there needs to be clarity around when and where outcomes will be reported. Commissioners also need to offer oversight and support to commissioned services especially where they are from the VCSE sector (see standard for more explanation).

8. Quality control:

The standards will include scope to review content of post diagnostic packages, training and support relating to sharing an autism diagnosis.

9. Resources need to be up to date:

The standards need to specify the system for keeping resources up to date and current.

10. Co-operation and Communication across GM:

This means sharing good ideas about best practice and quality and ensuring there is good communication to encourage joint working.

GM Autism Post Diagnosis Standards for Adults

A note about investment guidelines for commissioners

According to the **Autism Prevalence calculator**, as at 2020 and based on the prevalence figure of 1.1%, GM has 24,130 autistic adults and 7190 children (31,320 in total). By 2035 Those figures rise to 25,920 adults and 7210 (33,130 in total). (It is worth noting that there are other prevalence studies internationally that set prevalence far higher and there is likely to be a further look at UK Prevalence in the future so the 1.1% is a minimum)

For adults, if we use the economic modelling in the 2009 National Audit Office report, if 8% of the autistic population were to identified and given some level of support, they estimated that the cost of investment in the diagnostic services would be saved (although admittedly by other parts of the Health and care system).

In numbers this equates to meeting the needs of 1930 adults now and rising to 2073 adults by 2035.

If we recognise that of those adults around 30% may also have a learning disability that leaves 1351 autistic adults with no learning disability now and 1451 by 2035.

For the purposes of these standards we recommend that areas look to offering post diagnosis support to everyone who is diagnosed as a minimum and more support to at least the 8% of the autistic population. **The NAO report** also showed that the higher the percentage of identification, the higher the return in savings in other areas of spending by pubic services.

1. There needs to be a coherent **pre-assessment offer** available that can be delivered in a variety of ways including face to face or virtual offers. People may need access to some of the same material present in the post diagnosis support, but it is expected that there will be separate groups, as this will be presented differently when considering versus gaining, a clear diagnosis. The offer should suggest strategies for managing difficulties and also that self-identification is a valid option.

2. A minimum of 5-8 of **one to one sessions** should be available following diagnosis, using a structured guided conversation such as **Spectrum Star**. The 5-8 post diagnostic sessions should not include diagnosis feedback sessions (these are counted separately, as they form part of the diagnostic process). The sessions could be with non-clinical staff who have good and appropriate levels of support and supervision.

3. Diagnosis reports need to be **strengths based** and includes some practical guidance on reasonable adjustments brief letter should also be provided, which confirms the diagnosis without including all the confidential information provided in the full report, with a covering letter with advice about who you should be sharing your report with.

4. There should be an offer of at least 10 **group sessions facilitated by paid peer mentors** in partnership with other facilitators based on specific themes e.g. Impact of autism, Information on other support available, disclosing the diagnosis, employment, what the diagnosis means, examples of reasonable adjustments that could be made and looking after mental well-being. We recommend a maximum number for these groups of around 12 people at a time. The reason for keeping the numbers to no more than 12 is because in programmes currently running in GM it has been shown that a much bigger group can result in some people feeling too overwhelmed to speak up. Groups could be run either virtually or face to face, although recent evidence has been that many autistic people (though not of course all) prefer the virtual model.

5. **Peer mentors** must be offered regular supervision, support and training even if they are working on a casual basis for specific hours rather than part of a salaried workforce. This is because the nature of the needs of the autistic people they support maybe wide-ranging and at times stressful and worrying.

6. There should be access to **On-going drop-in service** that is open to all regardless of eligibility after the post diagnostic offer is finished. This might be run by a VCSE service, including existing services that may not be autism-specific but with the right training and guidance to staff could be appropriate. These group may help with low level support needs such as advice on benefits or travel-passes but also be an opportunity for friendship and social connection. The working group strongly felt that this ensures that crises are less likely to arise for the autistic person.

7. Access to time **limited counselling/ psychological therapy** for those whose needs are too complex for them to be able to access primary care psychology. This can be accessed from a VCSE provider or NHS providers should be part of a stepped care model of psychological support.

8. **Autistic people with a learning disability** are expected to have post diagnostic support offered that is equitable to that offered to those without a learning disability. It is expected that those receiving support from a Community Learning Disability Teams and having received a diagnosis of autism, or waiting for assessment, will receive support from these teams. However, it is recognised that many people with a learning disability may not be known to a community learning disability team and the pre- and post-diagnostic support will be adjusted if necessary to meet the needs of individuals who require this.

9. **Autistic people with a Mental Health conditions in inpatient settings** are also likely to need some post diagnostic support and there needs to be consideration of how this can be provided. There needs to be consideration of context and appropriate support within that context.

10. **Skill set for professionals delivering Post Diagnostic support** includes significant experience of work with autistic people, genuine insight, good clinical skills, kindness, care, compassion, willingness to listen and skills to create a warm/ welcoming atmosphere.

