

Report of the Autism Task and Finish Group (TFG) to the Overview & Scrutiny Committee (OSC) on 29th April 2025

Findings and Recommendations of Barnsley OSC's Autism TFG

1.0 INTRODUCTION

- 1.1 As part of their work programme, the Overview & Scrutiny Committee conduct three separate task and finish groups during the autumn to allow for a more-in depth investigation into topics that have been identified by elected members as facing particular challenges or warranting more robust scrutiny.
- 1.2 For 2024/25 the three Task and Finish Groups established by the committee were:-
- Autism (All Age)
 - Barnsley Carers (All Age)
 - Barnsley Council's Great Childhoods Ambition
- 1.3 This report provides a high-level summary, and outlines the key findings, conclusions and recommendations of the Autism Task and Finish Group. References to other neurodevelopmental conditions are made throughout the report due to their intersections with autism, and reflect discussions held during the group's meetings.
- 1.4 It is worth acknowledging that, there is significant correlation between the three task and finish groups of the OSC as effective pathways and support for those with autism and for Young Carers enable those cohorts of children and young people to thrive.
- 1.5 The members that took part in the TFG were:-
- Cllrs Will Fielding (TFG Lead Member), Roy Bowser, Steve Green, Janine Moyes, Deborah Pearson, Mick Stowe and the Committee's Primary School Parent Governor Representative, Liz Iles. The group also invited Tracey Hughes from Healthwatch Barnsley to participate as a special advisor given her knowledge of working in the community.
- 1.6 Over the course of the investigation, the group met with key officers (witnesses) from NHS South Yorkshire Integrated Care Board (SYICB) (Barnsley Place), South West Yorkshire Partnership NHS Foundation Trust (SWYPFT), Barnsley Hospital NHS Foundation Trust (BHNFT), Barnardo's, the Probation Service, Barnsley Council's Special Educational Needs & Disabilities (SEND) and Inclusion Service, Early Start, Prevention & Sufficiency Service, Youth Justice Service, Employment & Skills Service, and Adult's Commissioning, who provided expert advice and guidance. Written evidence was also utilised from young people via the Youth Voice & Participation Team.
- 1.7 The TFG also visited the Central Family Hub along with members of the Great Childhoods Ambition TFG to see what the early help offer looks like in practice for our children, young people and families.
- 1.8 The group would like to take this opportunity to give thanks to all officers who engaged with the process and provided information to support their investigation. Additionally, the group would like to give special thanks to the service users and Autism Strategy Stakeholder Group representatives who participated in the series of meetings and provided valuable insight.



2.0 BACKGROUND

- 2.1 Members had become aware of the increasing prevalence of people being diagnosed with autism in Barnsley, as well as those awaiting support from relevant services. Members were keen to better understand what local services are available in terms of diagnosis, as well as support for those with autism.
- 2.2 The group became aware of recent work to develop a local All-Age Autism Strategy for Barnsley and were keen to provide 'critical friend' challenge and oversight of this work to ensure it is robust in terms of improving outcomes for local people and making sure that the service-user voice is heard.
- 2.3 As defined by the National Autistic Society (NAS), 'autism is a lifelong developmental disability that affects how people communicate and interact with the world'. However, it is important to note that not all autistic people see themselves as disabled. The NAS highlight that 'autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses'.
- 2.4 The National Strategy for Autistic Children, Young People and Adults 2021-26 was published in July 2021. Since 2023, local organisations have been working together, undertaking public involvement, to gain views, experiences and feedback into the development of an All-Age Autism Strategy for Barnsley. The following six key themes have been highlighted as those that would have a significant impact on people with autism's lives and are reflected in both the national and local strategies:
- Theme 1: Improving understanding and acceptance of autism within society.
 - Theme 2: Improving autistic children and young people's access to education and supporting positive transitions into adulthood.
 - Theme 3: Supporting more autistic people into employment.
 - Theme 4: Tackling health and care inequalities for autistic people.
 - Theme 5: Building the right support in the community and supporting people in inpatient care.
 - Theme 6: Improving support within the criminal and youth justice systems.

