



AwtistiaethCymru.org

Tîm Awtistiaeth Cenedlaethol
National Autism Team

AutismWales.org

Annual Report 2022/23

"The training we received was invaluable, it was informative, interesting, and easy to follow. What we really loved about it, were all the extra training videos and support on your website which we could access in our own time, a directory at our fingertips."

"The training has raised the awareness everyone at the school and how different situations need to be managed to support our autistic learners."

"I have learned a lot and have recognised and related these conditions in people I know, and so it has definitely been very valuable for me - it has raised my awareness significantly about autism."



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As you will see from this year's annual report (2022-23) it has been, once again, a very busy and productive year. The practices that were developed against the background of the pandemic have helped to shape the work of the team and the move online offered huge opportunities to connect with wider audiences and be proactive as needs emerged. A wide range of online events and training has been developed and delivered which were accessible to more people and helped us to continue to build excellent resources on our website. The website remains one of our key offers to the autistic community and professionals across Wales.

The roll out of the Code of Practice for Autism Services has offered an opportunity to engage with the wider workforce across Wales and the lunch and learn webinars have proved to be particularly effective. The team have worked closely with Local Authorities and Health Boards to assist in their implementation of the Code.

In addition, virtual working has enabled us to further develop our coproduction. We established effective and diverse autistic adult advisory groups, and multi-disciplinary working 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 autistic community, professionals and other colleagues has ensured that whatever we do is useful and makes a difference to the lives of autistic people and their families in Wales. Our 'Once for Wales' ethos informs our projects and developments to ensure consistency and equity, lessens duplication and is more cost effective.

This year has also seen the team expand its remit to encompass a wider Neurodivergence (ND) agenda. Additional staff and a transformation plan have ensured that the move to become a National ND team is delivered in a planned, effective and measured way.

Our work is varied and robust 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 autistic people and their families but there is also much to be celebrated. The move to ND is both exciting and challenging but building the firm groundwork has already begun in 2022-23.

As always, our thanks go to Welsh Government for the continued core funding to support the successful implementation of the WG ASD Refreshed Strategic Action Plan, associated Delivery Plan and the Code of Practice for autism. Our thanks also go to the WLGA for their continued support and guidance.

- The National Autism Team

Chapter 1: Collaborative Working

Working with the autistic community:

Co-production is a main priority for the National Autism Team (NAT). Autistic people are at the core of all working groups and shape all work, resources, training, and events.

Autistic UK Wales have worked closely with the team in the development of advisory groups of autistic people. This ensures that the autistic community are being engaged with in an accessible and meaningful way.

As a principle, the team value the contribution from autistic people and recognise the time, energy, expertise and commitment they give to projects.

The team have worked closely with advisory groups this year to produce the eLearning modules: Understanding Autism and Understanding Effective Communication and Autism, and to produce a series of advice sheets for autistic adults.

Local Authority Autism Leads:

The team work closely with the Autism Leads in local authorities across Wales. The team have continued to facilitate the quarterly National Autism Leads network meetings virtually, as well as quarterly regional meetings for North Wales Leads and South and West Wales Leads.

The Autism Leads played an essential role in disseminating information from the team locally and informing national policy and guidance through local networks and engagement in a grass-roots approach.

Read examples of best practice from the Autism Leads in our Case Studies Compendium [here](#).

Steering groups:

Members of the NAT have sat on numerous steering and research groups over the past year, to ensure that the needs and interests of autistic people and their families are represented in these groups. Groups the team have representation on include:

- **TEC Cymru/TERMS**
- **Nyth/Nest Steering Group**
- **Inclusive Active Travel subgroup**
- **Disabled People's Employment Steering Group**

Spanish delegation meeting:

On 28th July 2022, the team met with delegates from the Gipuzkoa Provincial Council from the Basque Region whilst they were visiting Welsh Government colleagues in Cardiff. The meeting provided an opportunity to share best practice from Wales and the Basque Region.



(The National Autism Team with colleagues from Welsh Government and Gipuzkoa Provincial Council)

Chapter 2: Communications

Website and User Stats:

AutismWales.org is managed by the National Autism Team. The website is kept up to date and acts as a hub for all national autism developments. It is one of the resources which helps the team achieve their aim to improve the lives of autistic people in Wales.

All resources are available bilingually on the website.

During 2022/23, the AutismWales website saw an increase of **80,047** users and a total of **283,665** page views. The average of new visitors to the website also increased to **94%**.

World Autism Acceptance Week:

World Autism Acceptance Week is a key event for increasing awareness, understanding and acceptance of autism. The team intensified their already proactive social media presence on Facebook and Twitter, rolled out in response to Covid-19, and shared multiple bilingual posts a day linking to resources surrounding autism acceptance on the Autism Wales website.

This year the team worked with members of the advisory groups to create content for social media about the importance of autism acceptance. Advisory group members produced quotes about their feelings on the topic and these were then formatted and shared on social media. The posts generated high engagement throughout the week and were the posts with the most likes and reshares.

The team delivered a series of webinars to Cwm Taf Morgannwg University Health Board during Autism Acceptance Week, to raise acceptance and understanding of autism through the promotion of the eLearning modules and other resources. The team also presented a talk to Cardiff Council employees at an event hosted by their Disability Network during the week.



(Graphics from WAAW social media campaign)

Engagement events:

The team participated in numerous in-person events over the course of 2022/23. These events were an opportunity to promote the team's work and resources and to create links with autistic people, their families and other professionals.

In person events attended this year include:

- The Mental Health and Wellbeing Show, 2022
- Autistic Minds Live, Cardiff
- Wales Housing Research Conference
- Gwent Police Enable Day
- Carmarthenshire World Autism Acceptance Week event

Ewan Richards - Digital Story:

The team produced a digital story case study interview with Ewan Richards. Ewan is autistic and recently gained a First Class Honours Degree in BSc Computing, and is currently studying for a Master's degree in Computing Software Engineering at the University of Wales, Trinity St David.



(Ewan Richards during filming for his digital story)

Ewan received a diagnosis of autism at the age of 11. In this interview, he talks about how his experiences in education and employment were impacted by this.

Ewan was featured in the team's Further Education video whilst studying at Coleg Sir Gar and has been an active member of all project advisory groups.

Watch the digital story interview [here](#).

Cross Party Autism Group presentation:

The team presented at a Cross Party Autism Group meeting on 19th January 2023. The presentation provided an overview of how the team are supporting the implementation of the Code of Practice for the Delivery of Autism Services and the team's main areas of work and resources.



Health Board Webinars:

In 2022/23, the team began delivering a programme of webinars for the Health Boards across Wales. The webinars were an hour long. The first 30 minutes provided an introduction to neurodiversity, gave an overview of the Code of Practice and its duties, and promoted the NAT's eLearning modules and Community of Practice sessions (to find out more about these sessions, see Chapter 4). The second 30 minutes of the webinar was protected time for attendees to log onto the health learning and development platform (ESR) to access and complete the module. This allowed time to make sure that all attendees could access the modules and that any technical issues could be addressed.

The first set of webinars were delivered to Hywel Dda University Health Board. **8** one-hour sessions were delivered and in total and **468** people attended the sessions. Of those **468** attendees, **302** people (**67%**) have completed the first eLearning module, Understanding Autism.

Upcoming sessions are planned with other Health Boards. So far, there has been one session with Swansea Bay Health Board, with **15** people in attendance.

Feedback:

The team collected qualitative feedback from these sessions. Feedback was extremely positive, with quotes including:

"Very informative training. Links and information are useful."

"I thought the trainer was very engaging. Her knowledge and passion came across very clearly."

"Fantastic! thank you for your presentation, time and knowledge were much appreciated by us all."

"There was a lot of information to take in by listening to the trainer."

"It met its aims and was useful."

Local Authority webinars:

The team delivered a similar programme of webinars for Local Authority staff. The webinar was one hour and provided an overview of the Code of Practice and its duties, as well as resources that the team have to support staff to fulfil these duties.

