

Tîm Niwrowahaniaeth Cenedlaethol

National Neurodivergence Team

# Annual Report 2023/4

"Keep delivering, keep educating people to give autistic people the best possible chance of having a good experience when engaging with services."

> "It's been a pleasure working with the National Neurodivergence Team over the past year. The team is very knowledgeable, and we've had some great feedback from our assessors on the awareness sessions held and CPD modules created. We hope to continue working together in the future to improve our process as much as we can."

We thoroughly enjoy working in partnership with the Team. They have provided our team with online training which has helped staff to become more confident and Autism aware.





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### Introduction

Our thanks to Welsh Government for the continued core funding and support, and for the WLGA for support and guidance.

2023-24 saw the team expand their role and become focused on neurodivergence. This aligned to the work of Welsh Government and reflected the growing commitment to the whole ND community. As is often said by the National Neurodivergence Team – the move was very much an evolution rather than a revolution. The expansion built on the firm foundations of the work around autism and actually, the team had also been focusing on cooccurring and related conditions for a number of years. Sadly, we lost Bethan Gilson in November 2023 from the team who secured an excellent job in Welsh Government. On a more positive note, we were fortunate that Ben Ewart-Dean joined the team in September 2023 and has really made a significant difference to the team's parent carer offer.

As you will see the team has continued to develop and deliver a range of varied and robust pieces of work and our annual report outlines key elements that show the broad depth of our work. We hope you find the report informative and of interest. There remains much to be done for neurodivergent people and their families but there is also much to be celebrated.

In addition, as in previous years, virtual working has enabled us to further develop our coproduction. We established effective and diverse advisory groups to help shape and inform our work. Thank you to all those who have been involved – your input has been invaluable. Working together with the neurodivergent community, professionals and other colleagues has ensured that whatever we do is useful and makes a difference to the lives of neurodivergent people and their families in Wales.

The National Neurodivergence Team

### Chapter 1: Collaborative Working

### Working with the Neurodivergent Community:

The aim of The National Neurodivergence Team is "to help improve the lives of Neurodivergent people in Wales" and co-production is fundamental to the work. Neurodivergent people are at the heart of all working groups, shaping all work, resources, training and events.

The team has continued to work closely with advisory groups of neurodivergent people, to ensure the neurodivergent community are engaged in an accessible and meaningful way.

As a principle, the team values the contribution of neurodivergent people, recognising the time, energy, expertise and commitment they give to projects. Alongside the advisory groups, the team has produced a third e-learning module: Understanding Assessment & Autism, which sits alongside the previous 2 e-learning modules: Understanding Autism and Understanding Effective Communication & Autism. The team has also co-produced a series of advice sheets for autistic adults. The communities of practice also have key neurodivergent contributors to ensure that the experience of neurodivergent people helps shape and inform professional practice, knowledge and understanding.

A new Neurodivergent Parents and Carers Advisory Group was also established with the first meeting taking place in January 2024. This was set up to hear the voice of neurodivergent parents and carers in Wales.

To mark the move from Autism to Neurodivergence, the team created an ADHD lived experience Advisory Group, which held its inaugural meeting in June 2023, and a new Task & Finish group was also established to explore the creation of ADHD specific resources.

### Local Authority Autism Leads:

The team works closely with the National Autism Leads in all 22 Local Authorities across Wales. The team has continued to facilitate the quarterly National Autism Leads network meetings virtually, as well as quarterly regional meetings for North Wales Leads and South Wales Leads.

The National Autism Leads continued to disseminate information from the team locally and played a key role in informing national policy and guidance through local networks. Regular meetings have facilitated the sharing of good practice amongst National Autism Leads.

The National Autism Leads also played a key role in the rollout of the Code of Practice as well as promoting the autism e-learning modules: Understanding Autism & Understanding Effective Communication and Autism with their networks.

#### **Steering Groups:**

A key part of the team's work is to ensure that stakeholders are aware of the work of the team and that they know about the resources we have to support them, whether they are from Health, Social Care, Education or are neurodivergent people and their families.

To ensure our resources are meeting the needs of our stakeholders, it is important for us to listen, gathering data on what resources or training may be useful, whilst also identifying challenges and barriers.

Our team has continued to work collaboratively across Wales this year with neurodivergent people, Health Boards, Local Authorities, 3rd sector, public and private organisations, including membership on a number of steering and strategic groups. We also attend a variety of in person events to highlight the work we do. Some of the Strategic groups/meetings we attended this year include:

- WG Cross Party Autism Group meetings
- We sit on the 7 Autism (ND) strategic groups across each RPB area
- Buckland Autism Employment Review Implications of Welsh Autism Strategy
- NIAG National Implementation and Assurance Group, Adult Learning Disability
- Ministerial Advisory Group
- ND Workforce Workshop, bringing together HEIW, WG, Social Care Wales, Local Authorities and Health Boards
- National ND MH Steering Group
- AET Monmouthshire ERG part of specialist panel developing a new education resource for Monmouthshire

Steering group meetings:

- North Wales Autism Leads Regional Hub
- Various Autism Stakeholder groups across Wales' Local Authorities
- Family support and NEST Community of Practice
- Welsh Government Best Practice Forum
- Mental Health Strategic Group
- Workstream Meetings
- Clinical Advisory Groups
- Programme Board

Shows and events attended: see Chapter 2, Communication

- Presentations at stakeholder meetings/events:
- Early Years Integration Transformation Programme
- Family First Network meeting
- Joint FIS Network and DEWIS in-person meeting
- Swansea Headteacher meeting
- Senedd Insight Neurodiversity in The Workplace Conference
- Cardiff and the Vale Disability Inclusion Service
- Integral Autism Conference, Riga, Latvia,16th December 2023, where members of the team were invited to give a presentation about the Code of Practice, ALN Policy context and the shift from Autism to ND
- Worked with ADEW (Association of Directors of Education in Wales)
- NAS Annual Professionals Conference
- Tourettes Action worked together to translate TA's e-learning module and facilitate uploading to HB and LA learning platforms.

### Chapter 2: Communications

### Website and User Stats:

**AutismWales.org** is managed by the National Neurodivergence Team. The website acts as a hub for all national neurodivergence developments and hosts a wide range of resources available bilingually and in multiple formats.

During 2023/24, the AutismWales website saw an increase of 93,073 users and a total of 331,622 page views, with the percentage of new visitors to the site at 91%

### **Social Media**

The team posted regularly on Facebook and Twitter in both Welsh and English. Social media statistics for 2023-2024 – Facebook saw an increase of 474 followers; Twitter/X lost 16 followers.

The team once again used National Autism Acceptance Month in April as a key opportunity for increasing awareness, understanding and acceptance of autism by posting multiple bilingual posts on Facebook and Twitter signposting to resources on the Autism Wales website, using quotes from members of the Autism Advisory Group.

During ADHD Awareness Month in October, the team undertook a similar social media campaign sharing quotes from members of the ADHD Advisory Group to raise awareness and understanding of ADHD. The team also sent out a request for ADHD video diaries on the website and via Facebook and Twitter.

The team continued to use social media to promote new resources on the website, including the Community of Practice sessions, and newly created Parents & Carers virtual advice sessions.

### Public engagement events:

The Team attended several events and conferences this year, delivering presentations and/or exhibiting to spread awareness and understanding of neurodivergence as well as sharing information and resources. This included an invitation to the Integral Autism Conference in Latvia, where members of the team spoke about the Code of Practice, ALN Policy and the move from Autism to Neurodivergence.

Some of the events the team attended are:

- Bevan Commission conference
- The Mental Health & Wellbeing Show
- Autistic Minds Live
- Capita Event, Birmingham
- Senedd Insight Neurodiversity in The Workplace Conference
- Pembrokeshire Family Event
- Integral Autism Conference, Riga, Latvia
- NAS Annual Professionals Conference

The team also delivered presentations at a variety of stakeholder meetings/events, including:

- Early Years Integration Transformation Programme
- Family First Network meeting
- Joint FIS Network and DEWIS in-person meeting
- Swansea Headteacher meeting
- Cardiff and the Vale Disability Inclusion Service
- Worked with ADEW (Association of Directors of Education in Wales)

### **Autism Understanding & Accepting Scheme**

This year the team combined The Can You See Me campaign and Autism Aware schemes to create an Autism Understanding and Accepting Certification scheme giving people confidence that where they see the certificate displayed, the organisation has a good understanding of autism. The DWP Job Centre staff in Wales were the first organisation to achieve Understanding and Accepting status.