3.0 SCOPE OF THE INVESTIGATION

- 3.1 Initially, the group met to discuss the scope of the investigation. This included TFG members outlining their key concerns including the perceived lack of support services, waiting times to access services and the complexities involved in navigating them. From the brief discussions held with officers outlining the work undertaken on autism in Barnsley, and the key themes in the strategy, the group acknowledged the complexities involved in each theme area.
- 3.2 Although some group members had direct knowledge and experience of autism and various services, as with theme 1, the group were keen to address their own contribution to improving understanding and acceptance of autism within society. As part of this, they agreed to hold a

series of meetings to get a high-level overview of each key area and to hear from those with lived experience of autism. This would give the group opportunity to provide 'check and challenge' sessions with officers and partners on the work being carried, to ensure that service user voices were being heard in the design and delivery of services, as well as having opportunity to make links and recommendations regarding the various elements.

4.0 FINDINGS FROM THE INVESTIGATION

Theme 1: Improving understanding and acceptance of autism within society

- 4.1 The officers talked through the development of the Barnsley All Age Autism Strategy 2024-2030, highlighting the coproduction with stakeholders including young people with autism, parents, carers, and professionals from health, education and the voluntary sector. The TFG were reassured that stakeholder involvement is being pursued on an ongoing basis as the strategy is finalised and resultant action plans are developed.



- 4.2 The group discussed how there is widespread awareness about autism, but a lack of understanding, which is what individuals with autism want others to improve upon, including professionals and the general population. Training and awareness-raising initiatives are central to this effort, aiming to provide more opportunities for people to learn, understand, and share experiences. The strategy highlights the intersectionality of autism with other conditions such as Attention Deficit Hyperactivity Disorder (ADHD), acknowledging the need for a holistic approach to support and understanding. It was also noted that it is essential to ensure that people who receive a diagnosis, as well as their carers, understand what it means, as feedback indicates that this is not always the case. Additionally, some individuals welcome the diagnosis, while others do not want that label; therefore, it is important not to assume that everyone is the same.
- 4.3 A key challenge highlighted in the strategy and discussed by the group is the need for data collection to better help understand the prevalence of autism in Barnsley and to inform future planning and support services. Current figures regarding the number of people with autism in Barnsley is based on percentage estimates of the population. Work is underway with GPs, so that those with autism are acknowledged on systems, so that, eventually, as is done for those with a Learning Disability (LD), individuals can be offered annual health checks, receive targeted information and advice, and reasonable adjustments for accessing services can be considered.

Theme 2: Improving autistic children and young people's access to education and supporting positive transitions into adulthood

- 4.4 The Draft Autism Strategy for Barnsley highlights the increasing number of children and young people receiving an autism diagnosis in Barnsley and the challenges they face in education settings and transitions. This is reflective of the national picture, alongside the

current enquiry by the Commons Education Select Committee into 'finding solutions to the crisis in SEND provision'. Despite the challenges, officers outlined commitments to work closely with education providers, support schools to be autism-friendly, reduce barriers to school attendance, and ensure opportunities for autistic children and young people to be educated within their local community.

- 4.5 Officers outlined the SEND Code of Practice which defines the support provided to children and young people with neurodiverse presentations, including those with autism, and speech, language, and communication needs. The importance of early intervention and the role of schools in providing support for children with autism was highlighted, alongside the need for a coordinated approach to support, involving various stakeholders such as health professionals, educators, and parents/carers. Officers outlined the variety of training available to all schools in Barnsley, including the Barnsley Autism Friendly Schools (BAFS) initiative, which aims to develop whole-school understanding and support for children with autism and other additional needs. Additionally, support available for parents and carers, including training programs and resources to help them understand and support their children with autism, was also discussed.
- 4.6 The group acknowledged the challenges faced, including that children's needs change, and that what works in one term, may not work in another. Similarly, that challenges can arise at key transitions, such as from primary to secondary school, and into adulthood. Also, that there are long waiting times for autism diagnosis. The group noted the various processes in place regarding support for those with additional needs and awaiting diagnosis but were keen to ensure that support and interventions are applied consistently, given that feedback from young people suggested that this was not always the case. Members were surprised by the number of services available; however, highlighted that there was a lack of knowledge of these amongst communities, and that they welcomed work being undertaken with stakeholders to address this.