In the West Wales region, **6** webinars have been delivered in total to staff working across Carmarthenshire, Ceredigion and Pembrokeshire. In total, **127** staff attended these sessions.

In Ynys Mon, a webinar has been delivered to a Children and Families staff conference.

The team also facilitated **4** webinars open to all local authorities in Wales. **120** people attended in total across the **4** webinars, with representation from the following local authorities:

- Blaenau Gwent
- Caerphilly
- Cardiff
- Carmarthenshire
- Conwy
- Denbighshire
- Gwynedd
- Monmouthshire
- Neath Port Talbot (NPT)
- Pembrokeshire
- Powys
- Rhondda Cynon Taf (RCT)
- Swansea
- Wrexham

Many more Local Authority webinar sessions are planned for 2023/24.

Feedback:

The team collected qualitative feedback from these sessions. Feedback was extremely positive, with quotes including:

"The course has been very helpful to support with the Social Work degree."

"It raised my awareness of the responsibilities of the LA and Health Board in relation to supporting individuals with autism."

"Got a better understanding and awareness of the responsibilities of the LA & Health board in supporting individuals with autism."

"I understand the COP framework better."

"Useful to hear this summary of things."

Code of Practice podcast:



(Screenshot from Code of Practice podcast)

The team coproduced a podcast on the Code of Practice with Autistic UK. The podcast is for autistic people and their families and aims to empower them with a better understanding of their rights under the Code. So far one episode has been published on the political context of the Code.

Listen to the podcast [here](#).

eLearning modules:

Two co-produced **eLearning modules** have been launched: 'Understanding Autism' and 'Understanding Effective Communication and Autism'. They are available on nearly all Local Authority learning platforms and on the Health Board ESR platform, with Local Authority and Health Board staff completing them through these systems. They are also available on the Autism Wales website for organisations who do not have a learning platform. It is recommended that all staff do these modules as part of their basic training, with some local authorities and health boards choosing individually to mandate them.



(eLearning module cover pages)

The modules are for those who want to improve the lives of autistic people and their families in Wales by gaining a greater understanding of autism. The two modules will give the workforce a basic level understanding of autism and the ways in which it can affect the daily lives of autistic people.

The modules were coproduced with an advisory group of autistic people and a working group of people representing professional organisations. They feature the voices and experiences of all advisory group members. Both are CPD accredited and have recently been nominated for the 'Online Course of the Year' CPD award.

Based on data from the Local Authorities and Health Boards, **1,906** staff have completed the modules so far, with more due to complete the module in 2023/24. Of those **1,906, 592** staff members in Ceredigion have completed the modules, **382** staff members in Gwynedd have completed the modules and **323** staff members in Wrexham have completed the modules.

The team are currently developing the next module in the eLearning series, which will focus on assessments.

Feedback:

The modules have received positive qualitative feedback from staff in Local Authorities and Health Boards, with quotes including:

"I just want to say I find your work very inspiring."

"This was the best course ever. Hearing the voices of the autistic people made this course dynamic!"

"Feedback on the module has been positive with terms such as 'useful', 'interesting' and 'informative' being used to describe the module."

"Very well delivered."

"A request was made for this module to become mandatory."

"We are receiving very positive feedback on the module both in our county and from other counties across North Wales."

"I was in a Dementia meeting this week where an eLearning module was discussed, and it was suggested they use the format you have used for your module and how having people living with the condition included in the training is such a benefit to the learners."

"I just want to tell you that it's great. I have learned a lot by going through it and have recognised and related these conditions in people I know, and so it has definitely been very valuable for me to do it - it has raised my awareness significantly about autism."

"The comments we have received are about how well structured the course is and that it is very easy to navigate. Very positive!"

Chapter 4: Training and Workforce Development

The National Autism Team are committed to improving understanding of autism across Wales. A vital way in which this is done is through providing opportunities for training and workforce development.

Communities of Practice:

The National Autism Team have continued to facilitate the Communities of Practice event series. These sessions are designed to upskill practitioners in their knowledge and understanding of neurodivergence and neurodivergent conditions. They are presented by leading specialists in the subject area. A number of sessions have been carried out this year:



Joint Community of Practice with Royal College of Psychiatrists' ND special interest group on Mental Health – Kirsten Barnicot, Jennie Parker and Simon Moseley:

On 7th April, 2022, the team worked with the Royal College of Psychiatrists' ND special interest group to jointly facilitate a Community of Practice on mental health.

Kirsty Barnicot and Jennie Parker presented on improving recognition, understanding and differentiation of autism and 'personality disorder'. Simon Moseley from North Wales Integrated Autism Service presented on autism and mental health.

The session was attended by **179** people and received positive feedback.

Fabricated or Induced Illness - Cathie Long and Rachel Gavin:

On 29th June 2022, Cathie Long and Rachel Gavin presented a Community of Practice on Fabricated or Induced Illness.

The session was attended by **130** people and received positive feedback:

"Thank you for the interesting discussions and ideas. Look forward to attending further COPs."

"Really useful information and discussions."

"Wonderful training. Thank you!!"

Tics and Tourettes – Tourettes Action:

On 4th October 2022, Tourettes Action presented a Community of Practice on Tics and Tourettes.



(Tourettes Action logo)

The session was attended by **55** people and received positive feedback:

"Excellent training, very informative. Thank you very much."

"Thank you. Very informative."

"Thank you – excellent training!"

When complexity gets even more complex - Helen Minnis:

On 26th January 2023, Helen Minnis presented a Community of Practice on complexity, trauma and neurodivergence entitled 'when complexity gets even more complex'.



(Screenshot - Helen Minnis presentation)

The session was attended by **144** people and received positive feedback:

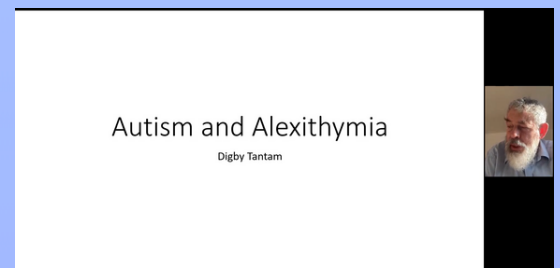
"Thank you for the useful training and discussion of a complex area."

"Excellent presentation. Thank you Helen."

"Fantastic presentation. Incredibly thought-provoking."

Alexithymia - Digby Tantam:

On 14th February, 2023, Digby Tantam presented a Community of Practice on alexithymia.



(Screenshot - Digby Tantam presentation)

The session was attended by **77** people and received positive feedback:

"Fabulous and thank you so much, fascinating."

"Many thanks for a very informative session."

"Thank you, great session! Looking forward to next months session."

ADHD - Steer and Dan Jones:

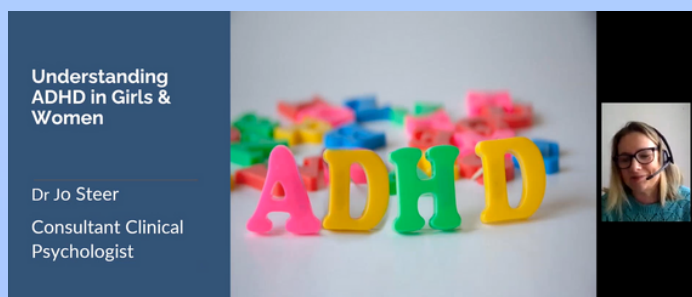
On 14th March 2023, Jo Steer and Dan Jones (The Aspie World) both presented at a Community of Practice on ADHD. Jo Steer presented on ADHD, women and girls and Dan Jones presented on autism, ADHD and OCD.