In addition, the team added a third e-learning module to the AutismWales website: Understanding Autism & Assessments.

The team also worked with Tourette's Action to translate their e-learning module, which sits on our website and has also been uploaded to the Health Board and Local Authorities learning platforms.

### Rebranding

During this year, the team adopted a new logo. This was created in partnership with the Advisory Groups and designed by Rhys Martin, who has links with the Western Bay IAS. The new logo reflects the wider scope moving from Autism Wales to Neurodivergence Wales.

### Chapter 3: Code of Practice



#### Awareness Raising of the Code of Practice and its Duties with Local Authorities and Health Boards

Work has continued to support the Welsh Government to roll out the Code of Practice on the delivery of Autism Services across Wales.

In 2022/23 the National Autism team began delivering a programme of webinars across Health Boards and Local Authorities and this has continued in 2023/2024. The aim of the 30-minute webinars is to raise awareness of the duties Local Authorities and Health Boards have under the Code. The webinars also highlight the support the National Neurodivergence Team can offer and the resources and training available to support people in their roles.

In 2023/2024 webinars were delivered across Cwm Taf HB, Hywel Dda UHB, Betsi Cadwaladr HB, Aneurin Bevan HB and Powys UHB. Uptake was varied but attendance at the Hywel Dda webinars was consistently high.

Webinars were also delivered in Local Authorities across Wales – these were well attended. The team delivered webinars across Torfaen, NPT, RCT, Denbighshire and Conwy and Ceredigion. Presentations on the Code were also delivered at several meetings including the Family First network meeting to highlight the duties teams have under the Code and to discuss and understand the resource needs of the teams, informing future resource development.

### **Evaluation of the Code of Practice – Part 1**

The Welsh Government commissioned an evaluation of the Code of Practice, which is being delivered in 2 phases. Work on phase one of the evaluation started in Spring 2023.

The aim of the Evaluation of the Code of Practice on the Delivery of Autism Services is to review the extent to which the duties in the Code are being met since its implementation, and to develop recommendations for improvements in meeting the duties of the Code. Areas being looked at as part of the evaluation are:

- Assessing compliance with the relevant sections of the Autism Code of Practice.
- Exploring the barriers and enablers to compliance with the Code.
- Exploring the impact of the Code upon service users; and
- Identifying potential areas for action (recommendations).

The team is supporting the evaluation process, regularly attending each RPB's regional autism strategic group meetings to support RPB's, Local Authorities and Health Boards to complete the audit of their services and develop a baseline assessment looking at their compliance with the Code. Individual support was also offered to those needing advice or guidance on compliance.

### **Code of Practice Workforce Focus**

A key focus of the Code is ensuring that Local Authorities and Health Boards have the right knowledge to be able to deliver the duties on behalf of their organisations.

Workforce managers in both Health and Local Authority workforce teams were invited to an online workshop in March, organised jointly by Welsh Government and the National Neurodivergence Team. The focus of the workshop was to discuss the Code of Practice; the duties in Section 3 of the Code; their compliance; and the barriers faced in meeting their duties and supporting their wider workforce.

This workshop was well attended, with all Health Boards' workforce teams and 18 of the Local Authority workforce teams represented. The National Neurodivergence team continues to work closely with workforce teams, raising awareness of our resources and the support the team can offer. The team also consults on which resources would help them support their workforces and meet their duties under the code.

Our 3rd e-learning module "Understanding Assessment and Autism" was released in February 2024, it is available on both Local Authority and the Health Board learning platforms. It is coproduced, bilingual and awaiting CPD accreditation.

During 2023, the team worked with Tourettes Action to translate their e-learning module – "Understanding Tourettes" into Welsh so that it can be used in Wales as a training resource. The team supported Local Authorities and Health Boards to upload this module onto their training platforms alongside the other Autism e-learning modules.

#### Feedback on our e-learning

The team collected feedback from people undertaking the e-learning. Feedback was positive with quotes including:

"The advice was very clear and easy to understand. I have been working with autistic people for some years, but I learned some very useful ways of making the first appointment more accessible. I now realise there are many ways in which I can improve my practice for the benefit of my autistic students."

"Fantastic learning module, great that autistic people give their own experiences, makes it more personable and much better to understand."

"Really helped me to understand that everyone is different."

"One of the best training modules I have ever done. Brilliant. Well done!"

"...very informative and a great beginning to help myself understand better how I can improve myself when working with autism."

"I enjoyed taking part in the module and found it very informative."

"I thought it was excellent, and I definitely feel I have more confidence and understanding which will help in the future."

"Thank you for your time to put this together. It was so good to hear from those in the know rather than professionals lecturing."

"I felt that there needed to be the voice of people with learning disabilities and autism....."

"I think the course could have been longer. I was fascinated with the level of detail" "authentic voices. I found the second part to be the strongest."

### Chapter 4: Training and Workforce Development

Underpinning the Code of Practice is the importance of having an effective, trained, and knowledgeable workforce that can deliver the duties on behalf of the organisations. Throughout the Code, there is a strong emphasis on training, awareness raising and understanding of autism. Although it is currently only Local Authorities and Health Boards that have duties under the Code, the importance of having the right skills and knowledge for the role that you do, applies to any organisation.

The National Neurodivergence Team is committed to driving cultural change. The team continues to provide opportunities for training and workforce development through our regular Community of Practice webinars and by delivering ND training either in person or virtually.

### **Education workforce**

The team receives many queries from teachers and schools, asking for training resources to help increase their knowledge and understanding and more clarity about alignment between the Code and the new Additional Learning Needs (ALN) system. (The current Code of Practice on the delivery of autism services does not align with the ALN system)

In response to this, and the positive feedback of our generic Community of Practice webinars, we commissioned a series of webinars targeted at the education workforce. Four bespoke webinars were held – details of each webinar below: **Supporting ND in the Classroom,** delivered on 12th July 2023 by Catrina Lowri of Neuroteachers. 151 people attended.

"Amazing session! The session was really refreshing, engaging, informative and passionate. So nice to see the flag being flown for neurodiversity, whilst embracing and enhancing the differences."

"It was an excellent training. I felt that I learnt a lot that is highly pertinent to my role and I keep going back over the notes that I made to ensure that I don't forget anything! I particularly found the fruit salad approach and the sensory differences sections particularly informative and really made me think about the learners that I support in my role. I feel like I understand them a little better now and can better support them. I've shared the link with colleagues and told them to watch out for the recording on the website. I loved it, thank you Catrina, and can't wait for the next one in November."

"One of the most engaging and interesting presenters I have heard in nearly 20 years"

**Neurodiversity & The Dyses,** delivered on 7th November 2023 by Catrina Lowri of Neuroteachers. 190 people attended

"A very informative workshop with first-hand experience really assisting in the understanding of the differing needs of the learners in the classroom and beyond. I look forward to further improving my understanding with the reading lists given. Many thanks."

"This was a very informative session, thank you for sharing your personal insight, experience and vast information. Your passion is evident, and your knowledge gratefully received to hopefully make the education setting a better experience."

**Exclusion Prevention & Neurodivergence,** delivered on 15th February 2024 by Catrina Lowrie of Neuroteachers. 324 people attended.

"This training was absolutely brilliant!" "Excellent" **Emotionally Based School Avoidance,** delivered on 12th March 2024 by Catrina Lowri of Neuroteachers. 507 people attended.

"Great session! Very engaging and informative, without overwhelming audience with jargon / excessive info. Very educating!"

"A thorough, knowledgeable and accurate delivery. It is very useful to hear that my existing practice is in line with Catrina's recommendations. I would happily listen to Catrina all day and will recommend that as many people as possible do exactly that."

