

Greater Manchester

**Post Diagnostic
Standards for Supporting
Autistic Children
and Young People and
their Families**





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Executive Summary

The GM Standards for Autistic Children and Young People set expectations of what good quality post-diagnostic care looks like for autistic children and their families. This document is a tool for levelling up services and removing the postcode lottery that has existed historically around commissioned services. This document does not cover the diagnostic assessment itself as this is covered by specific guidance from The National Institute of Health and Clinical Excellence (NICE).

These standards emphasise that services should be provided based on need, not just on diagnosis. They ask localities to consider a broad range of services in each of the four quadrants of the Thrive model and think about:

- The needs of neurodivergent children who may be on assessment pathways, but have not yet been seen.
- Information that young autistic people and their families receive about autism at the point of diagnosis.
- Ongoing support and care autistic young people and their families require.

Developing this document has shown that many strands of information and support need to be in place for autistic young people to thrive. The standards are heavily health focused but also contain guidance for education, social care and the voluntary sector. It is essential that all agencies work together and share resources to achieve good practice.

These standards are aspirational, but also need to be achievable, so localities do not feel overwhelmed by the task ahead. For this reason, we have chosen 12 foundation standards for localities to review over the next 12-24 months. Each locality will be provided with an audit tool to measure themselves against these standards, and a more comprehensive tool to help with service mapping. The foundation standards are

listed here but the full version is in the main body of the document. If localities feel they are close to achieving the foundation standards, they can continue to move forward by referring to the core text.





Foundation Standards for 2023

1 Service mapping/audit:

All localities are to map what is available to young neurodivergent and autistic people and their families pre assessment and post-diagnostically. Localities are directed to use the mapping tool that accompanies these standards to complete this exercise. This should help localities to be transparent and clear about their local offer and will identify gaps for future service development.

2 Local website:

Each locality will summarise what help is available for young people and their families based on their need, including services that families can access prior to assessment. Minimum standard is a signposting offer on a specific neurodiversity and autism web page linking to the local offer and GM website. Each locality to have an identified person to review information and verify accuracy.

3 Diagnostic reports:

Reports need to be: meaningful and affirming; written in strengths-based language; connect young people and their families to positive autism role models and information; and signpost young people and their families to ongoing support in areas of need. Reports need to evidence that assessments have followed NICE guidance and contain advice about reasonable adjustment. The young person will receive a written outcome of their assessment, incorporating their communication needs and linking them to sites such as Understanding Autism and to websites and social media links that promote a positive autistic identity and welcome the person to the autistic community.

4

Immediate post-diagnostic support – Young People:

The minimum standard is for services to commit to offering at least one follow up session post-diagnostically for the young person and to share information here about:

- understanding autism
- supporting wellbeing
- support in education and work
- access to community support
- signposting to local, GM, national websites.

A higher standard would be to offer a series of appointments, workshops, mentor meetings or ongoing drop ins for young people.

5

Immediate post-diagnostic Support – Parents and Carers:

The minimum standard is for services to commit to at least one follow up session post-diagnostically for parent/carers to share information about:

- understanding autism
- adapting to and supporting communication difference
- making reasonable adjustments at home which allow young people to thrive
- support in education and work
- the local provision map, including parent support groups
- signposting to relevant local, GM and national web pages

Localities should provide parents with the opportunity to meet other parents at workshops or drop-ins and this must be an offer that parent carers and wider family members can access at any point on their journey (not just immediately at the point of diagnosis).

6

Communication:

All autistic young people should have access to a one-page profile (e.g “About Me”) or Communication Passport that enables the people around them to adapt to the autistic young person’s communication preferences. Children and young people should have access to evidence based interventions aimed at supporting communication and understanding.

7 Sensory Profiles:

Localities will provide all autistic young people and their families with access to information about their sensory profile and how they can best cope with sensory overload. Families need access to sensory workshops or 1:1 support as a minimum standard.

8 Behaviour and stress:

Each locality will have a core ongoing offer around understanding behaviour and stress with a rolling programme of groups e.g. Riding the Rapids. As a minimum standard each locality will have a Riding the Rapids champion who co-ordinates the group offer and who will maintain a link with the GM RTR community of practice. A higher standard would be to offer group interventions pre assessment for families of neurodivergent children and to evidence provision of Behaviour Support Plans for those where more intensive support is needed.

9 Health Passport:

All children with autism should receive a health passport if they have frequent attendance at medical appointments, that outlines reasonable adjustments that have to be made to support their needs in outpatient clinics and if admitted as an inpatient.

10 Autism Navigator:

All ten localities need to have a designated autism navigator or support officer, preferably someone with lived experience who has good local knowledge and can signpost neurodivergent young people and families as needed and ensure local co-production takes place with parent carer forums and with autistic young people.

11 Education:

As a minimum standard there also has to be a meeting with school within three months of someone receiving their diagnosis to look at what reasonable adjustments need to be in place for the young person to thrive. All localities also need to produce a document outlining their Ordinarily Available Provision for preschool, primary and secondary age children.

12 Mental health:

An autism lead in each CAMHS and mental health provider needs to be identified to take forward the next stage of standard setting and ensure a community of good practice is formed across GM. This can be co-ordinated through the Autism Hub.



Steering Group

These standards have been co-ordinated through a partnership between the Greater Manchester Autism Consortium (GMAC) and Manchester Foundation NHS Trust.

The Steering Group for the standards included local clinicians, commissioners and people with lived experience. Whilst predominantly health-led, there has been wider consultation with colleagues in education, social care and with Parent Carer Forums across the region.

Membership of the steering group:

Sandy Bering (Strategic Lead Clinical Commissioner – Mental Health & Disabilities, NHS Greater Manchester Integrated Care); Jo Bromley (Strategic Lead for Autism and Learning Disabilities, CAMHS, Manchester University NHS Foundation Trust); Hazel Errey (GMAC); Andy Smith (Creative Director, Spectrum Gaming); Samera Haynes-Khan (Parent Seminar Coordinator, GMAC); Alison Hunter (Specialist Speech and Language Therapist, Manchester University NHS Foundation Trust); Kelly Judd (Bury2gether, Parent Carer Forum); Cheryl Knupfer (Strategic Lead for Autism, Stockport Metropolitan Borough Council); Rachel Lancaster (Consultant Clinical Psychologist, Pennine Care NHS Foundation Trust); Kiera Lubbeke (Specialist Speech and language Therapist, Autism Clinical Lead, Stockport NHS Foundation Trust); Lorraine Price (Neurodevelopment Pathway Manager, Wrightington, Wigan & Leigh NHS Foundation Trust); Mari Saeki (Project Lead, GMAC); and Emma Wilson (Specialist Nurse for Early Years, Team Lead for Early Years Health & Development Team, Wrightington, Wigan & Leigh NHS Foundation Trust).

A Note on Language:

In common with the GM Autism strategy “Making Greater Manchester Autism Friendly” (2022), 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. 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 children who may be on waiting lists for services; who may think, process information, or interact differently to their neurotypical peers, but who may not yet have had any formal assessment.

The term ‘Positive Behaviour Support’ refers to an evidence-based framework that aims to increase quality of life and reduce restriction and restraint (Gore 2015). It is not meant to imply that autistic people need to have new behaviours or be taught to ‘fit in’ with the neurotypical majority.

What is autism?

Autism affects how people communicate and interact with the world. A conservative estimate is that one in 100 people are autistic and The National Autistic Society estimates there are around 700,000 autistic adults and children in the UK.