The session was attended by **120** people and received positive feedback:

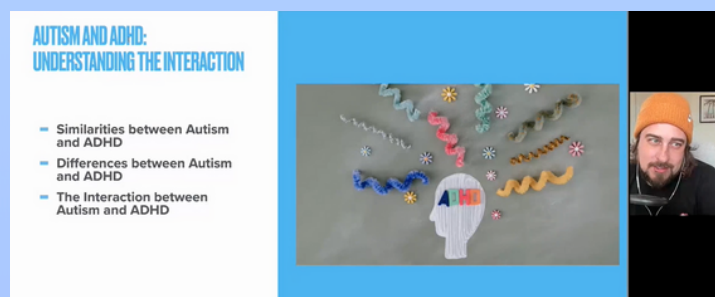
"Diolch, Brilliant speakers!"

"Amazing, thank you. I have thoroughly enjoyed your sessions."

"Thank you for a really helpful and informative talk."



(Screenshot from Jo Steer's Community of Practice presentation)



(Screenshot from Dan Jones' Community of Practice presentation)

Watch all Community of Practice recordings [here](#).

Capita:

In 2022/23, the team continued their ongoing commitment to provide training to Capita. Staff from Capita were trained this year, in addition to training sessions provided to the organisation in previous years. The sessions generated positive feedback from attendees:



(Capita logo)

"Wonderfully informative."

"The two representatives were great with a full range of knowledge and their contribution was well received."

"Fantastic session on a subject which I have struggled with in the past, new learning and I would feel much better assessing someone with this condition, thank you."

Dwr Cymru Vulnerable Customers Team:

On 27th April 2022, the team trained the Vulnerable Customers Team at Dwr Cymru. This session was attended by **20** staff members and received positive feedback:



"The training we received was invaluable, it was informative, interesting, and easy to follow. What we really loved about it, were all the extra training videos and support on your website which we could access in our own time, a directory at our fingertips."

Primary Health Aneurin Bevan University Health Board (ABUHB) – Understanding Autism:

On 29th June 2022, the team trained staff working in primary health in ABUHB. The session focused on understanding autism. It was attended by **130** people and received positive feedback:



"We are happy to work with you; we're grateful you exist!"

"We will also complete the eLearning, thank you for all the information today."

Integrated Wellbeing Network – Understanding Autism:

On 11th October 2022, the team trained the Gwent Integrated Wellbeing Network. The session focused on understanding autism. It was attended by **35** people and received positive feedback:



"Amazing training session, thank you so so much!"

"Thank you – you are doing an AMAZING job."

"Thank you both! Brill training session!!"

"Thank you so much Fran and Sioned - such an informative session."

Museum of Wales – Understanding Autism – Train the Trainer:

On 7th February 2023, the team ran a train the trainer session for the Museum of Wales. The session focused on understanding autism. It was attended by **8** people and received positive feedback:

AMGUEDDFA CYMRU

(Museum Wales logo)

“Frances was clear, informative and was able to answer questions we had.”

“Thank you, we really appreciate this service and the fact it's free! Diolch yn fawr!”

“Many thanks to Frances for the training - very approachable!”

GP training – Hywel Dda University Health Board (H DUHB):

On 16th February 2023, the team provided training to GPs in HDUHB. The session was attended by **100** people and received positive feedback:



(Hywel Dda University Health Board logo)

“I can't fault the way the training was delivered; it was very well organised and carried out”.

“The information provided and resources which I can refer to is all very useful and will be studied further by myself”.

“Trainers were very knowledgeable, and staff took a lot away from it, a future update in person would be welcomed!”

C.A.L.L. ND Helpline training:

Across March 2023, the team trained call handlers at C.A.L.L. helpline. The session focused on upskilling attendees in neurodiversity and neurodivergence and the support available across Wales, so that they were able to effectively provide support to callers to the new Welsh Government ND listening line. The sessions received positive feedback:

“Diolch yn fawr. Very informative. Hope for a brighter future.”

“Very insightful, thanks both. Diolch.”

“Thank you, Fran, and Sioned. Incredibly informative.”



(C.A.L.L. Helpline logo)

Chapter 5: Integrated Autism Service

Data highlights:

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 captured through the Outcomes Star an outcomes measurement tool and qualitative data through case studies.

The following data highlights were observed across the IASs in 2022/23 and show that referrals to the services continues to increase. For more detailed information please see the full data report appendix.



- **9,755** interactions were made with adults
- **5,143** referrals to the service were made for adults with **57%** of these self-referrals
- **72%** of referrals for adults requesting autism diagnostic assessments and **28%** were requesting support
- **973** adults received a diagnostic assessment
- **623** adults received a positive diagnosis of autism
- **1,817** interactions were made with parents/ carers
- **399** referrals to the service were made for parents/ carers with **89%** of these self-referrals
- **89%** of referrals were for parent/ carers of autistic adults and **11%** were for parent/ carers of autistic children
- **4,346** interactions were made with professionals
- **1,732** new contacts with professionals
- **61%** of contacts were from health professionals, **20%** were professionals from local authorities and **7%** were professionals from the voluntary sector

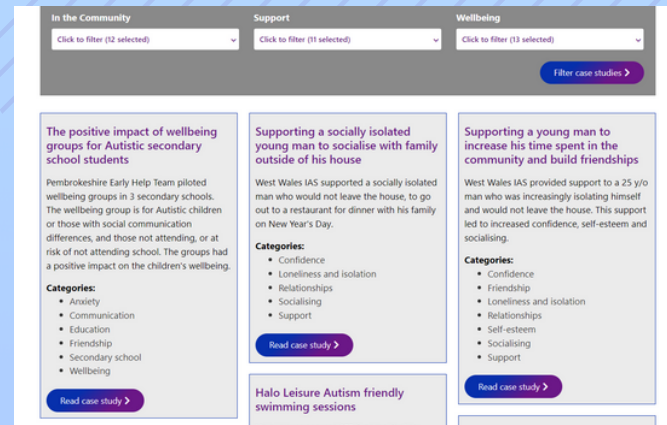
For the full 2022/23 IAS data report, see [Appendix 1](#).

Case Studies Compendium:

The best practice Case Study Compendium showcases the range of effective work being carried out across Wales.

Each case study features the voices of autistic people and/or the parent/carers of autistic people, reflecting on how the support and interventions put in place have had a positive impact on their lives.

The Case Study Compendium is a vital tool for promoting the positive work being carried out by the seven integrated Autism Services across Wales. Read the case studies [here](#).



(Screenshot of Case Studies Compendium)

Practice Exchange:

In 2022/23, the team established a Practice Exchange event series for staff working within the Integrated Autism Services (IAS). The events are held quarterly and focus on topics identified by those working with the IAS'.

They provide an opportunity for staff across the seven IAS' to come together to share practice to ensure that there is a cohesive, joined-up approach to their work. It is also an opportunity to provide peer support and share strengths and challenges.

Training:

The team continued to facilitate training opportunities for the Integrated Autism Services in 2022/23.

Induction:

In June 2022, the team provided induction training for new starters in the IAS. This provided an overview of our work and resources. The session was attended by **10** people.

West Wales IAS Call Handlers:

In November 2022, the team provided training for call handlers in West Wales Integrated Autism Services. The session was attended by **5** people.

DISCO:

In July and October 2022, the team funded DISCO training. This was attended by **15** people.

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, **3,343** staff have undertaken the early years training programme and **121** Early Year Settings have received their Learning about Autism award. **9** of these were during 2022/23.



"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, **261** schools across Wales have achieved their Learning about Autism award. During 2022/23 a further **16** schools achieved their Learning about Autism award.



Over the past year, Learning about Autism primary school training has been undertaken by **1,523** Teaching staff (**11,157** in total) and **1,365** Learning support Staff (**11,157** in total). Furthermore, **3,095** children have completed the Autism Superheroes scheme (**53,807** in total).

The following quote was received by a primary school who completed the programme in 2022/23 and shared how they will adapt their day-to-day practice.

“... as well as making changes within our classroom environments, we have developed a nurture classroom for pupils with mainly autistic traits/diagnosis, putting into practice the training we received and coupling it with our nurture training. A number of staff have also requested and received further training to develop our approaches across the school. We will also be including the resources provided to educate pupils about autism at different times during the year to maintain their knowledge and understanding of their peers.”