"Excellent training, so powerful and informative. Thank you!"

The role of the ALENCO is key in ensuring the needs of pupils with ALN are met within their school environment. To offer our support to ALENCO's the team attended ALENCO forums across Wales providing a short presentation with an overview of the work of our team and the resources we have to support them in their roles.

ALENCO forums attended in 2023/24

- Swansea LA 28th June 2023. On online forum attended by 56 people.
- Carmarthenshire LA 3rd October 2023. In person forum attended by 95 people.
  \*A great event. It was well worth attending. \*Thank you for the session and sharing information/resources \*I think more emphasis on schools completing certification might have helped. Need buy in from headteachers to realise the importance and relevance to truly inclusive ethos
- Caerphilly LA 26th October 2023. In person forum attended by 46 people.
- RCT 25th January 2024. In person forum attended by 47 people. ALENco's mentioned the ND workshops as one of/the most useful aspect of the training day and commented that they would apply knowledge from the ND workshops to current working practises as a classroom practitioner.
- NPT 21st February 2024. In person forum attended by 86 people.
- Bridgend LA 14th March 2024. A virtual session attended by approximately 150 people including all headteachers, senior leaders, group managers and Director.

"Thank you for your excellent contribution. I thought your presentation and the associated advice provided was first-rate. The feedback we have received from meeting attendees has been extremely positive." We are working with Higher education providers to look at increasing knowledge and understanding for those training to become teachers and other undergraduate courses. This is part of a wider piece of work to look at how we can increase understanding of ND at undergraduate level.

As part of this piece of work, the team delivered Understanding Neurodiversity training to the following groups:

•Aberystwyth University PGCE course – 20th April 2023. In person training attended by 62 people.

"Frances delivered an extremely useful and informative course our PGCE students. The resources were engaging and purposeful and allowed student-teachers opportunities to reflect on how they respond to learners who present with difficulties in many different ways. Diolch yn fawr."

• Aberystwyth University BSE Nursing course – 11th October 2023. In person training attended by 68 people.

"Very informative and useful session. Thank you for your time"

• Aberystwyth University HCL3 course – 17th October 2023. In person training attended by 24 people.

"Excellent lecture, thank you!"

"I found the lecture very informative and well delivered."

"An incredibly comprehensive lecture with additional insight into neurodivergence, diolch."

• **UWTSD PGCE Course** – 14th December 2023. In person training attended by 70 people.

### **Community of Practice Webinars**

We have received consistent feedback that the delivery of these Community of Practice webinars continues to support people to change their practice as a result of gaining new understanding and learning on ND after attending. We listened to our stakeholders and targeted our COP webinars to cover the topics which people told us were of interest and the further understanding gained would help them in their roles.

The Community of Practice webinars can be attended live by Professionals and the recordings are accessible on our website for anyone to view.

During 2023/2024 we held the following Community of Practice webinars:

**Sensory Processing, Autism & Identity**, delivered on 25th April 2023 by Rachel from Our Sensory World. 130 people attended.

"Thank you very much, for an amazing session."

"Thank you, it's been really interesting."

"That was so informative and useful, thank you!"

"Excellent, excellent presentation! It's soooo wonderful to hear from autistic people with lived experiences of autism. Autism Wales you guys get the best people for us all to learn from! Great work, thanks"

**Tic's & Tourettes,** delivered on 9th May by Dr Tara Murphy and Jo Kilgraff. 138 people attended.

"Thank you so much that has been so useful."

"Thank you, Joe and Tara, a really interesting session!"

"Fantastic session, I have learned so much."

"This has been very useful, thank you."

"Will be doing a lot more research about ADHD and Tics"

**Foetal Alcohol Spectrum Disorder (FASD),** delivered on 8th June 2023 by Adoption UK & Professor Raja Muherejee. 144 people attended.

"Excellent presentation. Thank you, National Team"

"Excellent presentations, incredibly informative."

"So much great information from both speakers, thank you so much"

**Pain & Hypermobility**, delivered on 20th September 2023 by Dr Jessica Eccles. 90 people attended.

"I just want to add that I found this fascinating! It's led me to reflect on my professional and personal experience of Neuro diversity, and the connection with hypermobility. This has, in turn, changed my way of thinking - for the better!"

"This was so informative, a fantastic community of practice that will support me both in my role and personally. Thank you so much."

"Very valuable session, great speaker, thanks for bringing us all together."

### **ND, OCD & Hoarding,** delivered on 5th October 2023 by Dr Lynne Drummond and Kayley Hyman. 139 people attended.

"Excellent session and so informative. The presenters were brilliant. Thanks for the learning opportunity."

"Both the presenters were very knowledgeable and were excellent in the way that they conveyed information. It was very interesting and informative, and I learnt a great deal. I would think it would be beneficial to all my colleagues to attend."

"Very interesting and delivered in such a sensitive way"

**Autism & Marginalised Communities,** delivered on 28th February 2024 by Professor Prithvi Perepa. 46 people attended.

"Very informative and interesting"

"Excellent session, thank you!"

"Thank you for arranging the Community of Practice sessions, I look forward to attending the next."

### Workforce Training

The team has delivered virtual or in person training sessions to a variety of our stakeholders. The aim of these training sessions is to increase understanding of ND and also give an overview of the work of our team, the resources we have to support, with a particular emphasis on the e-learning modules available.

**National Fostering Association:** 24 people received in person training on 25th April 2023 covering Understanding Neurodiversity.

"We thoroughly enjoy working in partnership with the NNT. They have provided NFA team with online Autism training which has helped staff to become more confident and Autism aware. The team have enjoyed these training opportunities and. Frances Rees has provided several group training sessions for NFA foster carers and we have received very positive feedback from the foster carers about the training sessions. The carers have reported they have found the sessions very helpful and relevant to their everyday fostering practice. They found Frances very knowledgeable, and she was also able to signpost carers to correct support services where necessary."

### **Capita**: 25 people received virtual training on 3rd May 2023 covering Understanding Autism.

"It's been a pleasure working with the National Neurodivergence Team over the past year. The team is very knowledgeable, and we've had some great feedback from our assessors on the awareness sessions held and CPD modules created. We hope to continue working together in the future to improve the PIP process as much as we can."

**ABUHB Integrated Wellbeing Network:** 27 people received virtual training on 16th May 2023 covering Understanding Autism

"Keep delivering, keep educating people to give autistic people the best possible chance of having a good experience when engaging with services."

"An excellent training course! very clear, informative and very approachable trainers. Thank you."

"Thank you very much for a very informative training session"

**National Fostering Association:** 14 people received in person training on 13th July 2023 covering Understanding Neurodiversity.

**CALL Helpline**: 6 people received virtual training on 19th July 2023 covering Understanding Neurodiversity.

**Capita**: 25 people received virtual training on 24th July 2023 covering Understanding Autism.

**Disability Sports Wales:** 15 people received virtual training on 13th September 2023 covering Understanding Neurodiversity

"very interesting course and I feel I have learnt so much on neurodiversity it will really help me with my delivery in sessions and will be a good addition to the existing training."

"The tutors that delivered this training had exceptional knowledgeable on neurodiversity"

"Diolch yn fawr, great session!"

**IAS & Wider MH:** 18 people received virtual training on 30th October and 3rd November 2023 covering ADOS ADIR.

**Wales Migration Partnership:** 8 people received in person training on 13th November 2023 covering Understanding Neurodiversity

"It feels like ALL teams in all organisations would benefit from this training. Particularly effective was Fran's additional evidence based on experience."

"Thank you for a very engaging and informative course."

"A well-balanced course which was well presented and interactive in parts, diolch."

**Capita**: 150 people received in person training on 21st November 2023 covering Understanding Neurodiversity.

Really positive – thank you! A lot of colleagues had expressed anecdotally that the session had resonated with their own personal situations, and had highlighted how they can better support their teams. Thank you for the resources you've shared – these are hugely helpful.

**SBUHB Upper Valleys Cluster PLTS Session for GP Practices**: approximately 50 people received virtual training on 29th November 2023 covering Understanding Neurodiversity.