Autism is often seen as a neurotype, which means autistic people share similar thinking styles. These tend to be different to neurotypical thinking styles. As the world is often designed by,

and for, a neurotypical style, the environment can often cause autistic people a great deal of stress. Getting the right support and understanding can make a huge difference to autistic people.

Andy Smith, founder of Spectrum Gaming, describes autism and the challenges of being autistic:

“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 our true strengths or prove our potential.

There is another big difficulty autistic people face, which 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”

Our aspiration is that these standards will help create environments and services that encourage autistic young people and their families to thrive.

(Andy Smith, 2022)

Purpose of the GM standards

These standards aim to set expectations around what good quality support looks like for autistic young people and their families. This document should be a tool to encourage levelling up of the support that is provided across the region, minimising the 'postcode lottery' which currently exists.

These standards link closely with the recently released GM Autism Strategy that aims to make Greater Manchester an autism-friendly place to live. The strategy outlines that all autistic people should get support after their diagnosis, feel understood and valued and should be able to find advice and help about services. The standards also take into consideration the advice in NICE guidelines relating to autism assessment and post-diagnostic support (NICE Guidance 2011, 2013) and documents produced by the North-West Learning Disability and Autism Operational Delivery Network (ODN) and is in line with emerging documentation and guidance from NHS England.

Since devolution, Greater Manchester has been working closely to ensure that common standards are created in a number of areas of work. Over recent years, alongside initiatives that local areas might have developed, there has been investment at a GM level into a number of health interventions, including PACT (Green et al, 2010), Riding the Rapids (Stuttard et al, 2014) and Positive Behaviour Support (www.challengingbehaviour.org.uk), to ensure there can be equal provision of evidence-based support across the region.

However, there has been no overview of support for those on assessment pathways or agreed clarity on what an appropriate offer might look like. With the development of the Integrated Care Board for the region, the need for a local set of standards is even more pressing. The purpose of this work is to both set standards for autism support and map and clarify the offers currently available in Greater Manchester.



Current Picture

Services across GM remain fragmented, with an inconsistent service offer to autistic children, young people and their families. The GM region is embedding the Thrive principles and framework, which aim to provide children, young people and their families with an appropriate range of services. This covers all four quadrants of care: Signposting, Getting Help, Getting More Help and Risk Support.

However, local areas are often unable to map out a full pre-assessment or post-diagnostic offer for young autistic people and their families. Assessment services and post-diagnostic support have not always developed in tandem, leaving families feeling unsupported following diagnosis. Not all families are ready for the information offered in a post-diagnostic workshop when it is first offered, but there is often no option to opt back in at a later date, or repeat that offer, or for it to be made available to wider family members.

A recent survey undertaken for the steering group also highlighted:

- In some areas, there may be disparity between what service providers described as their post-diagnostic offer, and what parents and carers felt they had received.
- The content of the post-diagnostic offer was extremely variable.
- Post-diagnostic support was aimed at parents and carers, but there was no known post-diagnostic offer for young autistic people themselves in any of the 10 GM boroughs
- Information and support was provided post-diagnosis, but not prior to assessment.

As many children and families are often waiting 12-24 months for a assessment to start, in practice, children, young people and their families do not have the targeted support when they need it. This in turn is likely to have a negative impact on quality of life, and other outcomes relating to communication and stress.

As a result of COVID-19 restrictions, some areas have moved their immediate post-diagnostic offer online and some have retained a hybrid model of face-to-face and online support. This variation suggested an opportunity for shared learning across GM, leading to the possibility of shared post-diagnostic support offers that could be accessed online from across the region.

Signposting is clearly an important part of any post-diagnostic offer, as national standards suggest, however there is huge variation in listings and clarity from region to region and a clear consensus for a 'one stop' GM wide website for parents and for young people themselves. In response to this, whilst these standards were being created, Spectrum Gaming were commissioned to develop a GM website run by, and for, young autistic people. Further work is required to create a parent and carer version.

Beyond immediate post-diagnostic support, there is also less guidance and homogeneity regarding longer-term support; particularly around issues relating to wellbeing and mental health. There is often a lack of transparency for young people and their families, who find it hard to navigate the services on offer. Knowing what is available in the locality and region should be the foundation on which service development can be built, yet many parents, carers and young people remain unclear what support they could access, and when care and support might step up and step down. In some adult services (e.g. Tameside, Bolton), there are well established roles for a professional to coordinate the support offer, but these roles do not exist within services for children and young people and their families. Without this kind of support, families who have additional difficulties accessing services, for example where English is a second language, may face further barriers in knowing what they or their child are entitled to.

It is envisaged the newly created GM Autism Hub at Manchester University NHS Foundation will play a role in audit, monitoring and development of these standards

COVID-19 Legacy

Since beginning work on these standards, the group are aware that the landscape in which services are being provided has changed post-pandemic. Services are just starting to realise the impact that isolation and lack of access to nursery, school and social environments may have had on our children and young people. The Education Endowment Foundation (2022) outlined new research suggesting that children's communication and language skills; their personal, social and emotional development; literacy; maths and physical development have all been affected by lockdown. This research suggests that within a primary school age

cohort, those children at the younger end of the school system have been particularly adversely affected, perhaps because more of their lifespan has been spent in lockdown conditions. In light of this and similar research, we recognise these standards are being released at a time of greater need.

We also recognise that waiting lists for diagnosis are getting longer and that we need to ensure support is in place prior to the assessment for the majority of young people and their families, and that support if provided whatever the outcome of the assessment might be.



Key Principles

The steering group for this project identified ten key principles that were to be applied to the development and delivery of the standards, stating provision should be:

1. Non-linear:

Interventions need to be available to all children and young people and their families regardless of where they are on their diagnostic journey. Many families do not follow a linear journey through a pre-assessment, diagnostic and post-diagnostic offer. Families have a right to the support they need at the time they need it, for example, the offer of post-diagnostic workshops could be left open if families and young people are not ready to access them immediately following diagnosis. Information needs to be available pre-assessment and following formal diagnosis to support and empower young people and their families.

2. Co-produced:

The voice of young people and their families are integral to these standards. Service offers, including those around training, should be co-produced.

3. Needs-led:

The standards recognise that by definition, autism is individual, and provision should be needs-led not diagnosis-led. There should therefore be a blend of specific and universal provision, whereby universal services ensure their offer is accessible and welcoming to autistic young people and their families. There is also a need to recognise that some neurodivergent people may want to access support prior to assessment. Needs-led care also means that neurodivergent children who are looked after, or cared for, should have intervention and support that acknowledges their neurodiversity.

4. Underpinned by Thrive:

GM has incorporated the Thrive model of service provision and this framework is used to set out these standards, in line with the other key principles. Thrive is centred around needs and allowing families and young people to access the right support at the right time. Interventions have not been divided into pre-assessment or post-diagnostic but are grouped according to which quadrant of Thrive they may fit. Thrive belongs to all agencies and is not the responsibility of one.

5. Strengths-based:

Interventions and support need to be provided on a strengths-based model, acknowledging realistic challenges that autistic people may face, whilst highlighting positive aspects of neurodivergence and committing to using strengths-based language.

6. Evidence-based:

The standards set out to incorporate interventions that are evidence-based and reflect good practice as outlined in national guidance. These standards include guidance on collating and reviewing outcome data to drive forward improvement and enhance quality of life, for autistic young people and their families.

7. Valuing of Peer Support:

Alongside evidence-based interventions, the standards will include guidance regarding the need for clear peer support and local peer networks. A key principle is that there needs to be a mixed offer of formal and informal support and that some support needs to be open access.