– Ynyshir Primary School

Find out more about the Primary School scheme [here](#).

The Secondary Schools Programme:



Since its launch at the beginning of September 2017, **7,101** staff have undertaken the secondary school Learning about Autism training programme, and **26,101** pupils have received the Sgilti lesson and taken their pledge. A further **4** secondary schools across Wales have received their Learning about Autism award this past year, resulting in **27** 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.

“It has raised the awareness everyone at Ysgol Bro Dinefwr and how different situations need to be managed to support our autistic learners.”

– Ysgol Bro Dinefwr

Find out more about the Secondary School scheme [here](#).

Pembrokeshire ALNCo forum:

On 8th February 2023, the National Autism Team spoke at the Pembrokeshire ALNCo forum, providing an overview of the work of the team and all training and education resources. The session was attended by **141** people.

The team will be speaking at all Local Authority ALNCo forums over the course of 2023/24.

What's next?

Community of Practice event series for professionals working in education:

In 2023/24 the National Autism Team will be coordinating a series of Communities of Practice for those working in education settings or those interested in neurodivergence and education. The sessions will be facilitated by Catrina Lowri of Neuroteachers, who is a neurodivergent person and educator.

The sessions will focus on:

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

View the recordings of these sessions, and more, as they became available [here](#).

Chapter 7: Transition to National Neurodivergence Team



2022/23 was a transitional year for the National Autism Team (NAT). From 1st April 2023, the team will become the National Neurodivergence Team (NNDT), in line with the widening remit of the Welsh Government policy team. The work of the team around autism continues and additional work is being undertaken to expand the remit of the team. To ensure that the work of the team is of high quality, evidence based and coproduced the move to ND will be effectively planned and implemented.

This year has been used to scope existing support and services for the neurodivergent community and to identify gaps. The work has initially focused on ADHD and Tourettes, the areas of identified most pressing need.

The team will be working with the neurodivergent community to create resources to populate a new website which is currently being developed. The resources which initially focus on ADHD including pre diagnostic and post diagnostic information, advice and guidance. These resources will gradually be developed for other neurodivergent conditions. AutismWales.org will continue to be functional and will be housed by the new website. A phased rebranding will take place in 2023/24.

Many pieces of work have been undertaken this year in readiness for the transition to the NNDT.

New appointments to the team – ND Transformation Manager and ND Family Support Officer:

In 2022/23, the NAT grew, recruiting two new members to the team.

The National ND Transformation Manager is responsible for overseeing the team's transition to neurodivergence. They will lead on all scoping work in relation to neurodivergent services and support available in Wales and will manage the creation of content for the new website and the rebranding of the team.

The National ND Family Support Officer is responsible for working with other agencies and parents to develop resources and training for those with a neurodivergent family member (e.g. parent/carer of an ND child, partner of an ND person) and those who are neurodivergent parent/carers or partners themselves.

Scoping for ADHD and Tourettes:

The National ND Transformation Manager has conducted a thorough scoping exercise into the current offer for ADHD and Tourettes services across Wales. This has involved meeting with providers of services and support, and looking at services available to adults with a neuro developmental disorder, including an exploration of the evidence base for effective services with recommendations. The scoping considered the positive and negative aspects of how services could be upscaled to a national model.

Community of Practice ND topics:

The team have widened the focus of their Community of Practice event series to provide attendees with a better knowledge and understanding of neurodivergent conditions. Sessions that took place this year focused on ADHD, OCD, Tourettes, complex trauma and neurodivergence and alexithymia.

Further sessions are planned which will focus on other neurodivergent conditions and related issues. These include sessions on:

- Tics and Tourettes
- Foetal Alcohol Spectrum Condition
- Hoarding and OCD
- Neurodiversity in the classroom
- Hypermobility and pain

Widening training packages – ND focus:

The team have widened the focus of their bespoke training packages. Training going forward will focus on understanding neurodivergence rather than understanding autism. This gives those being trained an understanding of autism, ADHD and other common co-occurring conditions, as well as an understanding of the philosophy of neurodiversity.

Collaborative working:

The team will be working closely with the neurodivergent community and specialist professionals to develop resources for neurodivergent people. An advisory group of neurodivergent people and an advisory group of professionals will be set up in the new financial year to ensure that the voices of the neurodivergent community guide this work.

The team attend the Welsh Government ND Ministerial Advisory Group and will be working closely with Welsh Government colleagues to help deliver the ND Improvement Programme.

During the scoping year, links have also been established with other organisations working within the ND sector, including ADHD Ireland and Tourettes Action.

Integrated Autism Service 2022/23 Data Report

1. Executive Summary

The year 2022/23 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 IASs across Wales and reflects the hard work and dedication of staff working within their capacity in 2022/23.

The following data headlines were observed.

- **9,755** interactions were made with adults
- **5,143** referrals to the service were made for adults with **57%** of these self-referrals
- **72%** of referrals for adults requesting autism diagnostic assessments and **28%** were requesting support
- **973** adults received a diagnostic assessment
- **623** adults received a positive diagnosis of autism
- **1,817** interactions were made with parents/ carers
- **399** referrals to the service were made for parents/ carers with **89%** of these self-referrals
- **89%** of referrals were for parent/ carers of autistic adults and **11%** were for parent/ carers of autistic children
- **4,346** interactions were made with professionals
- **1,732** new contacts with professionals
- **61%** of contacts were from health professionals, **20%** 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 ([Autistic Spectrum Disorder- Updated Delivery Plan 2018-21](#)). 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.

3. Adult Data

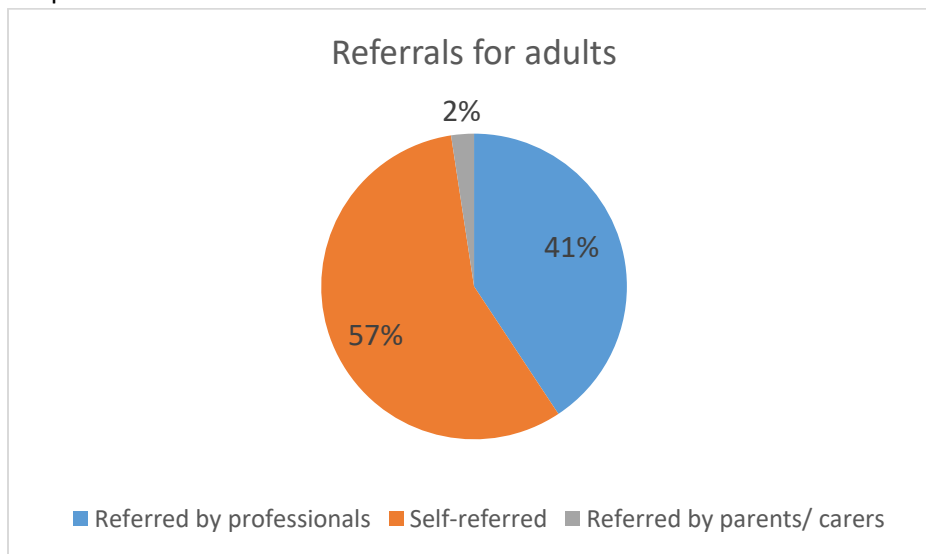
For adults who are unable to access advice or support from statutory services due to eligibility exclusion, and where the provision is not available elsewhere, the IAS provides diagnostic assessment and post diagnostic information and support for autistic adults. Below is data related to this provided by the IASs in 2022/23.