**Capita**: 23 people received virtual training on 6th December 2023 covering Understanding Autism.

**CVUHB Disability Inclusion Service**: 10 people received in person training on 13th December 2023 covering Understanding Neurodiversity

**National Fostering Association Ceredigion/Carmarthenshire Region**: 10 people received in person training on 18th January 2024 covering Understanding Neurodiversity.

"Fran & Ben were a pleasure to listen to. They clearly have a great depth of knowledge in this field. Their support and advice is a great help. Sometimes it's the small things that can make a huge difference and change the way we look or interpret things. Thank you."

**National Fostering Association, Swansea/Port Talbot Region:** 24 people received in person training on 22nd January 2024 covering Understanding Neurodiversity.

**CANOPI:** 42 people received virtual training on 28th February 2024 covering Understanding Autism & Neurodiversity.

"Well-pitched for the variety of professionals in the group. Really engaging and informative. Fully recommend."

"I thought this was extremely informative and am looking forward to accessing the additional resources."

"Please keep on developing the different areas to level you have for Autism and soon for ADHD - really useful resource and have already mentioned to friends." The team delivered ND training to Police forces across Wales, work continues to upload our e-learning modules to their learning platforms.

**South Wales Police School Education Programme:** 22 people received virtual training on 18th May 2023 covering Understanding Neurodiversity.

"I think the training could have been delivered over a two-day period as there was so much information."

**Dyfed Powys Police School Education Programme:** 12 people received in person training on 12th September 2023 covering Understanding Neurodiversity.

"Our Dyfed Powys Police Schools Officers recently received a training input from Fran which provided them with an invaluable insight into neurodiversity. The training was well structured and delivered in an engaging manner. There was ample opportunity for participants to share personal experiences and the advice given was both professional and practical."

**Gwent Police School Education Programme:** 15 people received in person training on 5th December 2023 covering Understanding Neurodiversity

"Very professional and informative input from Frances"

**North Wales Police School Education Programme:** 18 people received hybrid training on 18th December 2023 covering Understanding Neurodiversity.

"I really enjoyed the training. it was really interesting and informative and will assist me with my work in the future when working with children. I would love to have more training around this subject."

"Although I could not attend in person I managed to link in on teams and found the presentation very informative and the presenters had very good knowledge of the subject."

"I thought the presentation was excellent, thank you."

### **Further Developments & Upskilling**

In April & May 2023 the team also met with North Wales Fire & Rescue Team and the Welsh Ambulance Trust to explore what training would be useful for their roles.

The team also developed a training offer for voluntary organisations and worked with HEIW to look at work-based learning.

Our e-learning modules have been uploaded to the Health Board and Local Authority learning platforms as well as being available on our website. We Care Wales (part of Social Care Wales) use our modules and resources as part of their training offer to new potential social care workers and the DWP Job Centre staff in Wales were the first organisation to achieve Understanding and Accepting status.

To reflect the move from National Autism Team to National Neurodivergence Team, in April 2023 the team undertook training to improve knowledge and understanding of ADHD.

### Chapter 5: Integrated Autism Service

The year 2023/24 has continued to challenge all seven Integrated Autism Services (IAS) in Wales in terms of demand and capacity, as can be demonstrated by the Review of the Demand, Capacity and Design of Neurodevelopmental Services report commissioned by the Welsh Government. However, this report shows key high-level data from all seven IAS across Wales and reflects the hard work and dedication of staff working within their capacity in 2023/24.

The following data headlines were observed:

- 10,406 interactions were made with adults
- 7,501 referrals to the service were made for adults with 57% of these selfreferrals
- 65% of referrals for adults requesting autism diagnostic assessments and 35% were requesting support
- 1,316 adults received a diagnostic assessment
- 1,070 adults received a positive diagnosis of autism
- 1,724 interactions were made with parents/ carers
- 465 referrals to the service were made for parents/ carers with 95% of these selfreferrals
- 92% of referrals were for parent/ carers of autistic adults and 8% were for parent/ carers of autistic children
- 4,179 interactions were made with professionals
- 1,866 new contacts with professionals
- 51% of contacts were from health professionals, 17% were professionals from local authorities and 7% were professionals from the voluntary sector

For the full 2022/23 IAS data report, see Appendix 1

### Feedback

Further information that can be used to demonstrate the work carried out by the IASs is feedback from people using the service and group evaluations. Here are some examples of feedback received by the IASs in 2023/24.

'Just want to say thank you for all the help you have given me. I have finally moved into a little house now... I don't think that would've happened without you... Thank you so much for everything you do for me...' NW IAS

'I would recommend it because the people I talked to were friendly but professional and made me feel comfortable.' C&V IAS

A family member praised a support worker and reported that it was the first time that their family member felt truly listened to and that since speaking with the support worker things have turned around for X, who has gone from spending most of her time in her bedroom to volunteering 6 days a week and thoroughly enjoying it. NWIAS

'The service was efficient, and information was easy to digest. The worker was polite, patient and adaptable. She worked to cease any stress or confusion and allowed the feeling of being overwhelmed to be reduced.' C&V IAS

Below is some information from groups held by some of the IASs.

·Cardiff and Vale IAS 'Understanding Behaviour Group'

All participants gave 5/5 for how informative they found the group. All participants would recommend the group to other parent/ carers. One participant noted that 'The sessions gave me a much better understanding as to why certain behaviours happen with my son. I particularly found the communication strategies useful'.

North Wales IAS 'Understanding Autism Group'

The conclusion to the evaluation of the group noted that 'From the small sample size, complete data indicated a positive impact on wellbeing, an increase of satisfaction with being autistic and feeling part of a group. Group participants valued the opportunity to be with other autistic adults, the group atmosphere and the opportunity to learn more about themselves.'

### **Practice Exchange**

The team continues to organise and facilitate Practice Exchanges. This provides an opportunity for the 7 IAS Teams to come together and share good practice to ensure there is a cohesive approach across Wales. It is also an opportunity to provide peer support and share strengths and challenges.

This year the following Practice Exchanges took place:

- Autistic Menopause
- Developing group measures
- Effective report writing
- Measuring what matters
- Effective outcome star practice

### Training

The National Neurodivergence Team recognises the importance of a skilled workforce and continued to facilitate training opportunities for the Integrated Autism Services across Wales.

The following training was commissioned and delivered in 2023-24:

- ADOS and ADiR diagnostic assessment training
- Autism and ADHD
- An introduction to ADHD
- Outcome Star training

### Chapter 6: Education

### Learning about Autism:

The Learning about Autism programme adopts a whole school approach to improve awareness and understanding of the needs of autistic children. The training is designed to generate discussions and increase understanding with all staff and pupils across the school/setting. The following data shows the take-up of the programmes across Wales.



### **The Early Years Programme:**

Since its launch at the end of September 2017, 3732 staff have undertaken the early years training programme and 125 Early Year Settings have received their Learning about Autism award. 4 of these were during 2023/24.



"Staff are now more aware of dealing with a range of situations and children's differing needs."

#### – Cylch Meithrin Parcyrhun

"We now have a visual daily timetable, have created a sensory area and a quiet area. All staff wear lanyards with visual pictures of activities on them."

– Cylch Meithrin Llanhari

Find out more about the Early Years scheme here.

### **The Primary Schools Programme:**

The primary school Learning about Autism programme was launched in March 2016. Since its launch, 271 schools across Wales have achieved their Learning about Autism award. During 2023/24 a further 10 schools achieved their Learning about Autism award.



Over the past year, Learning about Autism primary school training has been undertaken by 1,809 Teaching staff (12,966 in total) and 1,436 Learning support Staff (13,284 in total). Furthermore, 3,174 children have completed the Autism Superheroes scheme (56,261 in total). The following quotes were received by primary schools who completed the programme in 2023/24 and shared how they will adapt their day-to-day practice.

"We now have a withdrawal sensory room for our mainstream ALN children. We also have adapted our 1 page profiles to include strategies to support autistic pupils."

"The way we support our autistic pupils has changed through the way we talk to and engage with them."

"Again, understanding is key. Especially understanding that the behaviours we see are not a choice being made by the learner. They are struggling and we need to meet their needs."