Theme 3: Supporting more autistic people into employment

- 4.7 Both locally and nationally it is evident that there is an employment gap for autistic people. There are several reasons for this including recruitment processes not being autism-friendly or people experiencing difficulty accessing the support they might need to get into and stay in work. The key commitments in Barnsley's Draft Autism Strategy are to improve knowledge, understanding, and awareness of autism across the workforce by increasing training and support for employers to implement inclusive practices. Also, to ensure autistic people know how to access employment services and understand the support available to obtain and maintain employment.
- 4.8 In addressing the challenges, officers outlined the Council's commitment to developing an inclusive economic growth strategy which aims to support young people and the wider adult population in getting ready for, entering, and progressing in work. As part of this, specific support for those with autism and other additional needs, includes Council collaborations with various services and employers to create work placements, work experience, internships, and ring-fenced apprenticeships. The offer is deliberately broad to ensure it is inclusive, providing opportunities for residents to gain further qualifications, receive pastoral support, and help participants gain work experience in a safe and secure environment, preparing them for full-time employment. The group acknowledged that there may be many middle-aged adults with autism and/or other neurodiversity which hasn't been recognised when they were younger but has created a barrier for them to access and remain in employment.
- 4.9 Having heard from those with lived experience of autism who had accessed these services, the TFG highlighted the importance of capturing their positive stories and utilising them to encourage others to take-up these opportunities. Officers recognised the need to strengthen

links with the Voluntary and Community Sector (VCS) as well as other businesses. The group discussed the importance of organisations involved sharing good practice, particularly to support smaller businesses who may have limited capacity to develop specific resources, such as employment policies. Similarly, the group were keen for officers to explore what support is in place for those with autism who want to start their own business.

Theme 4: Tackling health and care inequalities for autistic people

- 4.10 Engagement work has highlighted that autistic individuals and their carers often face difficulties accessing health services and making informed choices about their care, which leads to health inequalities for people with autism. Officers outlined how there has been a significant increase in the number of young people waiting for autism assessments in Barnsley, which has resulted in growing waiting lists. This reflects the national picture and challenges with diagnosis for other neurodiverse conditions, such as ADHD. An area of good practice is the Adult Autism Pathway which is operating in line with national standards.
- 4.11 Based on feedback from various stakeholders, the TFG were keen to emphasise the importance of early diagnosis. Officers and clinicians highlighted the work being done to address the children and young people's pathway, including bringing stakeholders together from various departments to look at what can be done. Work is underway to develop a comprehensive offer of support to those awaiting diagnosis and to help support people from the point their needs are identified, such as in schools. Some services are not autism specific but are aimed at providing support to challenges commonly associated with autism, such as help with sleep, diet and communication. The group highlighted the difficulties for parents/carers in navigating these services and were advised that a stakeholder group, including service users and carers, were currently focusing on designing an accessible 'Offer While You Wait' in support of this. The importance of post-diagnostic support was also noted, so that those diagnosed with autism of all ages, as well as their parents/carers understand what it means, and what support should subsequently be put in place, whether this be in for example, school or the workplace.
- 4.12 The challenging resource envelope for delivering services was discussed. This not only included finances, but acknowledged workforce shortages, with local services all recruiting from the same, small group of professionals. Officers highlighted the work being done as a region to recruit professionals, including making roles attractive, with the opportunity to move around regional services, thereby creating development opportunities. Officers also discussed the work being undertaken to explore having a Multi-Disciplinary Team (MDT) diagnosis for children and young people, which would look at all neurodiverse conditions, such as autism and ADHD, in one assessment. The TFG were particularly keen on this approach being considered to support pathways being easier to navigate and to avoid service users waiting for one diagnosis, only to find that they need to be considered for other conditions, particularly given the links with autism and other neurodiversity.
- 4.13 In terms of tackling health and care inequalities for autistic people, the importance of all health and care staff being trained in neurodiversity was highlighted. In particular, the need for neuro-informed practitioners within mental health services, to ensure that effective support can be provided to meet presenting needs. It was noted that elements of this needed to be addressed nationally, such as ensuring those on medical courses at university are given sufficient education and training on neurodiversity. However, work was being done in local settings to upskill staff and develop relevant policies where possible. Barnsley Hospital highlighted some initiatives they'd put in place including having an 'Autism Reality Experience' which overloads the senses to help staff have a better understanding of the challenges for those with autism. Also, launching an 'emergency care bag' which contains a range of sensory tools and equipment, and activities to support people to access emergency care services.