8. Accessible and Equitable:

Interventions and support listed in these standards need to be accessible to all families, including those who have English as a second language, and those caring for children who are looked after. Communities who are marginalised and may distrust services may also need a different approach to engage them. We recommend that all areas complete an Equality Impact Assessment when reviewing their standards, and that local issues relating to health inequalities are considered in developing services.

9. Involve Co-Operation and Communication Across GM:

Equitable access to training, workshops and online resources across all 10 GM localities will benefit families and young people. Sharing good practice and cooperating with other localities is a key foundation principle of this guidance.

10. Audited:

These standards have a corresponding audit tool for localities to complete. This will help review gaps in local provision and inform service development.

It is highly likely that each locality will need to look at a training strategy to deliver and enforce these standards. Although this is outside the scope of the current document, we recognise there will be a need for GM wide coordination on this.

We strongly suggest that the diagnostic teams in the GM localities develop, or maintain, strong links with their local autism strategy groups, and the local parent forums and other parent and young people led organisations. This ensures a strong connection with lived experience and monitoring of the quality of autism support. If no such group exists, we recommend that a strategy group is developed as a priority for this work.

The next section of the document details the standards in full.



The Standards

1. Getting advice and signposting

This quadrant of thrive is about information sharing and making links for young people and families. Some young people and families may only need the information provided here.

1.1 Access to Information

Good quality, up to date information about autism and other neurodiversity relating to attention, communication and sensory processing, should be available for parents and young people at any point they wish to access it. Information should include links to relevant national, GM and local websites (e.g. National Autistic Society, GMAC, GM Autism Hub, local Parent Carer Forums), and should be framed within positive neurodiverse language. We recommend that each area develop specific websites, or webpages on existing local websites, for ease of access. We will work towards collating links to these on one GM wide website.

1.2. Pathways and Processes

Information about diagnostic pathways and referral process should be available on the local offer, along with how to access support to complete a referral (e.g. how to access interpreters). This should also include a reference to the universal provision and reasonable adjustments that might be made within that. Information should also be available regarding what support can be accessed based on need. For example, there may be sleep workshops; webinars relating to the code of practice and education support; groups on managing anxiety; all of which can be accessed based on need rather than

diagnosis. Where diagnostic assessments have been outsourced by NHS providers, this should be clear and transparent, with clarity around CQC registration, assessments completed in concordance with NICE guidelines and clear links back into local services. Reports commissioned privately should also follow these standards. If service access is through schools, information on routes into services for those who are home-educated needs to be available.

1.3. Mapping of local provision

As part of their local strategy group, we would recommend that services map the offer of support in their area across the 4 quadrants of Thrive; signposting, getting help; getting more help and risk support. Mapping should include what services and support can be accessed without a diagnosis and what is available post-diagnostically and should cover conditions relating to wider neurodivergence.

As a minimum, the map needs to cover support for:

- Sleep
- Sensory processing
- Communication
- Attention and concentration
- Understanding stress and behaviour (including information about autistic burnout - see below)
- Mental health and wellbeing
- SEND Support
- Informal peer support and support groups
- Autism and LGBTQ
- Support for diverse communities
- Support for traumatic experiences
- Support for cared for/looked after children

The GM Autism Hub will seek to co-ordinate a GM wide website summarising these provision maps. The hub can also highlight areas of good practice and advertise groups and webinars that can be accessed by all in GM. Every locality needs to have a named champion in their locality to check on accuracy. Information can also be highlighted on the Local Offer and across websites of statutory and voluntary sector services in each local area. This will improve connectivity and ensure parents can access information from a variety of locations.

1.4. Diagnostic Reports

Each local area will have reviewed the format and function of information given in their assessment reports. When a diagnosis of autism is given, the reports should: pick up the themes of using neurodiverse positive language; include a pen portrait written by, or with, the family or young person (or include their All About Me profile); clarify what adjustments the young person may need to be made to environments, in order that they can function better in those environments; and include signposts to ongoing support available locally (preferably electronically using QR codes and similar links). It is assumed that young people have given their consent to assessment if they have capacity. Young people should therefore receive a written summary of their assessment and any outcomes, which takes into account their communication preferences and profile. Reports should also provide links to websites such as Understanding Autism, and social media that promote a positive autistic identity, and welcome the person to the autistic community. References to appropriate information on YouTube, that shows a positive portrayal of autism, such as the animation Amazing Things Happen, can be included for wider family members. Often young people and their families have waited a long time for an assessment and

their report needs to be useful, hopeful and affirming. Report templates should be reviewed locally with young people, their parents and carers, to ensure they are setting the right tone and delivering the right information. Young people who receive a different diagnosis to autism or no diagnosis at the end of their assessment also need information about ongoing support.

1.5. Autism Navigators

Each locality would benefit from a local autism navigator, to support children and young people and their families who have queries about what support is available, based on need and targeted around neurodiversity. This role could ideally be developed with someone with lived experience and could be hosted by any agency. The autism navigator would have a role in ensuring the local provision map was kept up to date and be responsible for linking in with groups for young people and for families, to ensure their voices are reflected in local development.

2. Getting help

Getting help represents the next level of support families might access beyond signposting. It can include specific interventions and might be linked to a specific need.

2.1. Immediate Post-diagnostic Support – Young People

Lack of self-acceptance has been proven to be detrimental to the long-term wellbeing of autistic people, and is noted as a risk marker for suicidality in autistic adults (Cassidy et al 2018). It is therefore imperative that services find ways of talking about autism that empower and celebrate autism.

Each area should have a post-diagnostic offer that can be accessed by young

people at any point. This offer should include a helpful and affirming report, with appropriate signposting and a welcome to the autistic community as outlined above. Services should commit to offering at least one session of information sharing or follow up, and to accept that young people may not access this session immediately. Follow up information can be offered face to face, virtually, individually, or in a group, and does not only have to be provided within school hours. Immediate post-diagnostic support should include the provision of good quality, autism positive information about:

- Understanding autism (including positive images and discussion of autistic strengths, a welcome to the autistic community, awareness of sensory differences and what makes a person unique).
- Supporting wellbeing (information about spoon theory (see reference section), managing a social battery, autistic burnout (see reference section) enjoying stims, ways to build resilience).
- Information about support in education and work (what adjustments or support is needed in school or college).
- Information about accessing other community support, including local provision map of peer support groups (having fun in the local area, meeting other people of a similar neurotype).
- Signposting to GM 'Understanding Autism' website and other relevant websites.

2.2. Immediate Post-diagnostic Support – Families

The immediate offer should include a report as outlined above, then an individual or group follow up, conducted face-to-face or virtually (depending on family preference), which should include information about:

- Understanding autism (including

positive images and discussion of autistic strengths, a welcome to the autistic community, awareness of sensory differences and what makes a person unique).

- Supporting young peoples' wellbeing (information about spoon theory, managing a social battery, enjoying stims, ways to build resilience).
- Adapting to, and supporting, communication differences (using visual supports in communication, allowing processing time, quiet, clear communication)
- Making reasonable adjustments at home, which allow young people to thrive (allowing time to recharge after school, making choices regarding social demands)
- Information about support in education and work (e.g. what is the SEN code of practice, link to SENDIASS)
- Information about accessing other community services; the local provision map, including parent support groups.
- Signposting to relevant national, GM and local websites (e.g. National Autistic Society, GMAC and/or GM Autism Hub, local Parent Carer Forums).

Ongoing drop-in support for parents and carers would be supported here. If areas do not have a post-diagnostic offer, considering an evidence-based option such as REACH (see reference section) would be advisable.