"We have an autism checklist to ensure our classroom environments are not too overstimulating for children. Every classroom now has a visual timetable. We have also begun putting together a Pupil Parliament ALN Group, so as they can provide feedback to staff and staff can go forward and implement any necessary changes. Our initial key focus is how we can modify lunchtimes to help autistic students manage their sensory needs."

"We have established clear communication channels between teachers and parents to discuss the progress and needs of autistic students with and this is something we pride ourselves on as a school."

"A whole school training approach, that incorporates both staff, children and the wider community has resulted in an increased acceptance of diversity; providing all those involved with a more in-depth and clear understanding of autism."

#### **The Secondary Schools Programme:**



Since its launch at the beginning of September 2017, 7,588 staff have undertaken the secondary school Learning about Autism training programme, and 26,953 pupils have received the Sgilti lesson and taken their pledge. A further 2 secondary schools across Wales have received their Learning about Autism award this past year, resulting in 29 schools in total having completed the scheme since its launch.

In addition, other support staff such as governors, catering and administration staff across settings and schools have achieved their Autism Aware certificates as part of the Learning about Autism programmes.

## Community of Practice event series for professionals working in education

In 2023/24 the team coordinated a series of Communities of Practice for those working in education settings or those interested in neurodivergence and education. The sessions were facilitated by Catrina Lowri of Neuroteachers, who is a neurodivergent person and educator. The sessions focused on:

- · Neurodiversity in the classroom
- Autism and co-occurring conditions 'the dyses'
- · Exclusion prevention and neurodiversity
- Emotional based school absence and neurodiversity

You can view the recordings of these sessions, and more, on our website:

https://neurodivergencewales.org/en/resources/videos/community-of-practicesessions/

### Chapter 7: Family Support

#### Family Support Neurodivergence Development Officer

The Family Support Development Officer role continued to be developed with an initial scoping exercise. This exercise was part of our team workplan and identified that our resources for parents and carers needed updating and expanding. It is important that we work together with parents and carers to ensure that our resources are useful and reflect need.

In August 2023 Ben Ewart-Dean joined the team as the newly appointed Family Support Neurodivergence Development Officer.

### **Parent Carer Advisory Groups**

The team had previously worked both before and during COVID with a Parents and Carers Advisory Group. In 2022-23, having a newly created Family Support Neurodivergence Development Officer role in the team ensured that the work of the Parents and Carers Advisory Group was restarted and expanded.

It was also identified by parents and carers that there was also a need for a Neurodivergent Parents and Carers Advisory Group, as some of the challenges and information may be different to non-ND parents and carers.

In November 2023 a bilingual survey was developed and sent to ND parents. The survey was inviting people to join the Advisory Group, in addition to gaining their views on what useful resources could be developed.

The advisory group meetings were held online and facilitated by the National Neurodivergence Team, however the meeting agenda and discussion was informed and led by parents and carers. There is currently a particular focus on resource updating and development. The ND Parents and Carers Advisory Group meetings are Chaired by Parents. The National Neurodivergence Team Chairs the Parents & Carers Advisory Group meetings as no parents currently wish to Chair.

The inaugural ND Parents & Carers Advisory Group meeting was held in early January 2024 and continued to meet regularly thereafter.

The first Parents and Carers Advisory Group meeting was held on 5th March 2024 and was attended by 50 parents and carers. From this initial meeting, key topics were identified, and future task and finish groups were set up to focus on co-producing resources for the identified topics.

### **Parent Carer Virtual Advice Sessions**

One of the identified needs from the initial discussions with parents & carers was the need for virtual advice sessions. The format of these sessions was similar to the Community of Practice webinars but specifically tailored for parent carers and focus on a range of topics relating to neurodivergence. Each session consists of a presentation followed by a Q&A. The presentation part of the session is recorded and available to watch on our website following the session. The first of these sessions was held on 20th March 2024: Autism and Family Dynamics delivered by Tony Attwood and 673 people registered to attend. 40 people completed a feedback form – the feedback was overwhelmingly positive with 100% of respondents saying they were happy with the content and format.

### **Engagement Events**

In March 2023 the team presented at a workshop in Pembrokeshire for parents & carers whose children are on the waiting list for diagnostic assessment. The presentation covered the Code of Practice and our resources and focussed on demystifying the diagnostic process.

#### Workstream 2

As part of the Sustainable Services Workstream 2, a Family Support task and finish group was set up. It was attended by stakeholders from across Wales and held its first meeting on 27th February 2024.

The task and finish group feeds into the overarching Workstream 2 multi agency group to highlight the areas of best practice and future development in the area of family support.

#### **Future Plans**

A programme of further Parent Carer Virtual Advice Sessions has been arranged and booked up until the end of 2024. Forthcoming topics include: Managing Meltdowns; Managing Anxiety; Support at School; PDA; and Staying Safe Online.

Continued working with the Parents & Carers Advisory Group to review existing parents and carers Advice Sheets, expanding them to cover wider neurodivergent conditions.

Coproducing a series of audio resources with the ND Parents & Carers Advisory Group.

Holding a series of stakeholder engagement events to raise awareness of available resources on the Autism Wales website.

### Chapter 8: Transition to National Neurodivergence Team

On 1st April 2023 the National Autism Team changed its name to The National Neurodivergence Team in line with the widening remit of the Welsh Government policy team.

It's important to emphasise that the work of the team around Autism continues with additional work being undertaken to expand the remit of the team to encompass wider neurodivergent conditions.

Strategically, the team continues to support Welsh Government's ND Improvement Programme and the roll out and further development of the Autism Code of Practice.

The team are key members of the Welsh Government ND Ministerial Advisory Group and work closely with Welsh Government colleagues to help deliver the priorities of the ND Improvement Programme. In line with this the National Neurodivergence Team and Welsh Government colleagues began developing a self-assessment framework in 2023. This will provide a tool for services to assess their practice and effectiveness.

### **Collaborative Working**

IIn April 2023, an Adult ADHD scoping was undertaken by the team. This fed into the Welsh Government expanded ND work. In further development of this work the National Neurodivergence Team also co-chair a Clinical Advisory Group for adult ADHD services in Wales.

To ensure continued close collaboration with the neurodivergent community, the team also established an Adult ADHD Advisory Group and an advisory group of professionals.

#### Resources

In November and December 2023, the team worked with ADHD Advisory Group members and professionals in North Wales, Cardiff and Newport to film material for an information film about ADHD and an ADHD e-learning module. The ADHD information film will provide insights from people with ADHD and professionals – covering the different types of ADHD, executive function and working memory, emotional regulation, rejection sensitivity dysphoria, procrastination, and more, alongside real-life experiences of how ADHD can impact on daily life.

The Understanding ADHD e-learning module was planned and developed in this year and is due to be completed and uploaded onto the Autism Wales website later in 2024.

### **Community of Practice ND topics:**

The Community of Practice webinars continued with a broader focus on neurodivergence. These include:

- **Tics & Tourettes,** delivered on 9th May 2023 by Dr Tara Murphy and Jo Kilgraff.
- Foetal Alcohol Syndrome, delivered on 8th June by Adoption UK & Prof Raja Muherejee
- **Neurodiversity in the Classroom,** delivered on 12th July 2023 by Catrina Lowrie of Neuroteachers
- Hypermobility & Pain, delivered on 20th September by Dr Jessica Eccles
- **Hoarding & OCD**, delivered on 5th October by Dr Lynne Drummond and Kayley Hyman
- Neurodiversity & The Dyses, delivered on 7th November by Catrina Lowri of Neuroteachers
- Exclusion Prevention & ND, delivered on 15th February 2024 by Catrina Lowri of Neuroteachers

# ND Training

To reflect the transition from National Autism Team to National Neurodivergence Team, the team accessed two days training on What is ADHD and how it impacts on daily life. This training was also offered to Welsh Government colleagues. In addition, the team attended Emma Woodhouse sessions on Autism and ADHD, which was made available to the National Neurodivergence Team, Welsh Government and all Integrated Autism Services.