Theme 5: Building the right support in the community and supporting people in inpatient care

- 4.14 As recognised in both the local and national autism strategies, it is essential that relevant support is in communities, including health, social care, mental health, housing support and community support services. The group met with officers responsible for commissioning specialist housing support for people with an LD and/or autism. This offer includes a variety of options such as purpose-built provision, supported living, or support for someone to remain in their own home. Officers outlined the work involved to identify needs, both currently, as well as forecasting for the future based on population data. Engagement is undertaken with local providers, so that work is done collaboratively to address needs, to ensure there is appropriate market shaping and planning of provision.
- 4.15 Officers gave examples of local provision, including housing to support people with LD and/or autism, where they stay in supported accommodation to gain skills for living in their own home and are then supported to move on. This includes helping them to find housing in the right location for them, such as near family. Specialist Residential Care is subject to Care Quality Commission (CQC) inspections, and where possible the Council will place people close to home. However, there are occasions where the appropriate accommodation is not available in the local area, or a court order may be in place which dictates the location of the placement. Legislation is now in place which requires local authorities to publish a 'Supported Housing Strategy' and work is underway to develop relevant local delivery plans.
- 4.16 As part of this investigation, the TFG undertook a visit to Barnsley's Central Family Hub. Family hubs are located across the Borough and deliver joined-up early help services for children from pre-birth up to 19 years (or 25 years if the young person has a disability). They bring together practitioners from a range of universal, targeted and specialist services in each local area, including schools, police, social care, private and voluntary sector and some adult services. TFG members were impressed by the range of services available, including Early Help Navigators to support families identify needs and get support in place, as well as the sensory space for SEND children. The group acknowledged the high-level of need and the challenge for services to meet increasing demands and complex needs in communities. It was evident that there was a strong service offer for families with young children, however support needed to be strengthened for older children. In terms of provision of services in the community, these not only need to recognise the needs of those with autism, but also the provision of support for their parents and carers.

Theme 6: Improving support within the criminal and youth justice systems

- 4.17 Both the local and national autism strategies recognise that improvements need to be made in the experiences of autistic people who come into contact with the criminal justice system. Data shows that people with autism are significantly overrepresented in the criminal justice system. Therefore, it is essential that initiatives to improve the understanding and early diagnosis of autism within the criminal justice system are progressed.
- 4.18 Officers outlined the work being done in Barnsley as part of the Youth Justice Service (YJS), which includes a diverse group of professionals such as nurses, education workers, speech and language therapists, and Child and Adolescent Mental Health Service (CAMHS) workers. Barnsley YJS officers have undergone specialist autism training and are utilising this in their working practices. Alongside service users, the team are developing a one-page profile for children in the service, which includes information on what the child needs from the service, what the service can expect from them, what their triggers are, and how they present during a crisis. The service has also introduced an accessible leaflet that explains the roles of all specialists in the service and are working with educational psychologists to develop a support package for parents and young people with neurodiverse needs to help them understand what their diagnosis means. The YJS is mindful of how important parents/carers are on the

journey of a young person with neurodiverse needs and how by bringing them together, they can support each other with developing skills to be effective advocates for their young person.