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

Interactions with adults	9,755
Referrals for adults	5,143
Referred by professionals	2,093
Self-referred	2,926
Referred by parents/ carers	124

Graph 3.1: The break-down of referrals for adults

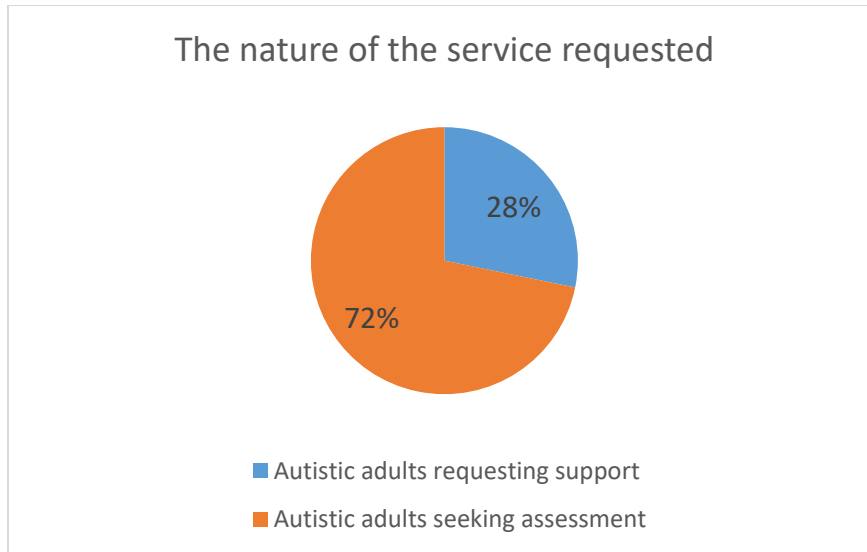


Referral requests can be split into two categories, individuals already with a diagnosis of autism but seeking support and adults seeking a diagnostic assessment. Below is a table and graph showing the nature of the referrals to the IASs.

Table 3.2: The nature of referrals for adults

Service Users		
	Autistic adults requesting support	1,255
	Autistic adults seeking diagnosis	3,192

Graph 3.2: The nature of services requested by autistic adults

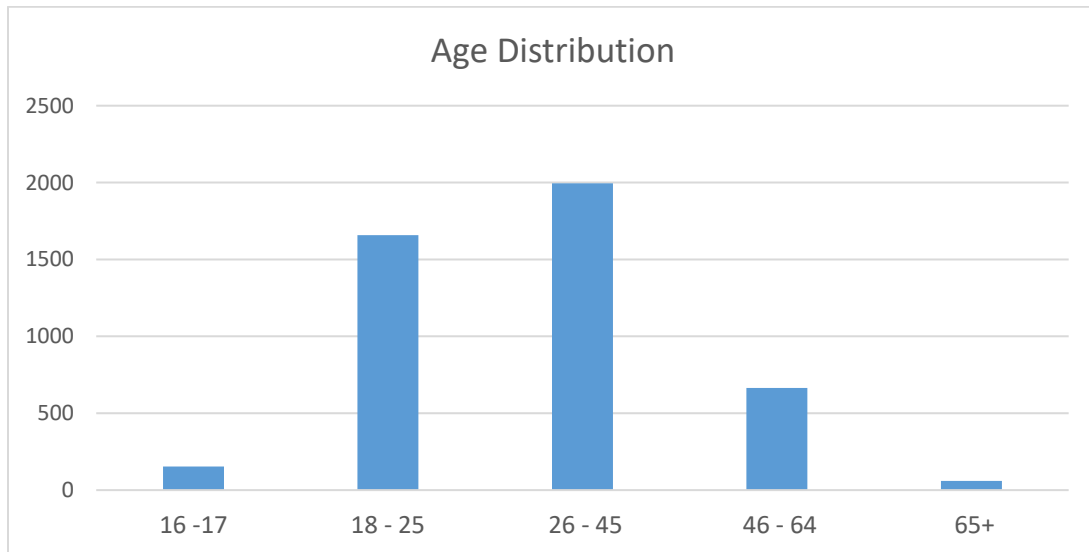


The age distribution of adults accessing the service is depicted in the following table and graph. The 'prefer not to say' option represents those for whom it would not be appropriate to automatically collect this data. This may include people seen in drop-in sessions or enquiry referrals.

Table 3.3: The age distribution of adults accessing services

Age Distribution	
16 -17	153
18 - 25	1,658
26 - 45	1,995
46 - 64	664
65+	60
Prefer not to say	638

Graph 3.3: The age distribution of adults accessing services

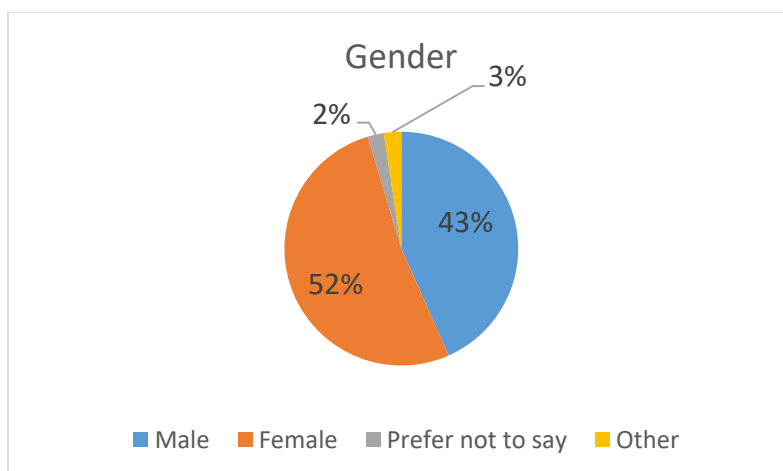


The gender of adults accessing the service is depicted in the following table and graph. The 'Other' section includes people who identify as alternative genders or for whom the data was not easily collated or identify.

Table 3.4: The gender of adults accessing services

Gender	
Male	2,246
Female	2,695
Prefer not to say	116
Other	124

Graph 3.4: The gender of adults accessing services

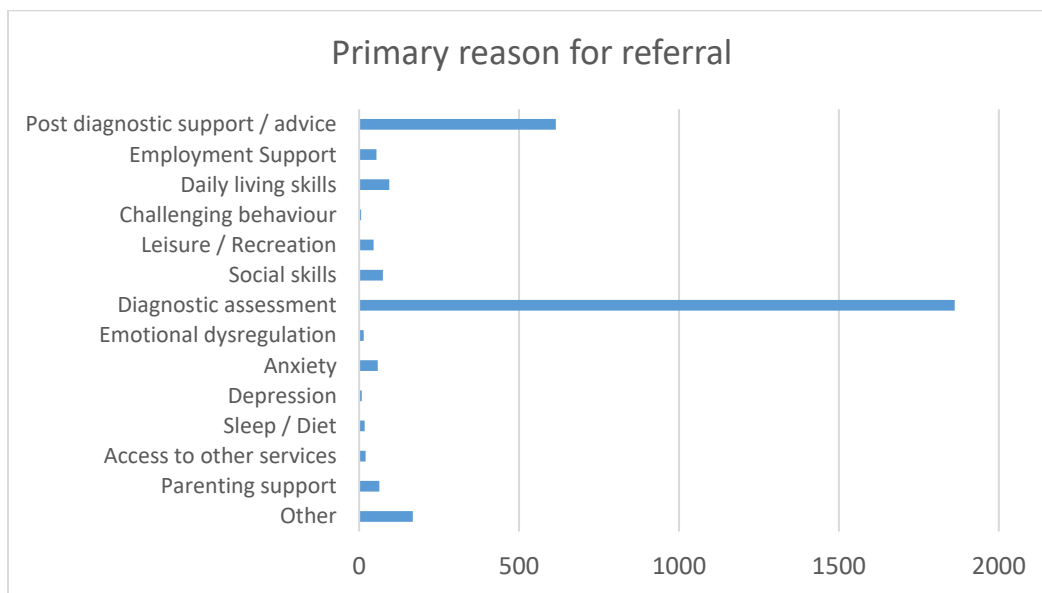


The table and graph below depict the primary reason that adults are referred into the service. This may change through initial discussions with the service but gives an idea of some of the difficulties that are identified by adults accessing the service.