In November 2023 the team worked with Tourette's Action to publicise their workshop in Swansea. The National Neurodivergence Team also secured funding to ensure that the workshop was made available to other professionals in Wales.

## Rebranding

During this year, the team adopted a new logo. This was created in partnership with the Advisory Groups and designed by Rhys Martin, via Western Bay IAS. The new logo reflects the wider scope moving from Autism Wales to Neurodivergence Wales.



## Integrated Autism Service 2023/24 Data Report

## **1.Executive Summary**

The year 2023/24 has continued to challenge all seven Integrated Autism Services (IAS) in Wales in terms of demand and capacity, as can be demonstrated by the <u>Review of the Demand, Capacity and</u> <u>Design of Neurodevelopmental Services</u> report commissioned by the Welsh Government. However, this report shows key high-level data from all seven IASs across Wales and reflects the hard work and dedication of staff working within their capacity in 2023/24.

The following data headlines were observed.

- 10,406 interactions were made with adults
- **7,501** referrals to the service were made for adults with **57%** of these self-referrals
- **65%** of referrals for adults requesting autism diagnostic assessments and **35%** were requesting support
- 1,316 adults received a diagnostic assessment
- **1,070** adults received a positive diagnosis of autism
- **1,724** interactions were made with parents/ carers
- 465 referrals to the service were made for parents/ carers with 95% of these self-referrals
- 92% of referrals were for parent/ carers of autistic adults and 8% were for parent/
- carers of autistic children
- 4,853 interactions were made with professionals
- 2,344 new contacts with professionals
  51% of contacts were from health professionals, 17% were professionals from local authorities and 7% were professionals from the voluntary sector

# 2. Introduction

There are seven Integrated Autism Services (IASs) across Wales, all funded by Welsh Government as part of its commitment to the implementation of the Strategic Action Plan for ASD (<u>Autistic Spectrum Disorder-Updated Delivery Plan 2018-21</u>). The first one launched in July 2017 and the last one to be operational came on stream in April 2019. The National Autism Team which is hosted by the Welsh Local Government Association together with Public Health Wales has been committed from the outset, together with the IAS Leads and the Community of Practice for Adult Diagnosis to ensure that the impact of the new Integrated Autism Service be measured.

The data presented in this report is captured through a database managed by Data Cymru. Data is

inputted by all IASs on a quarterly basis and sent through Emyr, Data Cymru's secure file exchange site, based on three categories Adult Data, Parent Carer Data and Professional Data. To enrich the data, further data is capture through the Outcomes Star an outcomes measurement tool and qualitative data through case studies.

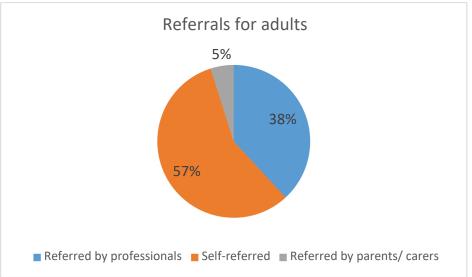


For adults who are unable to access advice or support from statutory services due to eligibility exclusion, and where the provision is not available elsewhere, the IAS provides diagnostic assessment and post diagnostic information and support for autistic adults. Below is data related to this provided by the IASs in 2023/24.

Below are the number of interactions and referrals relating to adults. Interactions can include informal discussions through e-mail, phone calls or face to face. These may or may not result in a formal referral to the service and may include signposting to other more suitable services. Referrals refer to formal requests for services from the IAS.

Table 3.1: The number of interactions and referrals for adults to the IASs

Ir	nteractions with adults	10,406
R	Referrals for adults	
	Referred by professionals	2,861
	Self-referred	4,274
	Referred by parents/ carers	366



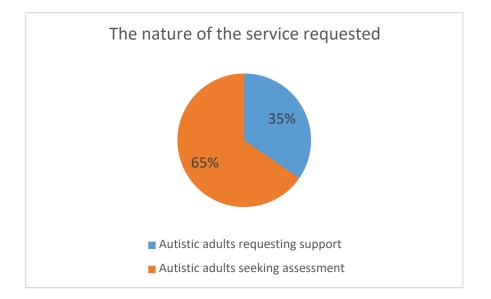
#### Graph 3.1: The break-down of referrals for adults

Referral requests can be split into two categories, individuals already with a diagnosis of autism but seeking support and adults seeking a diagnostic assessment. Below is a table and graph showing the nature of the referrals to the IASs.



Table 3.2: The nature of referrals for adults

Service Users		
	Autistic adults requesting support	2,586
	Autistic adults seeking diagnosis	4,882



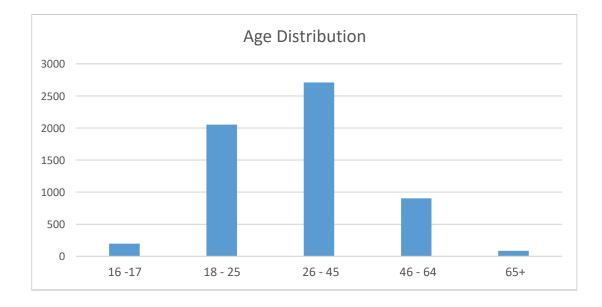
#### Graph 3.2: The nature of services requested by autistic adults

The age distribution of adults accessing the service is depicted in the following table and graph. The 'prefer not to say' option represents those for whom it would not be appropriate to automatically collect this data. This may include people seen in drop-in sessions or enquiry referrals.

Table 3.3: The age distribution of adults accessing services

Age Distribution	
16 -17	196
18 - 25	2,051
26 - 45	2,709
46 - 64	904
65+	84
Prefer not to say	1,557





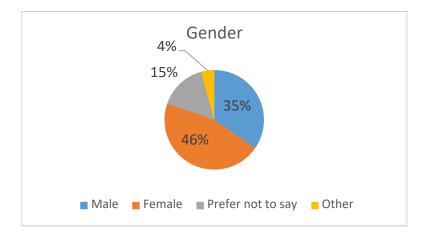
Graph 3.3: The age distribution of adults accessing services

The gender of adults accessing the service is depicted in the following table and graph. The 'Other' section includes people who identify as alternative genders or for whom the data was not easily collated or identify.

Table 3.4: The gender of adults accessing services

Gender	
Male	2,599
Female	3,420
Prefer not to say	1,162
Other	320

Graph 3.4: The gender of adults accessing services



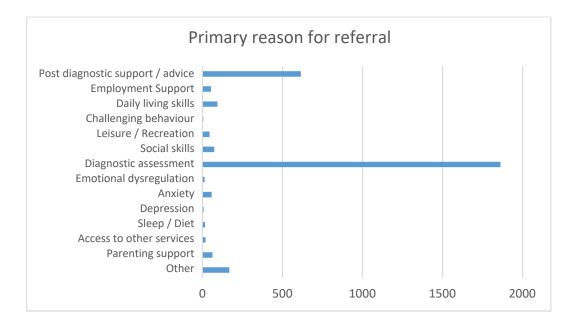


The table and graph below depict the primary reason that adults are referred into the service. This may change through initial discussions with the service but gives an idea of some of the difficulties that are identified by adults accessing the service.