2.3. Communication

Autistic children may need support with different aspects of communication, and there will be no one therapy that will meet all need. A supportive communication environment, where the needs of autistic children are understood, and communication can be supported by visuals, is essential.

Autistic Young people should have a one-page profile or communication passport

(examples in appendix). This would include information about the autistic young person's communication and any adaptations needed, to ensure the young person is able to access a range of environments.

Schools and settings need to be able to demonstrate the use of "Communication Friendly Strategies" (e.g. Elklan or Wellcomm). All staff should understand how to simplify their language and use visuals to support autistic children, who may have differences in how they understand verbal language and how they send messages. Schools and other settings should consider Communication Access training (see references), which gives information about how to support people with a range of communication differences.

For some families, bespoke interventions may be required. For younger children, NICE guidelines state that communication interventions should contain play-based strategies that support parent and child interactions, or teacher/teaching assistants and child interactions. These interventions aim to build trusting relationships and the 'building blocks' of communication, which include skills such as shared attention. Interventions such as PACT, More Than Words and Video Interactive Guidance are evidence-based – the former two specifically for autistic children.

Autistic children should have support to ensure they are able to make their needs known. This could include introduction of appropriate visual supports (e.g. Choice boards, Picture Exchange Communication System (PECS), Pragmatic Organisation Dynamic Display (PODD) books, Communication Books), as well as consideration of the communication environment, to ensure that there are opportunities for the autistic child to communicate during everyday activities and routines.

For older children, interventions which focus on supporting communication across a neurodiverse spectrum. Helping children and parents recognise where communication breakdown may be occurring, and how to foster communication repair will be important.

Some autistic young people may want to develop friendships with their peers or other neurodiverse young people. Schools and other settings should have access to appropriate interventions that foster positive relationships, e.g. Lego therapy, Circle of Friends.

2.4. Sleep

Each locality needs a clear offer around sleep support, across the age range. Families need access to an intervention aimed at helping them understand: the sleep process; the barriers currently in place to achieving good sleep; options for improving sleep; and a bespoke sleep plan. These interventions could be delivered individually or in a group, and could take place face-to-face or virtually. NICE guidelines advise that following the offer of basic information and signposting, the first step in a sleep pathway should be making environmental adjustments to support sleep. This offer could be made to families based on need and regardless of diagnosis. This should be flexible enough to incorporate the needs of the neurodiverse child, and recognise that these children may need something more bespoke than neurotypical children.

2.5. Eating

Avoidant Restrictive Food Intake Disorder (ARFID) was formally recognised as an eating disorder in DSM-V (2013). Whilst eating difficulties are very common for autistic people, ARFID is a specific diagnosis describing a diet very limited in volume and/or range. However, numerous research studies and much anecdotal

reporting has noted the relatively high co-occurrence of autism and ARFID.

Given that Arfid is still a relatively new diagnosis, research as to best practice and evidence-based interventions is still in its infancy. However, it is clear that access to assessment, diagnosis, psychoeducation is very important, as is a person-centred approach. Support to address nutritional risk is also a necessity suggesting an important interface between physical and mental health practitioners and the need for good MDFT working.

At the Getting Help stage, localities should provide children and young people with a review of diet and weight, advice on dietary supplements and information about ARFID. Interventions such as Sequential Oral Sensory (SOS) Approach may be considered. For young people where there is concern regarding an eating disorder, such as Anorexia or Bulimia Nervosa a referral should be made to the local Eating Disorder Service who have a responsibility to offer autism-informed care.

2.6. Toileting

Each area should have a designated worker within their local continence service, who has training in understanding autism and neurodiversity, and who can give advice pre-assessment and post-diagnostically. Adaptation of neurotypical toileting strategies to meet neurodivergent needs should be considered including, for example, use of adapted communication tools.

2.7. Physical health

Wherever possible, autistic young people should be supported to access generic health services. All services are required to make reasonable adjustments to their practice, in order to accommodate the needs of neurodiverse and autistic young people. If children are attending multiple health appointments or need a

planned procedure in hospital, the team around the child, including school and community health staff, should co-create a communication or hospital passport with the young person and their parents or carers. An example health passport is listed in the references. The plan should include reasonable adjustments that can be made by the hospital team, and pay particular care to supporting communication and managing the sensory environment of the hospital.

To support autistic and neurodivergent children in hospital, acute settings should have autism training for staff, staff who are identified autism champions, play therapists who can help prepare autistic children for procedures, and a system to minimise time spent in potentially over-stimulating waiting areas.

If autistic children and young people are admitted to hospital as an emergency, it is recommended that an emergency Team Around the Child meeting is convened, with the young person and colleagues in community health who know that child and family well (e.g. school nurse, learning disability nurses, speech therapist); and that a hospital passport and care plan detailing the reasonable adjustments that the young person needs, is co-created at this point if one does not already exist. Services should look at 'More Than Words: Supporting Effective Communication with Autistic People in Health Care Settings' for guidance.

2.8. Sensory Support

Understanding sensory needs is essential to families making reasonable adjustments, and for children to thrive. Pathways need to be able to offer clear access to sensory support services (usually through Occupational Therapy teams) for autistic children and their families, and for those neurodivergent children who are on waiting lists. Sensory support can be individual or group-based, but

should be delivered with facilitators who understand the evidence-base and sensory needs of neurodiverse children. Sensory workshops should cover understanding of sensory needs, suggestions of reasonable adjustments, changes that can be made to improve the sensory environment, and opportunity for discussion with a specialist Occupational Therapist (OT).

Sensory training also needs to be available to staff (particularly those in schools), to ensure all key people in a child or young person's life can understand how best to support their sensory needs.

2.9. Mentoring

Some of the post-diagnostic support needed is not related to specific issues, but relates more to promoting understanding and wellbeing for young people. Within this, it is important that young people can access mentoring, to help them think about what they might want to achieve; and offer support and guidance around issues that are important to them. This could take different forms e.g. extra sessions of support at school, one-to-one coaching. Currently services organise around particular issues e.g. anxiety, but good post-diagnostic care should also support autistic young people to think about what autism means to them and what their goals are. It would be important for this service to be available at anytime the young person wants to access it.

2.10 Anxiety, Mood, Wellbeing and Mental Health

If home, education or leisure environments do not fit easily with neurodiverse preferences and interaction styles, it can produce immense anxiety and stress. Good mental health often stems from people feeling supported to be themselves and having opportunities to engage in the everyday activities they enjoy. Forest schools, or peer led activity groups, provide

vital support, understanding, tolerance and acceptance. This can make a profound difference to someone, enabling them to engage with the more difficult aspects of day-to-day life in a neurotypical world.

Utilising learning from the Autism in Schools project (see examples in appendix), it would benefit autistic children and young people, if all schools could demonstrate what support was being provided to encourage wellbeing, including what reasonable adjustments are being made to support anxiety and stress. A multiagency meeting with school, the young person and their family, and the diagnostic team should occur within three months of autism diagnosis, to consider how to maximise wellbeing in the school environment.

Learning to manage emotions and self-regulation is important for good mental health, but interventions offered in this area are unlikely to be successful if reasonable adjustments have not been made to the environment and interventions around mental health and wellbeing need to be considered in this light.

Child and Adolescent Mental Health Services (CAMHS) provide therapy for mental health conditions in accordance with NICE guidance and are responsible for assessing mental health risk. Therapeutic support might also be offered by other providers in the voluntary sector (e.g. 42nd Street).