- 4.19 Officers from Barnsley YJS and Probation highlighted regional collaborations with various partners including South Yorkshire Police (SYP), the Crown Prosecution Service (CPS), and South Yorkshire Mayoral Combined Authority (SYMCA). Work has included mapping out the various services, with the aim of reviewing documentation to make it more accessible for people with additional needs following feedback. The importance of all those coming into contact with people in the criminal and youth justice system to have neurodiversity training was discussed, as well as the need for effective transitions from young people's to adults' services.

5.0 CONCLUSION & RECOMMENDATIONS

- 5.1 Throughout the investigation, it was evident that capacity in services, both in terms of staff and other resources is challenging. Often, it is the same officers who are responsible for numerous key priorities due to the nature of their work. Whilst recognising there is lots of evidence of good practice and plans in place to tackle the challenges, the TFG have made a number of recommendations to support continual improvement with a view to achieving local priorities and improving outcomes for the residents of Barnsley. In support of this, members would like to highlight the following:

5.2 **Recommendation 1 – Hold an All-Member Information Briefing (AMIB) to provide Elected Members with improved understanding of autism**

As highlighted in the findings, it is important that understanding and acceptance of autism in society is improved. By Members being upskilled, this will help them to think about how we can make Barnsley a more autism-friendly town, and where reasonable adjustments could be made in communities to support those with autism and their carers. Members are engaged in their local communities, including some of them being school governors, and can therefore utilise their knowledge to encourage others to uptake training, make considerations for those with autism and their families, as well as signpost to support services.

5.3 **Recommendation 2 - An Elected Member from the TFG becomes part of the Autism Strategy Stakeholder Group**

Linked with the previous recommendation, having an Elected Member on the group will assist with keeping Elected Members upto date on the work surrounding autism, as well as provide opportunity for them to contribute to delivery plans, utilising their knowledge of communities and Council functions.

5.4 **Recommendation 3 – The term 'neurodiversity' be specified on the Council's Equality Impact Assessment (EIA) Template**

The Council is required to make reasonable adjustments to accommodate employees and members of the public with disabilities including those who are neurodivergent. This helps to ensure that all the Council does is accessible to and meets the needs of all residents and that no one is likely to be significantly disadvantaged. A number of specific considerations are highlighted; however, given the increasing prevalence of neurodiversity amongst the population, the TFG feel this should be specifically shown as a prompt when completing an assessment. The group would also encourage other organisations to take this same action where this is not in place.

5.5 **Recommendation 4 – Work is progressed to ensure that communication regarding available support services is improved**

Both amongst those who responded to the autism strategy consultation and TFG members, there is a perceived lack of support services for people with autism, including those awaiting diagnosis and others seeking early help. The group are aware that work is underway to map

available support services, and it is hoped that this will improve the current position. The group are keen for positive experiences in accessing various services is utilised to encourage others to engage with them. Also, to ensure that existing schemes such as Safe Spaces, resources in libraries including sensory toys, and accessible cultural activities are promoted to people with autism and their families, utilising existing communication channels such as the Local Offer and Area Council/Ward Alliance social media pages etc.

5.6 Recommendation 5 – Utilise existing autism/neurodiversity policies from various organisations to share with others

The group are keen for best practice and resources to be shared amongst local organisations, particularly for those who may not have capacity to create their own. It would be helpful for employers to share good practice on how they've made reasonable adjustments in their employment practices, such as during recruitment and supporting their employees with neurodiversity.

5.7 Recommendation 6 – Work is undertaken by Enterprising Barnsley to consider specific support for people with autism and/or neurodiversity wanting to start their own business

In discussing employment options, the TFG highlighted the benefits of people with autism owning their own business, so they have flexibility in their work, which meets their individual needs and utilises their strengths. This could include providing information on specialist grants or support they may be able to access.

5.8 Recommendation 7 – Work is progressed by SYICB alongside clinicians and evidence-based practice to explore having an MDT diagnosis approach for all neurodiversity in one assessment

Given both personal experiences in the group, as well as hearing from constituents and other stakeholders, the group are keen for this option to be explored. Having noted the challenges people face in navigating various pathways, it was felt that this would help improve this, as well as remove the frustration of getting an assessment completed, only to find there are others needed. It is also hoped that this approach will enable appropriate support to be put in place in a timelier way, as it will address all the presenting needs, rather than treating them in isolation.