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

Primary reason for referral	
Post diagnostic support / advice	704
Employment support	42
Daily living skills	71
Challenging behaviour	12
Leisure / recreation	38
Social skills	36
Diagnostic assessment	3,883
Emotional dysregulation	28
Anxiety	75
Depression	25
Sleep / diet	46
Access to other services	18
Parenting support	57
Other	144

Graph 3.5: The primary reason for referral into the service

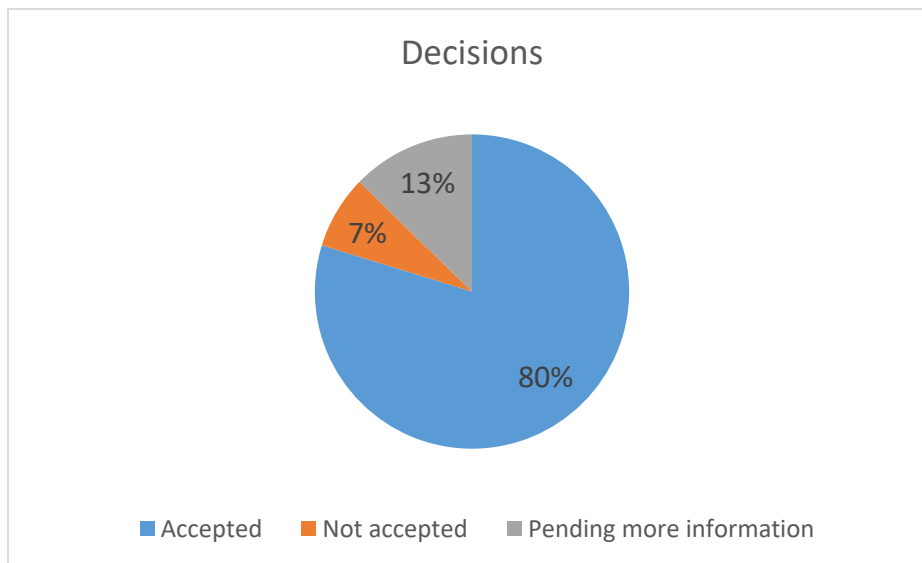


Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 3.6: The outcome of referrals into the service

Referral Outcomes	
Decisions	
Accepted	4,091
Not accepted	386
Pending more information	652

Graph 3.6: The outcome of referrals into the service

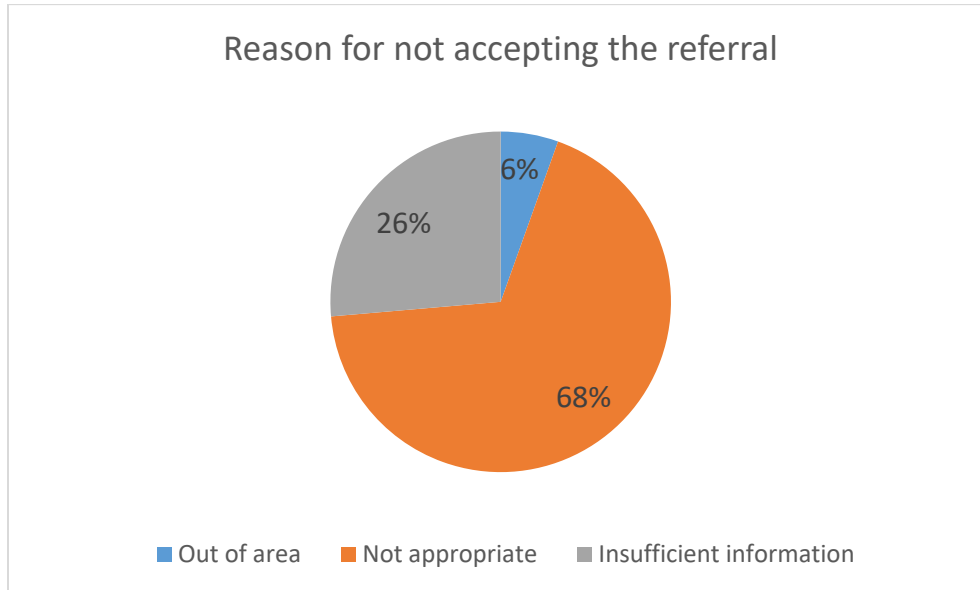


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including someone who is receiving support from other services such as learning disability services or mental health services, or not appropriate due to age.

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

Reason for not accepting the referral	
Out of area	22
Not appropriate	274
Insufficient information	106

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

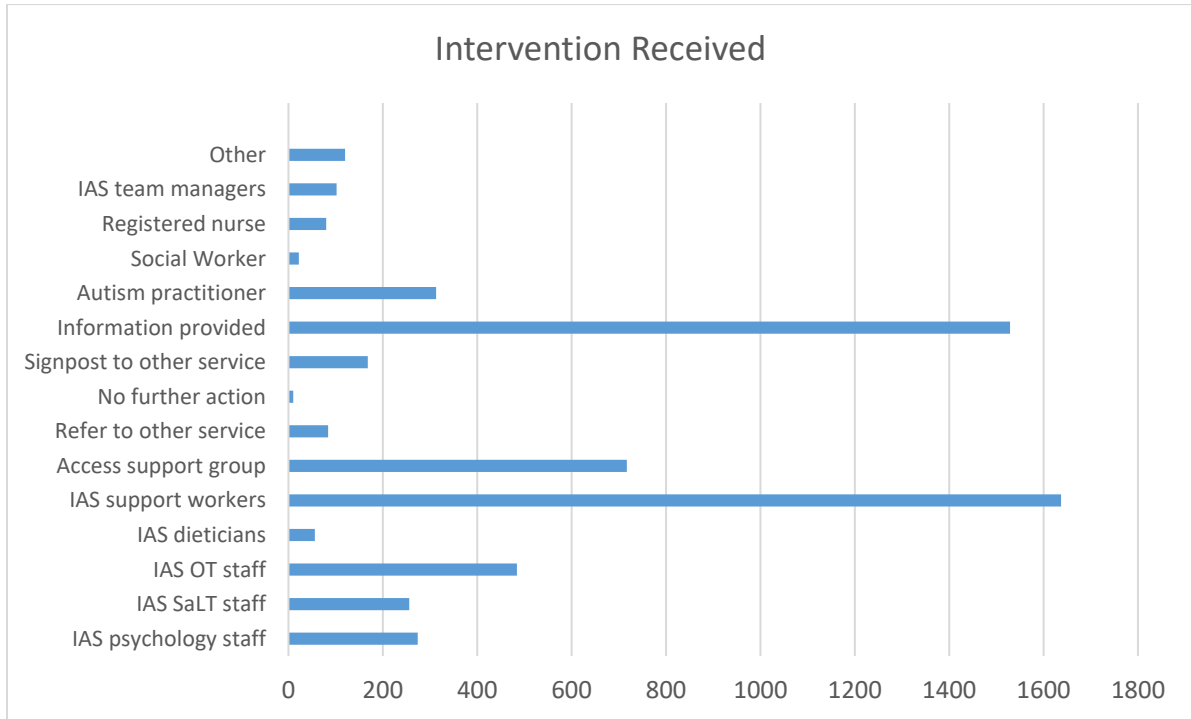


The table and graph below depict the interventions received by adults accessing the service. This gives an idea of what kind of services autistic adults need.