As highlighted by the local paper 'Towards a Better Future: North West CAMHS independent Review' (2021), services have a significant way to go to achieve an equitable, transparent standard of care across quadrant 2 and 3 of the Thrive model in GM. The first step here is for there to be regional agreement as to what a core offer should look like at the Getting Help and Getting More Help stages of Thrive. These standards recommend that a piece of work takes place over the next twelve months, in conjunction with the GM Autism

Strategy working group on Mental Health, and with reference to documentation provided by the Operational Delivery Network, in order to clarify the CAMHS getting help offer.

Clarity is needed around when support should be provided by Mental health in Schools Teams, Thrive hubs in the community and other first line CAMH services, and when specialist CAMHS input is required. However, there remains a responsibility for any mental health provider to evidence that staff are autism-aware and able to adapt interventions to better suit the needs of autistic young people. Adapting practice to need is likely to benefit services in the longer term, as good autism practice is likely to be good practice for all. In the shorter term, mental health providers may need to identify a lead, to link in with their local Autism Strategy Group, to ensure that autism is on the agenda, in terms of staff training and adapting practice. Oliver McGowan training (see references) passed into law as mandatory training for health and social care providers in May 2022. Agencies working in partnership with the statutory sector need to demonstrate they have accessed this.

2.11. Stress and Behaviour

Some autistic young people may feel very stressed in certain environments and may communicate this through their behaviour. If they are unable to express in words what is leading to that stress, parents and carers may need support to unpick situations and consider what behaviour is really saying. Once parents understand behaviour they can think about environmental changes and what support the child needs to feel less stressed. This kind of support can be provided individually or through a group such as Riding the Rapids (RTR).

GM has funded 130 places for staff from statutory and voluntary services across GM to be trained to deliver Riding the Rapids,

which is an evidence-based, 10-week group intervention specifically for parents of autistic children. Riding the Rapids (RTR) provides peer support to parents, as well as skills in understanding behaviour, and how best to support their child or teenager. Each locality will need to provide a RTR champion and be part of the GM RTR community of practice, ensuring model fidelity and delivery of a consistent RTR offer across the region.

Families should also be able to access support around understanding behaviour prior to a formal assessment or diagnosis. Groups need to be available which help support parents to view their child's behaviour through a neurodivergent lens. Currently, there is no evidence-base for such provision, but there is emerging, innovative practice across the region, which could be shared and quality controlled as part of the development work that will need to accompany these standards.

2.12 Support from Education

Children and young people spend a large portion of their time in school, but often in settings that are designed for the neurotypical, that prove immensely stressful for those who are neurodivergent. Schools can play a crucial role in supporting children and young people's understanding of themselves and their diagnosis. Changes in staff understanding and reasonable adjustments to the environment, can make a massive difference to young autistic people.

All neurodiverse children, regardless of their diagnosis, should receive good 'Ordinarily Available Provision', i.e. the range of activities, opportunities and strategies that are offered as basic good practice to meet additional needs, without the need for a formal diagnosis or specialist support. Some areas have established an Ordinarily Available Provision document for early years and primary provision, and some are

now working on guidance for secondary provision. These standards recommend that all localities should have an Ordinarily Available Provision document, which sets out what is available to children and young people at this stage.

If a child or young person needs additional support beyond that which can be met by Ordinarily Available Provision, they qualify for Special Educational Needs (SEN) support. This means parents, the young person if appropriate, the SENCO and teacher create a structured support plan with clear targets for how the additional or different support is going to create meaningful change. This plan is put into action for a specified time period and then reviewed. This is the 'Assess-Plan-Do-Review' cycle. Some children stay on a Assess-Plan-Do-Review cycle through their educational career. Others have the Assess-Plan-Do-Review approach periodically (the process is not linear). Others move on to needing an Education Health and Care Plan (EHCP). This is called the graduated approach and is part of the SEN Code of Practice. As part of this approach, schools should seek to enrich their offer by building a team around a child and involving other professionals such as educational psychology, and speech and language therapy as needed.

All parents have a right to see their child's teacher, have a meeting with the SENCO, be involved in the creation of their child's plan, contribute to the plan and the target's being set, and be involved in the review. Parents also have a right to independent advice and can involve their local SENDIASS at any time. These are basic standards that should already be in place, based on existing legislation and are the foundations of education support in this document.

However, a large part of providing good support goes beyond the individual to a whole school approach. Training and developing a culture where schools expect to make reasonable adjustments is key.

As a guide, we are recommending all schools use learning that is being collated from the Autism in Schools project in Greater Manchester (see references for more information), alongside the recent guidance document produced by young people for Spectrum Gaming.

Autism in Schools is a transformation programme aimed at promoting whole school cultural change and understanding of autism, and was rolled out across Greater Manchester in 2021. The project has sought to build relationships and networks of support, by involving the Parent Carer Forum in schools, and providing opportunities for parents to meet together and work on the SEND policy. The project is trialling learning modules that have been rolled out on a whole school basis, and shared with parents and carers. Autism in Schools also involves autism awareness and hearing the voice of young autistic people. Schools in the project have devised a bespoke 'Understanding Myself' offer for children and young people and their peers. Discussion around understanding autism has been rolled out in whole school assemblies, classrooms and in group work. Work has been carried out to develop friendship groups specifically for autistic children and young people and for wider peer groups.

Over the next 12 months, training and the 'Understanding Me' resources should become available to all. Training also needs to encompass more than autism awareness. For SEND support to be successful, training needs to be available to staff to understand neurodivergent learning and thinking styles. The national curriculum is set by government and therefore cannot be influenced, but understanding and adapting to neurodivergent thinking styles can significantly improve autistic children and young people's understanding of the curriculum.

Independent education providers should also seek to attain the standards set out in this document. Families who are

home educating are currently unable to access resources available in educational provision, but could be connected to local parent support groups. As part of these standards, we suggest each area has a named contact in education, for those who are home educated or Not in Education, Employment and Training (NEET).

2.13 Support from Social Care

There is statutory guidance about what should be offered to families from Local Care Organisations. However, this offer is often confusing to parents and needs to be made explicit and transparent. Each autism strategy group needs to map what is available across the Thrive quadrants from social care, for all neurodivergent children and their families if this information is not already available.

Along with mental health, transparency around the social care offer and identification of gaps needs to be part of the next wave of development in terms of standards for pre-assessment and post-diagnostic care.

All staff in social care should understand autism and other neurodiversity, to enable them to make appropriate reasonable adjustments to their services. They should all have received appropriate training, be competent in accessing the young person's voice, and should have access to consultation with core CAMHS.

3. Getting more help

Services in the third Thrive quadrant reflect the need for more intensive or specialist support and are accessed by fewer young people and families with higher levels of need.

3.1. Sleep

A more personalised and bespoke individual support package around sleep needs to be offered at this point. Each locality needs to identify the provider responsible for this action and this may also involve links with short break providers to enable families to get some rest.

3.2 Bespoke Mental Health Intervention

Some young people may be unable to access universal mental health interventions, despite reasonable adjustments being made by the universal service. In this instance, there needs to be a clearly identified route to highly specialist practitioners, within CAMHS or from providers in the voluntary sector, and a clearly defined offer of what support would look like. Young people may need individual support plans which are highly bespoke.

As for section 2.11, a provision map of services needs to be developed to clarify pathways and processes for families of neurodivergent children who need a more specialist mental health service. Within this, regional services such as Deaf CAMHS would also need referencing.

