



AwtistiaethCymru.org

Tîm Awtistiaeth Cenedlaethol
National Autism Team

AutismWales.org

Supplementary Annual Report 2020/21

"...Highly beneficial in raising awareness of Autism and providing deeper understanding and insight into the daily challenges faced by those living with autistic characteristics."

"Although I have worked for many years with autistic children, I feel I now have a better understanding of how the world looks from their perspective."

"...It is developing their understanding that we are all different and those qualities should be respected and celebrated."

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Introduction

Our thanks to Welsh Government for the continued core funding to support the successful implementation of the Welsh Government ASD Refreshed Strategic Action Plan and associated Delivery Plan.

The National Autism Team's (NAT) Annual Report for 2020/21 provides a supplementary report to the substantive document produced in 2018/19. 2020/21 proved to be a very difficult year as the team had to adapt to a new way of working and some projects had to be adapted or postponed. However, as the annual report demonstrates the NAT and their partners continued to develop and deliver a whole range of resources, training and key information throughout the period. The move online also offered huge opportunities to connect with wider audiences and be proactive as needs emerged.

The All Wales Virtual Autism Team came together to produce key information and guidance at a crucial time to underline the wealth of experience and expertise we have in Wales. This work proved challenging in a constantly changing landscape however, as demonstrated on the Covid 19 section of the website, VATW effectively rose to that challenge. Thank you to everyone who contributed and gave their time and expertise.

The new website, which has been developed and informed by the voice of the autistic community, has proved to be another key development during this period. The website remains one of our key offers to the autistic community and professionals across Wales.

As you will see in the report 2020/21 offered the opportunity to develop and deliver online training and events to whole range of audiences. From DWP colleagues, education settings, employers, IASs, Autism Leads, third sector partners, Local Authorities, Health Boards and the autistic community themselves we were all able to adapt, stay connected and work together in new and innovative ways.

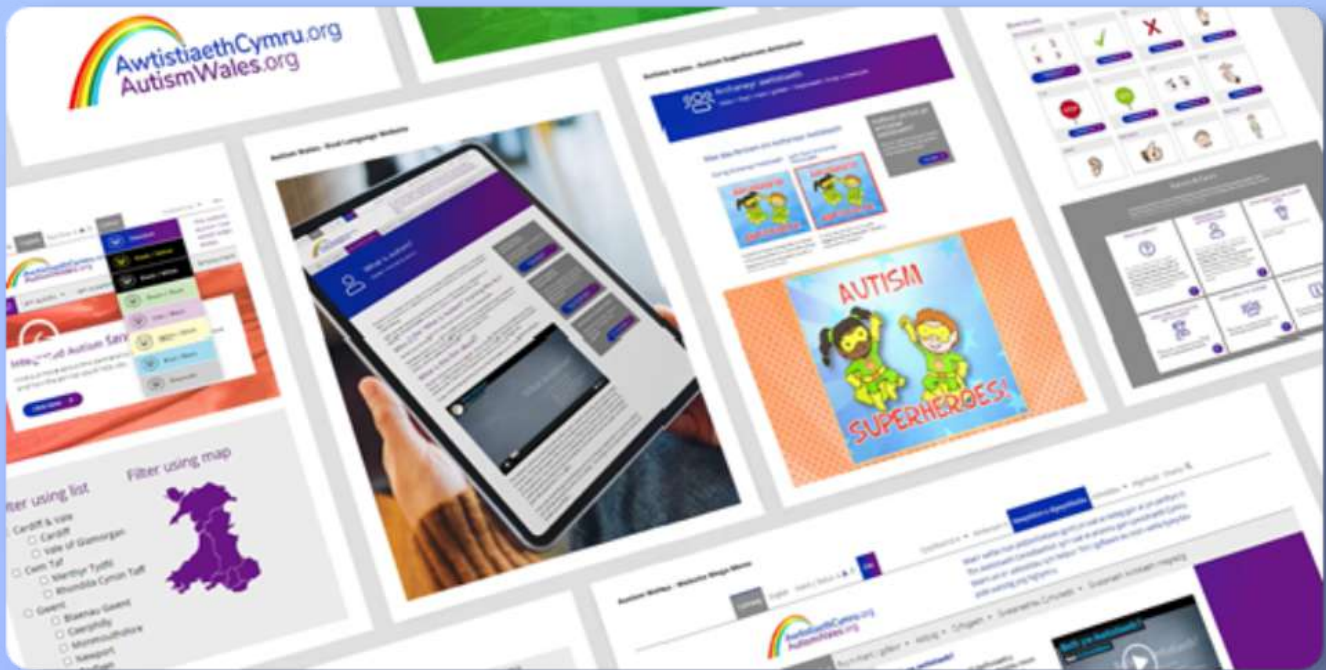
We hope you find the report informative and of interest. There remains much to be done for autistic people and their families but there is also much to be celebrated.