Table 3.8: The interventions received by adults within the service

Intervention Received	
Diagnostic assessment	1,279
IAS psychology staff	274
IAS Speech and Language Therapy staff	256
IAS Occupational Therapy staff	484
IAS dieticians	56
IAS support workers	1637
Access support group	717
Refer to other service	84
No further action	10
Signpost to other service	168
Information provided	1529
Autism practitioner	313
Social Worker	22
Registered nurse	80
IAS team managers	102
Other	120

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 2022/23 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	1.9
Average weeks from referral accepted to start of intervention	5.1
Timeliness of diagnostic assessment	
Average weeks from point of referral received to accepted	3.1
Average weeks from referral accepted to start of intervention	95.1
Average weeks from initial appointment to diagnosis / outcome	5.0

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	973
Number of assessments that lead to a positive diagnosis	623

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	360
Number of people who attended group sessions	974
Number of formal complaints received	10
Number of compliments received	313

4. Parent/ Carer Data

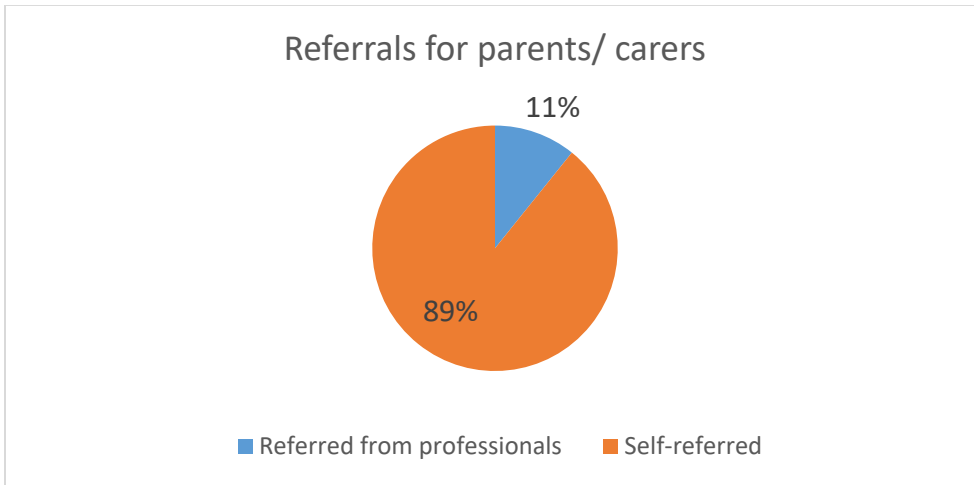
Whilst not working directly with children and young people, the service works in partnership with other organisations to support parents and carers. Below is data related to this provided by the IASs in 2022/23.

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

Interactions with parents/ carers	1,817
Referrals for parents/ carers	399
Referred from professionals	43
Self-referred	356

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

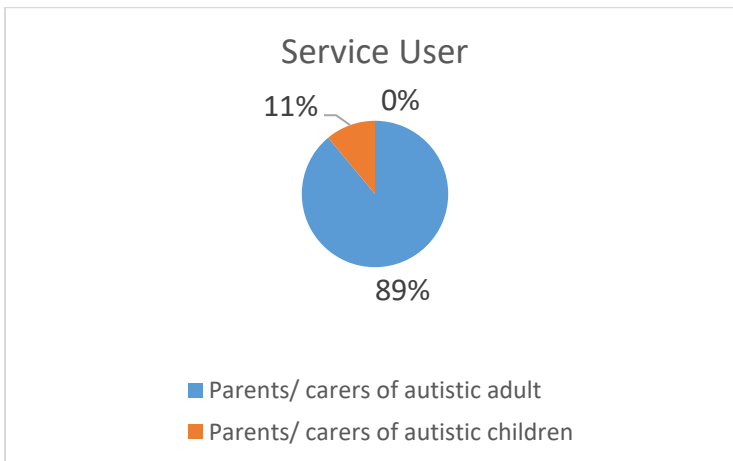


The table and graph below show whether service users are parents and carers of autistic adults or children. The 'other' category includes parents/carers who care for both those over and under 18 and instances where the data was unavailable.

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

Service User	
Parents/ carers of autistic adult	145
Parents/ carers of autistic children	18
Other	0

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

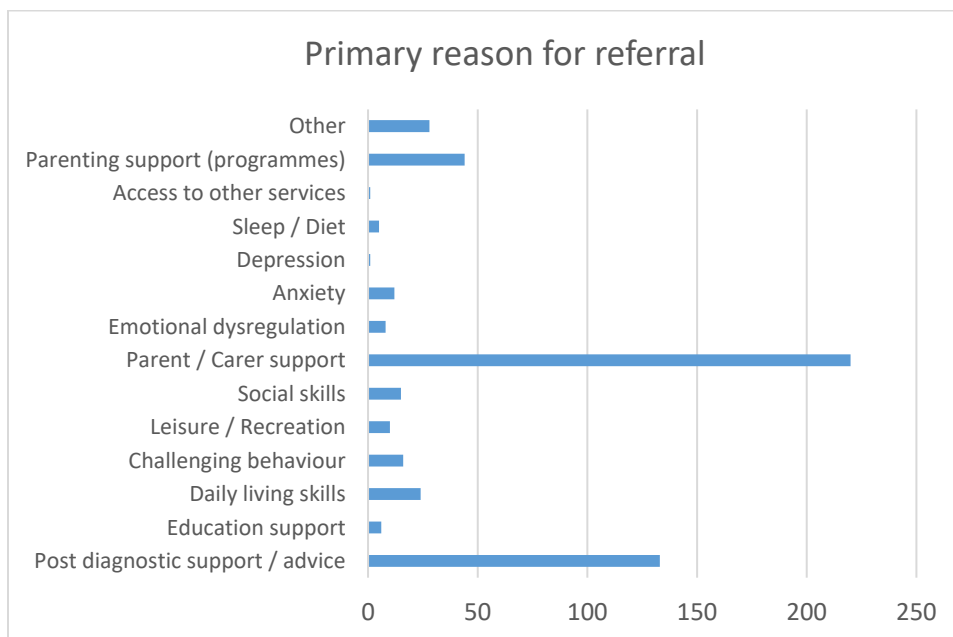


The table and graph below depict the primary reason that parent/ carers are referred into the service. This may change through initial discussions with the service but gives an idea of the support that parent/ carers are seeking.

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

Primary Reason for referral	
Post diagnostic support / advice	133
Education support	6
Daily living skills	24
Challenging behaviour	16
Leisure / Recreation	10
Social skills	15
Parent / Carer support	220
Emotional dysregulation	8
Anxiety	12
Depression	1
Sleep / Diet	5
Access to other services	1
Parenting support (programmes)	44
Other	28

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

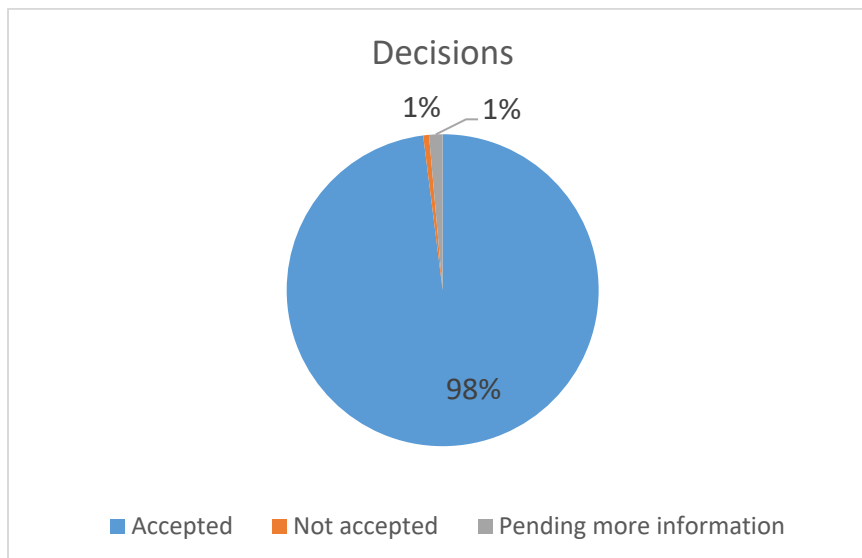


Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 4.4: The outcome of referrals into the service

Referral Outcomes		
Decisions		
	Accepted	491
	Not accepted	3
	Pending more information	7