3.3. Stress and Behaviour – Individual Support Plans

Some children and young people will need access to a more bespoke individualised support plan, that is agreed across agencies. Support plans, particularly for children who do not communicate with spoken language, should be multidisciplinary and multiagency, with contribution from speech and language therapists, occupational therapists, specialist nurses, clinical psychologists, social workers, school staff and other professionals as necessary. Support plans should always be person-centred, with the child and family voice held firmly at the forefront. Audit tools should be employed to ensure plans stay person centred, aim

to improve quality of life, look to adapt environments, support understanding and reduce restraint and restriction.

3.4 Sensory Support

Families who have accessed sensory workshops and still need more tailored support should have the opportunity to undergo a sensory assessment with a specialist Occupational Therapist and develop a personalised support plan.

3.5. Physical health

When the needs of the young person are such that the universal health service is unable to meet their needs, even after adjustments have been made, families should receive specialist support to access basic health care e.g. referral to a specialist dentist.

3.6 Bespoke social care support

Some children, young people and families will need bespoke support from children's social care teams. This is based on an assessment of need by social care teams, and may include short breaks provision (daytime and overnight), support to siblings, support to access alternatives to education in the community, and crisis support. As in Section 2.13, whilst there is statutory guidance about what should be offered to families, the offer is often unclear for parents and families. In collating these standards the steering group felt that further consultation needed to take place across social care to inform clear guidance for this section.

As part of a wider GM offer, families at this stage should expect to have a keyworker, who will be a single point of contact for them, and who will help to co-ordinate the services that families might need. It is envisaged that keyworkers will work with families who are graded orange on the Dynamic Support Databases. (see section 4 Risk Support below).

3.7. Support in Education

Schools and education settings are expected to have a Quality First teaching offer for all pupils, including those with SEND, as well as making full use of available resources within the local area, such as Educational Psychology, Speech and language Therapy, specialist outreach services and websites. The aim is to have a rich, multi-agency SEN Support offer, that involves the family and the young person, so that requesting a statutory assessment is only necessary when all other avenues of support have been explored.

For many children, a well coordinated Assess-Plan-Do-Review process may meet their needs for all, or for a large part of, their time in education. When a decision is made to seek more support than this, through applying for an Education, Health and Care Plan (EHCP), this decision should be taken by the team around the child, including parents, SENCO, teachers and relevant health professional. Each locality needs to be make information available to all parents about this process, including for parents who have English as a second language.

4. Risk support

The fourth Thrive quadrant relates to families who are likely to be on the Dynamic Support Registers in each locality. Dynamic Support Registers are held by the local Integrated Care System (known as Clinical Commissioning Groups until July 2022) and identify people with a learning disability or who are autistic, who display or are at risk of developing, behaviour that challenges, or who are at risk of hospital admission because of a mental health condition.

This quadrant involves intensive joint working across education, health and social care.

4.1. Intensive Support Teams

Three Intensive Support Teams (based on the Ealing Model) have been commissioned across GM. These teams will work a small number of young people who show behaviour that challenges others. They aim to use a person-centred, behaviour support framework, reduce restraint and restriction, improve quality of life, improve understanding of behaviour and keep children in their family and community.

These teams will take referrals through the Dynamic Support Registers. Their step-down procedures will depend on the strength of the response in the 'Getting More Help' quadrant, and the assurance for families and young people that there are local, appropriate services that care can be stepped down to. These teams will require separate audit and will be reviewed under the Learning Disability and Autism Operational Board for GM.

4.2. Care, Education and Treatment Review (CETR)

A CETR is a meeting about a child or young person, who has a learning disability and/or autism, and who is either at risk of being admitted to, or already admitted to, an in-patient psychiatric service. Families have a right to access a CETR, have clear information about the process, and the young person's voice and wishes should be central to this process. A CETR should produce a clear plan of support that ensures the young person receives safe, good quality care, treatment and support. The CETR has clear standards agreed by NHS England. There are links to CETR guidance in the reference section. Everyone who knows the child well or may support the child or young person in crisis should be involved in CETR planning.

4.3. Crisis Intervention Teams

Across greater Manchester, a number of new mental health crisis teams have recently been established, including:

- Rapid Response Teams (RRT): Practitioners provide 72 hours of intensive support to young people in crisis who would otherwise have to go to a hospital Emergency Department. These teams can be accessed through GP or CAMHS referral.
- Home Intensive Treatment teams (HITT): Practitioners work with young people who need ongoing intensive support, beyond the RRT offer, to help keep them in their community and prevent hospital admission.

These teams will interact with core CAMHS, but should have training and consultation with specialist autism practitioners to ensure the needs of autistic young people can be considered in crisis. These teams are all new at the time of going to press, and it is likely that the standard around their crisis care will evolve over the next 12 months. How to access these teams and their place in the mental health care pathway needs to be transparent.

Next Steps

These standards are not exhaustive. They are 'live' and will be updated every 6 months, with a comprehensive review in 2025, to assess if they are making a difference for autistic young people in Greater Manchester. It is anticipated that each area will want to map and monitor its own offer and an audit document will be produced to facilitate benchmarking.

An Autism Hub has been funded for Greater Manchester, which can support localities to map service provision and audit their pre-assessment and post-diagnostic offer. The hub can also have a role in ensuring GM is sharing resources, driving forward a shared GM website and developing communities of good practice.

Effective pre-assessment and post-diagnostic support requires vision, commitment, energy, co-production and the willingness to change and learn. However, if our aim in GM is to create a place for autistic children and their families to thrive, we need a shared commitment to what this looks like and be prepared to develop services across GM in accordance with these standards.

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On behalf of the Steering Group for the Autism
Post-diagnostic Standards for Children and Young
People

14.11.22



References

● Autism Strategy Greater Manchester

Making Greater Manchester Autism Friendly (<https://www.autismgm.org.uk/>)

● Autistic Burnout

<https://www.spectrumnews.org/news/autistic-burnout-explained/>

<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/autistic-adults>

<https://www.goodtherapy.org/blog/autistic-burnout-an-often-misunderstood-element-of-autism-080620197>

<https://theautisticadvocate.com/2018/05/an-autistic-burnout/>

● Autism in Schools Project Greater Manchester

Autism-Accelerator-Phase-1-evaluation.pdf (contact.org.uk)

<https://drive.google.com/file/d/1DMbqNV3M8xEFXiCbpSHPEd1PRA5Hdfc-/view?usp=sharing>

● Alternative and Augmentative Communication Resources

<https://acecentre.org.uk/>

● ARFID

Koomar T, Thomas TR, Pottschmidt NR, Lutter M and Michaelson JJ (2021) Estimating the Prevalence and Genetic Risk Mechanisms of ARFID in a Large Autism Cohort. *Front. Psychiatry* 12:668297.