5.9 Recommendation 8 – Support for parents and carers for those with autism is featured in Barnsley's Autism Strategy

The group are mindful that often, for those with autism to thrive, there are parents and carers alongside them who provide essential support, including navigating services and advocating for them. This can be a challenging role which can lead to parents and carers having their own support needs. The group are pleased that parents and carers are part of the autism stakeholder group, so can ensure that their voice is heard. However, are keen for officers focusing on the autism strategy to be linked with those responsible for supporting carers.

5.10 Recommendation 9 – A visit is arranged for OSC members to Barnsley Youth Justice Service

During discussions, the group were impressed at how considerations for those with autism and other neurodiverse conditions was being embedded into working practices. The group were keen to learn from this good practice and also learn more about the services delivered in this specialist area of Children's Services.

5.11 Recommendation 10 – The OSC considers autism as a topic on the work programme in 2 years' time, once the strategy is finalised and action plans are progressing

The group are keen to ensure that Members receive an update and provide critical friend challenge of work as it progresses to ensure it is meeting the needs of local communities.

5.12 The group is aware that the Member of Parliament (MP) for Penistone and Stocksbridge, Marie Tidball, is the Chair of the All-Party Parliamentary Group (APPG) on Autism. The TFG will write to her to make her aware of this report and welcome any knowledge and expertise she can share with local officers as a result of her role, to assist in progressing this work and improving public services for autistic people.

6.0 NEXT STEPS

6.1 This report is presented to the Committee for discussion and approval. Once approved by the Committee:-

- the Task and Finish Group Leads and the Chair of the Committee will present the report to Cabinet (for information only unless any recommendations are subject to a key decision).
- Scrutiny Officers will work with lead officers to provide an appropriate response report within the guidelines and timescales of the Terms of Reference for the Committee and the Council's Constitution. The response reports will be added to the work programme of the Committee at the most appropriate time.

6.2 It should be noted that although there are no direct implications from this report; in preparing the response, the appropriate officers/services should fully assess and identify any implications relating to legal, finance, risk, equality, communications and employees that may impact the service as a result of the recommendations made by the committee.

7.0 GLOSSARY

ADHD	Attention Deficit Hyperactivity Disorder
AMIB	All-Member Information Briefing
BAFS	Barnsley Autism Friendly Schools
BHNFT	Barnsley Hospital NHS Foundation Trust
CAMHS	Child and Adolescent Mental Health Service
CQC	Care Quality Commission
CPS	Crown Prosecution Service
EIA	Equality Impact Assessment
LD	Learning Disability
MDT	Multi-Disciplinary Team
MP	Member of Parliament
NAS	National Autistic Society
OSC	Overview and Scrutiny Committee
SEND	Special Educational Needs & Disabilities
SWYPFT	South West Yorkshire Partnership NHS Foundation Trust
SYICB	South Yorkshire Integrated Care Board
SYMCA	South Yorkshire Mayoral Combined Authority
SYP	South Yorkshire Police
TFG	Task and Finish Group
VCS	Voluntary & Community Sector
YJS	Youth Justice Service

8.0 BACKGROUND PAPERS

- Barnsley Draft All-Age Autism Strategy 2024-2030:
https://syics.co.uk/application/files/4917/2719/1435/Barnsley_Draft_Autism_Strategy_2024_FINAL.pdf
- SYICB: Developing an All-Age Autism Strategy for Barnsley:

<https://southyorkshire.icb.nhs.uk/get-involved/open-time-limited-opportunities-get-involved/developing-all-age-autism-strategy-barnsley>

- The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026: <https://assets.publishing.service.gov.uk/media/60f72556e90e0764c6eb39f5/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf>
- National Autistic Society Website: <https://www.autism.org.uk/>

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Date: 16 April 2025