Graph 4.4: The outcome of referrals into the service

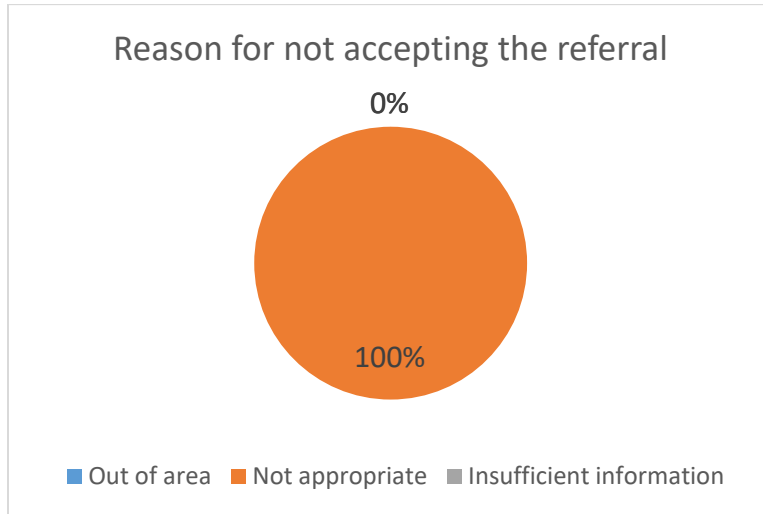


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including those who are receiving support from other services.

Table 4.5: The reasons for not accepting referrals into the service

Reason for not accepting the referral	
Out of area	0
Not appropriate	3
Insufficient information	0

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

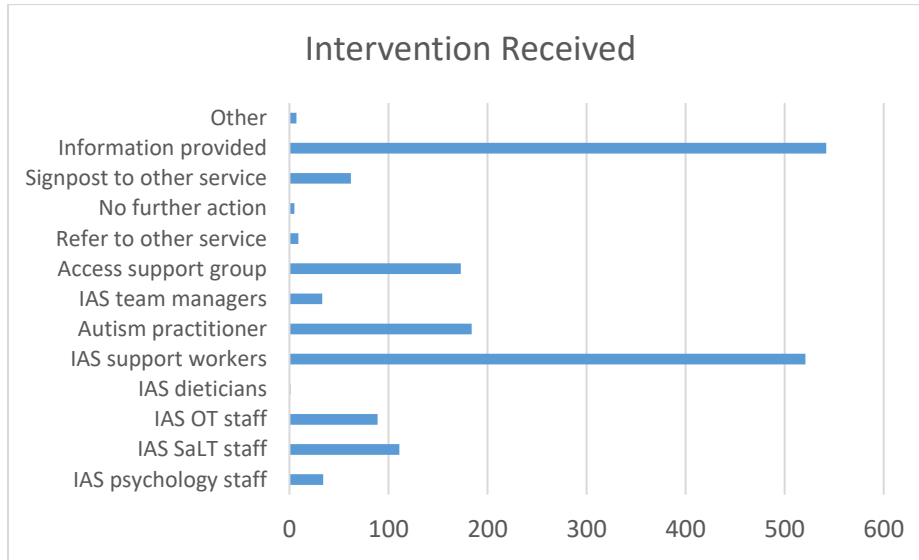


The table and graph below depict the interventions received by parent/ carers accessing the service. This gives an idea of what kind of services parent/ carers need.

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

Intervention Received	
IAS psychology staff	34
IAS SaLT staff	111
IAS OT staff	89
IAS dieticians	1
IAS support workers	521
Autism practitioner	184
IAS team managers	33
Access support group	173
Refer to other service	9
No further action	5
Signpost to other service	62
Information provided	542
Other	7

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 2022/23 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 2022/23 year.

Table 4.5: Additional information for parents and carers

Additional Information	
Number of support group sessions held	117
Number of formal complaints received	5
Number of compliments received	121

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 2022/23.

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	4,346
New contact with professionals	1,732

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	744
Request for training	101
Other general enquiry	862

Graph 5.2: The primary reason for contact with the service

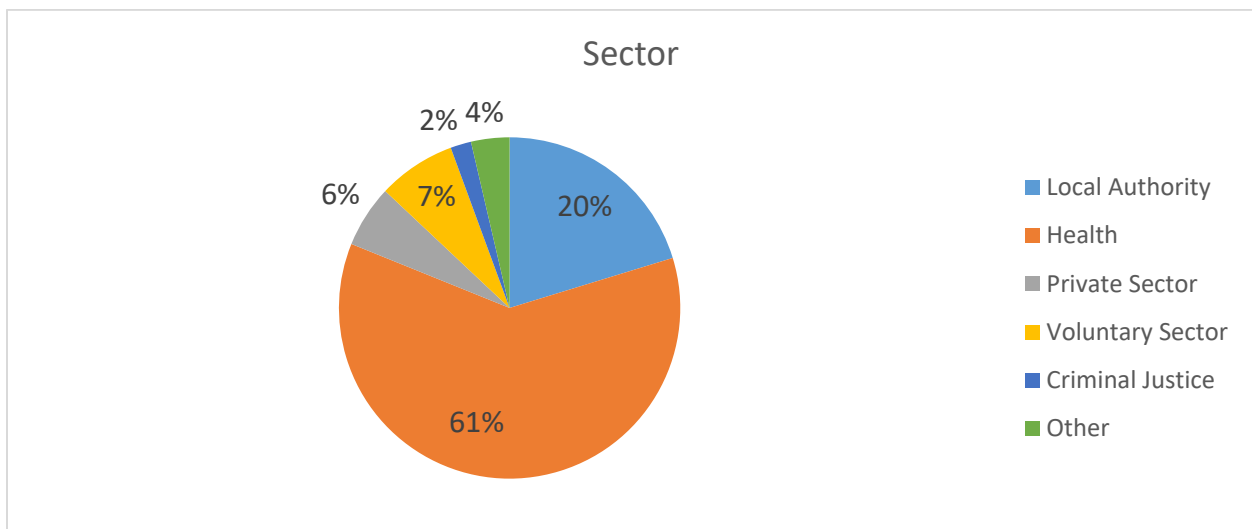


The following table and graph show the sector which professionals contacting the services are from. The 'other' category may include professionals working in the civil services such as DWP employees or the information may not be available to include.

Table 5.3: The sector professionals contacting the service are from

Sector	
Local Authority	351
Health	1,054
Private Sector	102
Voluntary / Third Sector	128
Criminal Justice	34
Other	63

Graph 5.3: The sector professionals contacting the service are from



6. Conclusion

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

For services provided to adults 57% of referrals were self-referrals from adults themselves. Seventy two percent of the referrals were for diagnostic assessment and 28% for support. Most of the age distribution of autistic adults accessing the service is between 18-45. The most frequently accessed interventions were work with IAS support workers, providing information, diagnostic assessment and accessing support groups. It can also be noted that there was a 21% increase in referrals to the service for adults in 2022/23 in comparison with 2021/22 figures. In addition, there was a slight decrease of 3.5% in diagnostic assessments undertaken in 2022/23 in comparison to 2021/22, although it should be noted that the figure for 2021/22 was a 52% increase from the previous year.

For services provided to parent/ carers 89% of referrals were self-referrals. Eighty nine percent of the referrals were from parent and carers of adults and 11% were from parent and carers of children. The primary reason for referrals were for parent/ carer support, post diagnostic support/ advice, parenting support programmes and daily living skills. The most frequently accessed interventions were providing information, accessing support groups, support from IAS support workers and support from Autism practitioners. It can also be noted that there was a 7% decrease in referrals to the service from parent/ carers in 2022/23 in comparison with 2021/22 figures, although again it should be noted that the figure for 2021/22 was a 32% increase from the previous year.

The data shows that a significant part of the services' work is engaging with professionals. The primary reason for referrals were general enquiries at 50% and request joint work/ consultation with client at 44%. In addition, 61% were professionals from the health board, 20% were from local authorities and 7% from the voluntary sector. It can also be noted that there was a 47% decrease in contacts with the service from professionals in 2022/23 in comparison with 2021/22 figures.