● CETR

<https://www.england.nhs.uk/learning-disabilities/care/ctr/care-education-and-treatment-reviews/>

https://www.mencap.org.uk/sites/default/files/2018-04/2017.134%20Information%20and%20advice%20resources_Care%20and%20treatment%20reviews.pdf

● Communication

Communication Access Training

Communication Access UK – Inclusive communication for all (communication-access.co.uk)

● COVID impact

Impact of lockdown: <https://discovery.ucl.ac.uk/id/eprint/10101297/>

<https://educationendowmentfoundation.org.uk/news/new-pandemic-adversely-affected-young-childrens-development-with-fewer-reaching-expected-levels-by-the-end-of-reception-class>

● Circle of Friends

<https://inclusive-solutions.com/circles/circle-of-friends/>

● Dynamic Support Databases

<https://www.england.nhs.uk/learning-disabilities/dynamic-registers-and-dynamic-systems>

● Elklan

Elklan.co.uk

● Lego therapy

<https://www.hacerlobien.net/lego/Ter-005-Social-Skills-Asd.pdf>

● Hospital Passports

<https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>

<https://www.kentcht.nhs.uk/wp-content/uploads/2021/03/East-Kent-Hospitals-passport.pdf>

<https://www.royalfree.nhs.uk/patients-visitors/disabled-facilities/patients-with-a-learning-disability/hospital-passport/>

● Mental health Reference

Cassidy, Bradley, Shaw and Baron-Cohen (2018) Risk markers for Suicidality in Autistic Adults

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● More Than Words (Hanan Intervention Programme)

<http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx>

● NICE Guidelines

<https://www.nice.org.uk/guidance/cg128>

Overview | Autism spectrum disorder in under 19s: support and management | Guidance | NICE (<https://www.nice.org.uk/guidance/cg170>)

NICE Quality Standard 5 (<https://www.nice.org.uk/guidance/qs51>)

● Oliver McGowan Training

<https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism>

● One Page Profiles

Example can be found here: <https://www.manchesterlco.org/about-me-templates>

● PACT

PACT Training - Accredited Training Course for Professionals (<https://www.pacttraining.co.uk>)

Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., le Couteur, A, Leadbitter, K., Hudry, K., Byford, S., Barrett, B., temple, K., MacDonald, W., Pickles, A. 'Parent mediated communication focused treatment in children with autism (PACT): a randomised controlled trial The Lancet, vol 375, Issue 9732, 19-25 June, pp 2152-2160

● PECS

<https://pecs-unitedkingdom.com>

● PODD Books (Pragmatic Organisation Dynamic Display)

<https://novitatech.com.au/podd-communication-books/>

● Positive Behaviour Support

Positive Behaviour Support (PBS) | Bild (<https://www.bild.org.uk/positive-behaviour-support-pbs/>)

Nick Gore

● Post-diagnostic Support – REACH

REACH-ASD | The University of Manchester (<https://sites.manchester.ac.uk/reach-asd/>)

● Riding the Rapids

Riding the Rapids www.encompasspsychology.co.uk

Stuttard, L; Beresford, B.A; Clarke, S.E.; Beecham, J, Todd.S and Bromley, J. 'Riding the Rapids: living with autism or disability - an evaluation of a parenting support intervention for disabled children.' Research and Developmental Disabilities, Vol 35, No 10, 2014, p2371-2383.

● Spectrum Gaming, Autism, Forest Schools

Andy's talks about autism can be found in full here: <https://www.spectrumgaming.net/training-consultancy>

Forest Schools Forest School and Autism: What works for us (<https://www.youtube.com/watch?v=OV3VzuYzdKQ&feature=youtu.be>)

● Spoon Theory

<https://musingsofanaspie.com/tag/spoons/>

● Video Interactive Guidance

<https://www.videointeractionguidance.net/>

● Wellcomm

<https://www.gi-assessment.co.uk/assessments/products/wellcomm/>

Appendix: Examples of Good Practice from across Greater Manchester

This list is not exhaustive but is designed to share ideas across localities.

Bolton Girls Group

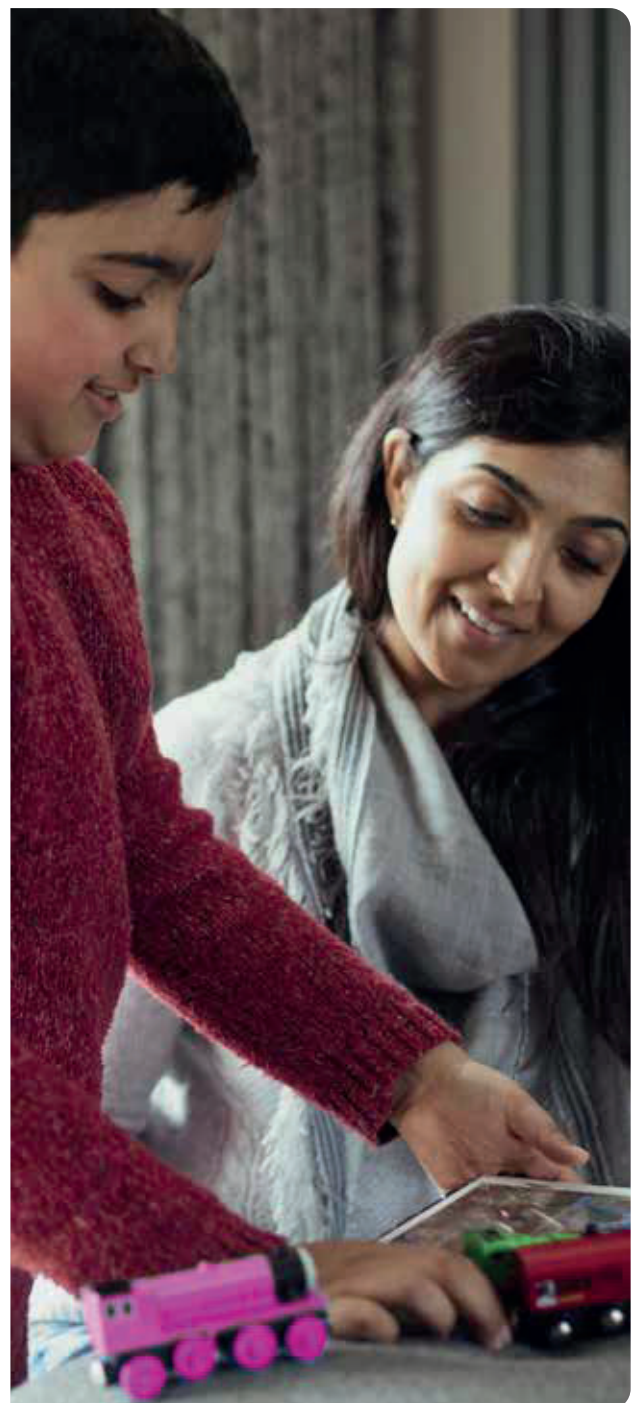
Contact: Jenny Wilkinson
jenny.wilkinson5@nhs.net

Bolton have a small task and finish group, addressing the under-identification of autism in girls. Membership of the group includes parents, carers, young people, teachers, specialist teachers, and the designated clinical officer for SEND, and is led by Educational Psychology staff. The group are developing a co-produced resource for settings that covers recognition, social communication and interaction differences in the classroom, support and resources, with case studies and lived experience from young people themselves. The guide aims to ensure practitioners have the knowledge and understanding to spot masking behaviours, and offers support to young people in helping them understand their diagnosis.

Wigan Drop In Sessions

Contact: Lorraine Price
lorraine.price12@nhs.net

Wigan provide monthly drop-in sessions for any parent whose child is on their pathway, providing an opportunity for signposting, dealing with immediate queries regarding support and giving parents an opportunity to meet other parents in the same situation. Drop-ins contain representatives from the SEND team, Parent Carer Forum, CAMHS, Speech and Language therapy and the Early Years team.



Stockport Webinars

Contact: Cheryl Knupfer
cheryl.knupfer@stockport.gov.uk

Stockport contacted over 300 families and asked them what issues they were currently facing and then arranged guest speakers to put on live webinars to address the areas of concern. All the webinars were recorded and are available to parents/carers via the PACTS Website. Additional training has been created on Positive Behaviour Support (PBS), Sensory processing (OT (Occupational Therapy)) and restricted diets. Seminars are open to all families in GM.

Bury PACT offer

Contact: Jane Case
j.case@nhs.net

Bury has introduced PACT into service over the last year. Providing... feedback from parents has been particularly positive with comments such as this..