Table 3.5: The initial primary reason for referral into the service

Primary reason for referral	
Post diagnostic support / advice	1,198
Employment support	46
Daily living skills	76
Challenging behaviour	15
Leisure / recreation	72
Social skills	80
Diagnostic assessment	4,882
Emotional dysregulation	40
Anxiety	84
Depression	56
Sleep / diet	53
Access to other services	70
Parenting support	40
Other	765

Graph 3.5: The primary reason for referral into the service

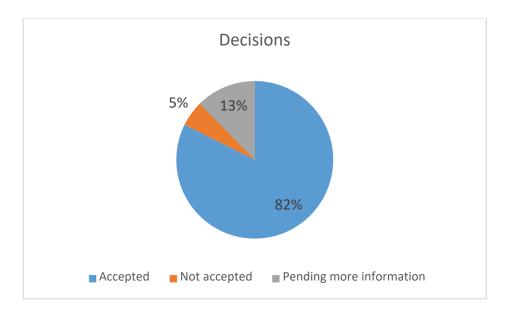




Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information. Table 3.6: The outcome of referrals into the service

Referral Outcomes	
Decisions	
Accepted	6,176
Not accepted	393
Pending more information	931

#### Graph 3.6: The outcome of referrals into the service

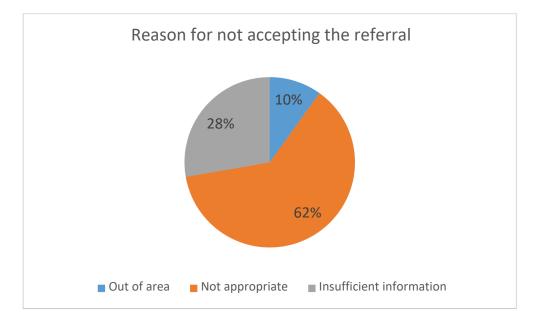


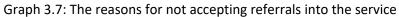
Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including someone who is receiving support from other services such as learning disability services or mental health services, or not appropriate due to age.

Table 3.7: The reasons for not accepting referrals into the service

Reason for not accepting the referral	
Out of area	39
Not appropriate	245
Insufficient information	109





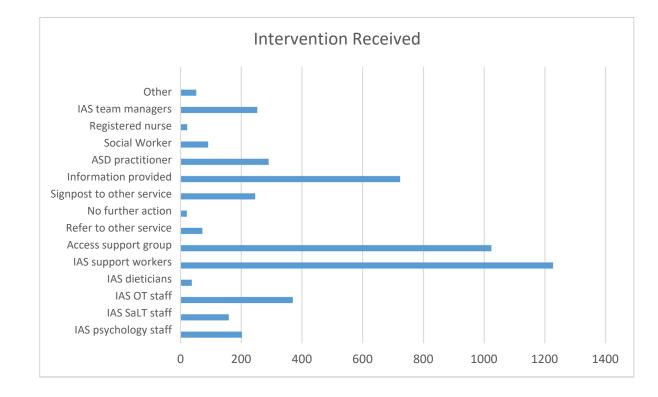


The table and graph below depict the interventions received by adults accessing the service. This gives an idea of what kind of services autistic adults need.

Table 3.8: The interventions received by adults within the service

Intervention Received		
Diagnostic assessment	1,316	
IAS psychology staff	202	
IAS Speech and Language Therapy staff	159	
IAS Occupational Therapy staff	370	
IAS dieticians	37	
IAS support workers	1,227	
Access support group	1,024	
Refer to other service	72	
No further action	21	
Signpost to other service	246	
Information provided	723	
Autism practitioner	290	
Social Worker	91	
Registered nurse	22	
IAS team managers	253	
Other	52	





#### Graph 3.8: The interventions received by adults within the service

The timeliness of support and diagnostic assessment are shown in weeks in the table below. The data is based on quarter 4 of 2023/24 only as it shows a more accurate picture of the current situation.

Table 3.9: The timeliness of support and diagnostic assessment as well as positive diagnosis data for adults

Timeliness of support	
Average weeks from point of referral received to accepted	3.3
Average weeks from referral accepted to start of intervention	14.4
Timeliness of diagnostic assessment	
Average weeks from point of referral received to accepted	8.1
Average weeks from referral accepted to start of intervention	86.6
Average weeks from initial appointment to diagnosis / outcome	5.7



The table below shows the number of diagnostic assessments carried out by the IASs and the number that led to a positive diagnosis.

Table 3.10: Diagnostic assessments

Diagnostic Assessment	
Number of autistic individuals who received an assessment	1316
Number of assessments that lead to a positive diagnosis	1070
Number of adults on the waiting list for diagnostic assessment at the end of the quarter	6246

The table below not additional information about the services, including the number of group sessions held, formal complaints and compliments received.

Table 3.11: Additional information about the services

Additional Information		
Number of support group sessions held	300	
Number of people who attended group sessions	1065	
Number of formal complaints received	9	
Number of compliments received	197	

## 4. Parent/ Carer Data

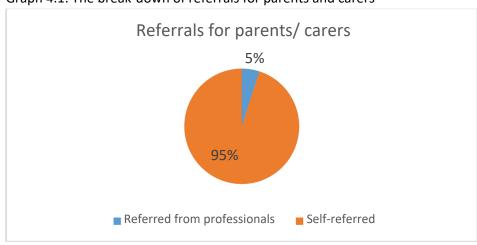
Whilst not working directly with children and young people, the service works in partnership with other organisations to support parents and carers. Below is data related to this provided by the IASs in 2023/24.

Below are the number of interactions and referrals relating to parents and carers. Interactions can include informal discussions through e-mail, phone calls or face to face. These may or may not result in a formal referral to the service and may include signposting to other more suitable services. Referrals refer to formal requests for services from the IAS.

Table 4.1: The number of interactions and referrals for parents and carers to the IASs

Ir	nteractions with parents/ carers	1,724
R	Referrals for parents/ carers	
	Referred from professionals	23
	Self-referred	442



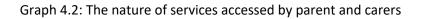


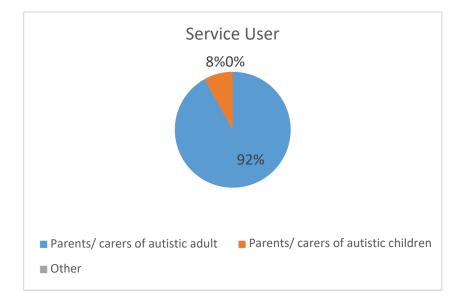
Graph 4.1: The break-down of referrals for parents and carers

The table and graph below show whether service users are parents and carers of autistic adults or children. The 'other' category includes parents/carers who care for both those over and under 18 and instances where the data was unavailable.

Table 4.2: The nature of services accessed by parent and carers

Service User	
Parents/ carers of autistic adult	159
Parents/ carers of autistic children	14
Other	0





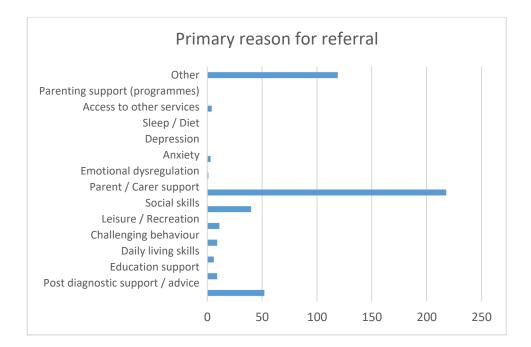


The table and graph below depict the primary reason that parent/ carers are referred into the service. This may change through initial discussions with the service but gives an idea of the support that parent/ carers are seeking.

Table 4.3: The initial primary reason for referral into the service

Primary Reason for referral	
Post diagnostic support / advice	52
Education support	9
Daily living skills	6
Challenging behaviour	9
Leisure / Recreation	11
Social skills	40
Parent / Carer support	218
Emotional dysregulation	1
Anxiety	3
Depression	0
Sleep / Diet	0
Access to other services	4
Parenting support (programmes)	0
Other	119

Table 4.3: The initial primary reason for referral into the service

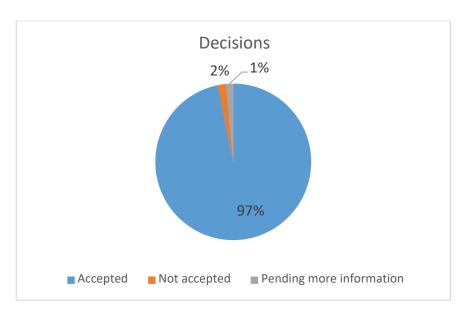




Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information. Table 4.4: The outcome of referrals into the service

R	Referral Outcomes	
C	Decisions	
	Accepted	454
	Not accepted	8
	Pending more information	7

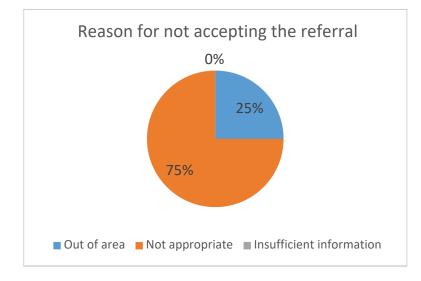
#### Graph 4.4: The outcome of referrals into the service



Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including those who are receiving support from other services. Table 4.5: The reasons for not accepting referrals into the service

Reason for not accepting the referral	
Out of area	2
Not appropriate	6
Insufficient information	0





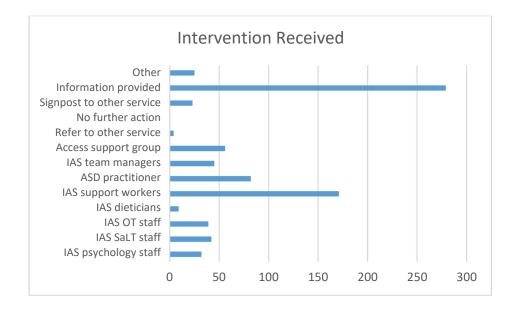
#### Graph 4.5: The reasons for not accepting referrals into the service

The table and graph below depict the interventions received by parent/ carers accessing the service. This gives an idea of what kind of services parent/ carers need.