11. **Skills set for Peer mentors** having a good understanding of their own autistic identity, the ability to travel independently or to attend online session, the ability to support other people who have had a recent diagnosis, be willing to undergo an induction process and to undertake a DBS, show kindness, care, compassion, willingness to listen and to create a warm/ welcoming atmosphere.

12. **All localities need to publish their current diagnosis and post diagnosis offer clearly** in a place that can be easily found. This may include a council or trust website, local offer pages and there will also be a page for each locality on the GMAC website. They must also ensure those pages are regularly updated and checked for accuracy.

13. **The post diagnostic groups should be run for people in their own locality so there can be appropriate on-going support offered by local services in the area the person lives.** The GM standards group feel this would not work as well outside of the person's locality.

14. **Commissioners need to consider the post diagnosis needs of autistic people in Transition to adulthood.** Young people receiving a diagnosis in the transition years can sometimes miss out on a post diagnosis offer and yet it can be very difficult to navigate those years newly diagnosed without support. The adult offer may need to be modified for this age group.

15. **Commissioners also need to offer oversight and support to commissioned post diagnostic services** especially where they are from the VCSE sector as they may not have the same resources as health providers to oversee organisational responsibilities such as the HR, staff benefits and development. The long- term sustainability of the funding must also be considered and become part of the established commissioning landscape in localities.

16. **Diagnostic teams should ideally remain involved with the person until the post diagnosis support is completed and not discharge the person until after the post diagnosis sessions are complete.** This is because there are often still questions about the diagnosis process that the post diagnosis team may not be able to answer. The link between the diagnosis teams and the post diagnosis service needs to be strong with good communication and referral pathways. However, if someone is joining the post diagnosis support a long time after diagnosis, this may not be possible

Conclusion

We expect that this will be an evolving document and as such reviewed at least annually to check for accuracy, appropriateness of language and against any emerging evidence and national guidance.

We hope to develop additional supplementary documents over time such as an audit tool.

Dr Anna Dodd (GMMH ASC District Clinical Lead) and Mari Saeki (GMAC Project Lead) on behalf of the Greater Manchester Autism Standards on Post Diagnosis support for adults group. October 2022

References

Making Greater Manchester Autism Friendly GM Autism Strategy 2019- 2022

Making Greater Manchester Autism Friendly Strategy 2022- 2025

National Audit Office report “Supporting people with autism through adulthood” (2009)

NICE Guidance autism spectrum disorder in adults: diagnosis and management - Guidance 142 (2012)

NICE Quality Standard 5 (2014)

The Department of Health and SC guidance on commissioning services for autistic people

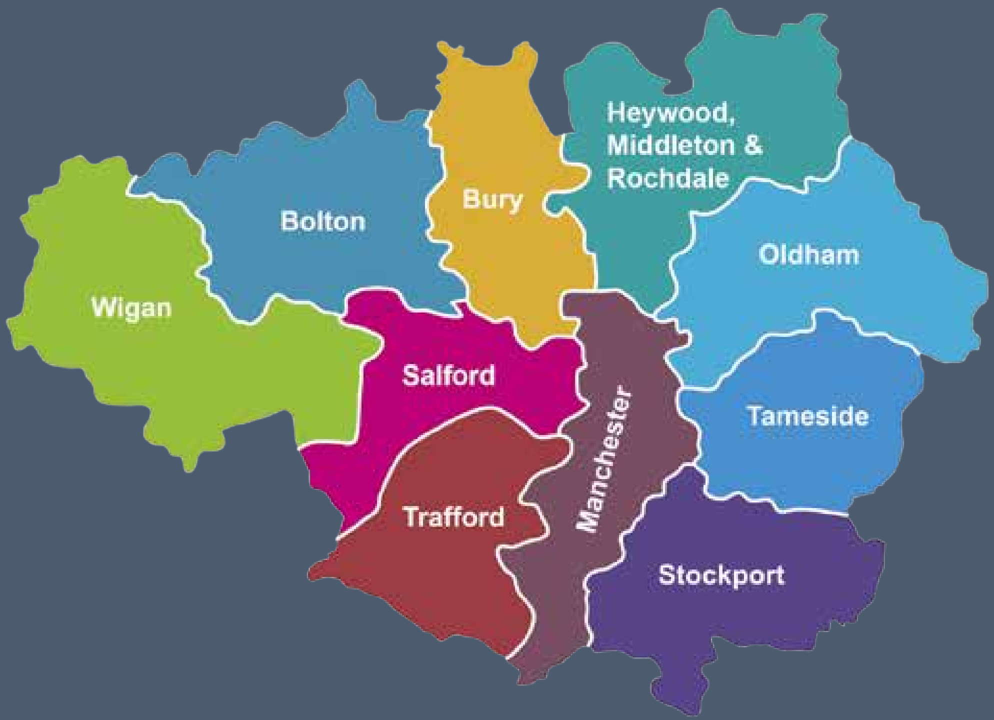
The Autistica Autism Support plan

The Westminster Commission on Autism’s report, ‘Support Surrounding Diagnosis

SHAPE study

Skills for Care guidance for Commissioners and Prevalence calculator

Spectrum Star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