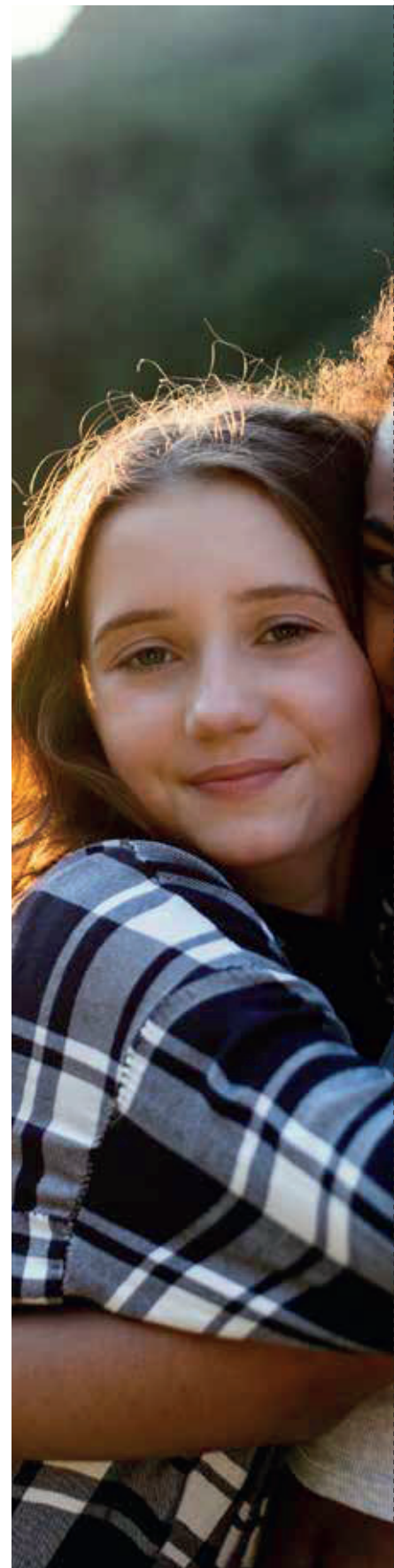
"I honestly cannot believe the difference it has made to all of us, and most importantly (my son). Even after just one session followed by the dissection, I could alter the way I communicate with my child for the better. It is a game changer, I now know from the sessions we have had (he) does not tolerate verbal communication whilst playing/learning, he likes to initiate play, he likes to bring me into his world as and when he needs to, he likes to hold control and take the lead, I'm in awe of this programme and the way you have delivered it, it's genius!"

Bury Sensory Support Offer

Contact: Rehabilitation for Independence
info@rfisupport.co.uk

Rehabilitation for Independence use a graduated framework and apply an educational approach through the facilitation of sensory training workshops for parents, the education workforce, and others supporting children in the Bury locality. Sensory training workshops support understanding of how our senses process information, early identification of possible sensory challenges, suggestions of reasonable adjustments that can be made in the home and school environments, and provide opportunity for discussion with a specialist Occupational Therapist.

Following attendance at a sensory workshop, parents have a triage meeting with a Occupational Therapist. During triage discussions specialist sensory advice is provided, and sensory strategies are discussed with parents. Actions may involve signposting to other services or recommendation for full sensory assessment. This is followed by provision of a detailed sensory report and individualised sensory diet/ activity program. If applicable a sensory feeding program may also be provided.





Forest School in GM

Contact: Andy Smith
andy@spectrumgaming.net

Spectrum Gaming has been running a forest school for autistic young people for over 2 years, and young people have reported huge benefits to the sessions. By following the forest school ethos, in addition to giving young people opportunities to connect with nature (which in itself is positive for wellbeing), young people report having an increase in sense of self and feelings of acceptance. If a forest school is setup in the right way, it offers a variety of ways to interact with the woods, making it easier for autistic young people to meet their sensory needs. Rather than thinking something is wrong with them, autistic young people can start to realise that it isn't their brain that is the issue, but an unsuitable environment. Learning this is massively empowering for young people. Forest school also has a balance of power which means learners are viewed as equal partners.

"It's impossible to put into words the impact that forest school has. Meeting other kids and feeling part of something great has had a massive impact. I would say that without forest school my son would be so isolated and misunderstood he is learning to accept himself for who he is and to be proud - I'm so grateful to all of the members including the kids at forest school."

Manchester/GM Riding the Rapids

Contact: Samantha Todd
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Riding the Rapids is a ten-week intervention for parents and carers to help them understand and support the behaviour their child shows when they are stressed or unhappy. The group ensures that parents meet other families in the 'same boat' and think about what the function of children's behaviour might be; what need the behaviour is meeting; and how that need can be met a different way. The course looks at tools for unpicking behaviour that seems to occur 'out of the blue' and helps families reflect on how that behaviour is helping their child. Through the weeks parents are encouraged to look through a lens of neurodiversity to learn how the environment can change to support the young person more effectively; what skills the young person might need to learn to help them cope better; what supports communication between the young person and their family and how to fit in more enjoyable activities together. Families also are encouraged to think about their own wellbeing and are given skills to take on their journey with them. There is Riding the Rapids for parents of primary age children and one for parents of teenagers. The teenage groups pick up issues related to independence, puberty and managing social media.

What parents say about the group: "This course helped me to understand the children's behaviours and to communicate with them effectively. Most importantly I learned to take good care of myself in order to look after my children and the family." "The whole course has been amazing, especially I have found the understanding behaviour really useful and how to cope and manage stress really helpful"

Stockport – Team Around the School

Contact: Cheryl Knupfer

cheryl.knupfer@stockport.gov.uk

Stockport have created a service that form a 'team around the school' to help staff support neurodiverse children who may need further assessment.

'It has been invaluable having (worker) from the new Pre-diagnostic ASD team come in and offer support for one of our complex children on the ASD pathway. It has meant we are getting more specialist support sooner and not waiting for a diagnosis. Jess has been into school and home which has meant she has formed a relationship with the child based upon all areas of the child's life. Having her knowledge of Autism and her perspective of what is needed to improve the situation in school has made a great difference in the provision we are providing for this child. In the time we have been working with her we have seen great steps of progress forward for this child. As a SENDCo it has also meant I can seek advice quickly on moving the situation forward. I believe this level of support has been exactly what we have needed at this moment of time, and I look forward to continuing to work with (worker) whilst we progress the provision for this boy even further.

Tameside Training on Neurodiversity

Contact: Philippa Robinson

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'An Introduction to Neurodiversity' Training delivered by Starling has been attended by 167 local professionals, including schools, voluntary sector organisations and local council workers such as Early Help and Edge of Care teams. All attendees made a pledge to make Tameside a neurodiversity-friendly Borough, for example:

'As part of my role I pledge to support schools to share best practice around neuro-inclusivity and to develop more neuro-inclusive schools and settings. As a service I pledge to consider neuro-inclusivity in recruitment and working practices and systems'

Following the training, 89% increased their knowledge and understanding of neurodiversity 86% ; increased their knowledge and understanding of neuro-inclusive practice and 83% felt more able to adapt their work to better include neurodivergent individuals

Autism in Schools Project Greater Manchester

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Autism in Schools Project was built on the work and learning from the North Cumbria and North East Accelerator Schools Autism Project. The Accelerator project aimed to reduce inappropriate educational exclusions and hospital admissions for children and young people with learning disabilities, autism spectrum conditions (ASCs) and/or challenging behaviour.

Autism-Accelerator-Phase-1-evaluation.pdf (contact.org.uk)



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