Table 4.6: The interventions received by parents and carers from the service

Intervention Received	
IAS psychology staff	32
IAS SaLT staff	42
IAS OT staff	39
IAS dieticians	9
IAS support workers	171
Autism practitioner	82
IAS team managers	45
Access support group	56
Refer to other service	4
No further action	0
Signpost to other service	23
Information provided	279
Other	25





#### Graph 4.6: The interventions received by parents and carers from the service

The timeliness of support for parent/ carers is shown in weeks in the table below. The data is based on quarter 4 of 2023/24 only as it shows a more accurate picture of the current situation. The table also includes additional information of the number of group sessions held and the number of formal complaints and compliments received over the 2023/24 year.

Table 4.5: Additional information for parents and carers

Additional Information	
Number of support group sessions held	123
Number of formal complaints received	5
Number of compliments received	100



## 5. Professionals Data

An important aspect of the IASs role is to work with and educate professionals from a variety of different services in order to support autistic people and their families. There is an identified training need among professionals and in particular health and social care staff and the IAS provides an element of this. The data below is related to the work carried with professionals by the IASs in 2023/24.

Below are the number of interactions and new contacts by professionals to the service. Interactions can

include informal discussions through e-mail, phone calls or face to face. These may or may not result in a formal referral to work with the service and may include signposting to other more suitable services. Contacts with professionals refer to more formal work with the service.

Table 5.1: The number of interactions and new contacts with professionals

Interactions with professionals	4,853
New contact with professionals	2,344

The table and graph below depict the primary reason that professionals contact the service.

Table 5.2: The initial primary reason for contact with the service

Primary reason for contact	
Request joint work/ consultation for a client	848
Request for training	143
Other general enquiry	1,179

Graph 5.2: The primary reason for contact with the service



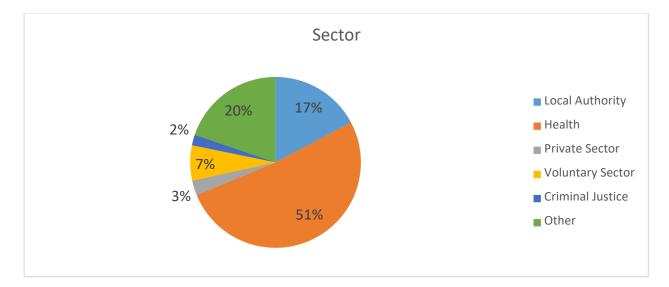


The following table and graph show the sector which professionals contacting the services are from. The 'other' category may include professionals working in the civil services such as DWP employees or the information may not be available to include.

Table 5.3: The sector professionals contacting the service are from

Sector	
Local Authority 416 Health 1,243 Private Sector 68	voluntary ,
Third Sector 161 Criminal Justice 49 Other 477	

Graph 5.3: The sector professionals contacting the service are from



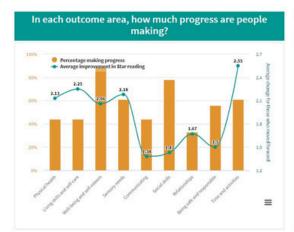


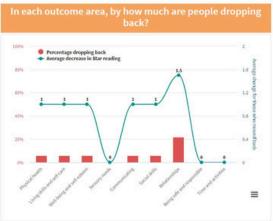
## 6. Outcomes Star and Additional Information

The Outcomes Star is an outcomes measurement tool that is used by the IASs when working with people on a one-to-one basis. The Outcomes Star can show the distanced travelled by people on identified outcome areas and is evaluated jointly by the person themselves and the worker supporting them. The IASs mainly use the Spectrum Star of which there are nine outcome areas.

Below is the IAS Distanced Travelled Report for the Spectrum Star 2023/24 period.









The report shows that every person made progress in at least one outcome area, with 94% of people making progress in three or more outcome areas.

Further information that can be used to demonstrate the work carried out by the IASs are feedback from people using the service and group evaluations. Here are some examples of feedback received by the IASs in 2023/24.

'Just want to say thank you for all the help you have given me. I have finally moved into a little house now... I don't think that would've happened without you... Thank you so much for everything you do for me...' NW IAS

'I would recommend it because the people I talked to were friendly but professional, and made me feel comfortable.' C&V IAS

A family member praised a support worker and reported that it was the first time that their family member felt truly listened to and that since speaking with the support worker things have turned around for X, who has gone from spending most of her time in her bedroom to volunteering 6 days a week and thoroughly enjoying it. NWIAS

'The service was efficient and information was easy to digest. The worker was polite, patient and adaptable. She worked to cease any stress or confusion, and allowed the feeling of being overwhelmed to be reduced.' C&V IAS

Here is some information from groups held by some of the IASs.

Cardiff and Vale IAS 'Understanding Behaviour Group'

All participants gave 5/5 for how informative they found the group. All participants would recommend the group to other parent/ carers. One participant noted that 'The sessions gave me a much better understanding as to why certain behaviours happen with my son. I particularly found the communication strategies useful'.

North Wales IAS 'Understanding Autism Group'

The conclusion to the evaluation of the group noted that 'From the small sample size, complete data indicated a positive impact on wellbeing, an increase of satisfaction with being autistic and feeling part of a group. Group participants valued the opportunity to be with other autistic adults, the group atmosphere and the opportunity to learn more about themselves.'

### 7. Conclusion

The data demonstrates that the demand on the IASs continue to grow with the services receive a high number of referrals and working with an increasing number of people.

For services provided to adults 57% of referrals were self-referrals from adults themselves. Sixty five

percent of the referrals were for diagnostic assessment and 35% for support. Most of the age distribution of autistic adults accessing the service is between 18-45. The most frequently accessed interventions were diagnostic assessment, working with IAS support workers, accessing support groups and providing information. It can also be noted that there was an 46% increase in referrals to the service



for adults in 2023/24 in comparison with 2022/23 figures. In addition, there was 35% increase in diagnostic assessments undertaken in 2023/24 in comparison to 2022/23.

For services provided to parent/ carers 95% of referrals were self-referrals. Ninety two percent of the referrals were from parent and carers of adults and 8% were from parent and carers of children. The primary reason for referrals were for parent/ carer support, post diagnostic support/ advice and daily living skills. The most frequently accessed interventions were providing information, support from IAS support workers, support from Autism practitioners and accessing support groups. It can also be noted that there was a 16% increase in referrals to the service from parent/ carers in 2023/24 in comparison with 2022/23 figures.

The data shows that a significant part of the services' work is engaging with professionals. The primary

reason for referrals were general enquiries at 54% and request joint work/ consultation with client at 39%. In addition, 51% were professionals from the health board, 17% were from local authorities and 7% from the voluntary sector. It can also be noted that there was an 35% increase in contacts with the service from professionals in 2023/24 in comparison with 2022/23 figures.

Outcomes evaluation through the Outcomes Star and service feedback shows that the IASs have had a positive impact on people's lives in 2023/24.