- The National Autism Team

New website and website provider

Although the ASDinfoWales website was a well-known and established website, which provided useful information and resources to autistic people, their families, parents/ carers, professionals, and the general public, the National Autism Team felt it was time for the website to be refreshed.

Towards the end of 2019/20, the NAT procured a new website provider via Sell2Wales. During April / May 2020, the team established a Project Board and two Stakeholder Groups – one for content, and another for testing. These meetings ensured that the development of the new website included the views and voices of autistic people, parents/ carers and professionals who were well versed in the old website.



On **Tuesday 29th September 2020**, the brand-new website AutismWales.org / AwtistiaethCymru.org was launched. Which included, refreshed new look website and domain name and improvements to user navigation and accessibility.

Since the launch the team have worked with the website providers and further improved/developed some of their existing resources:

- Interactive and narrated versions of the Autism Superheroes comic and story books
- A 'User dashboard' to personalise the site for the user
- Improved employment resources and workbook for autistic employees

What's next?

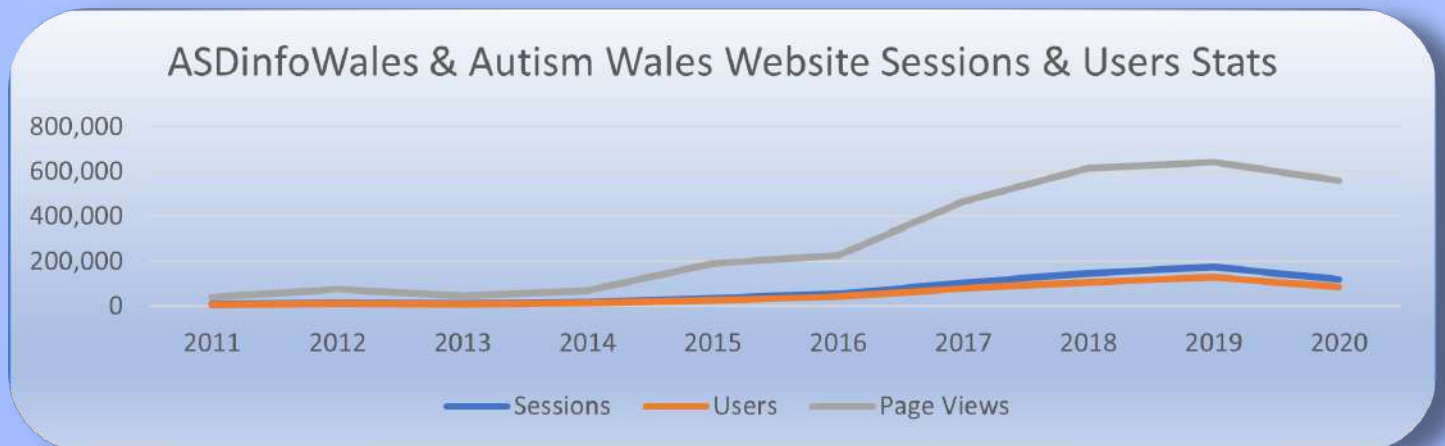
During 2020/21 the team will continue to improve the content and resources available across the website, such as:

- Unique user accounts created for Welsh Primary and Secondary Schools
- Easy Read versions of resources and documents
- A 'Children and Young People's Zone'
- Interactive Case Studies Compendium to capture the good practice taking place in autism services and Local Authorities in Wales

ASDinfoWales / AutismWales website stats

[AutismWales.org](https://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.

During the transition to the new website there was one month worth of data that was not captured via google analytics, which was reflected in 2020 statistics. Although the numbers show the users decreased by 34% and page views by 13% (559,967 page views in 2020), the average duration users were at the website increased by almost one minute and the number of pages viewed per session also increased by 21%.



All Wales Virtual Autism Team & NAT Response to the Covid-19 Pandemic



In response to the Covid-19 pandemic and the world moving online, the National Autism Team set up the All Wales Virtual Autism Team. The Team included members of the National Autism Team, autistic people and professionals from across Wales who have worked in the field of autism for many years. The Virtual Autism Team Wales was set up to provide accurate, useful, and up-to-date information, advice, and guidance during the COVID-19 emergency to autistic people in Wales, their parents and carers and professionals.

The group met virtually to identify key themes, information, advice, and guidance from a variety of sources. These were then used to collate and disseminate information on the 'most pressing' issues in a user friendly and accessible way. The resources provided by the Team covered themes such as General information, Transition, Virtual Assessments, Mental Health, Wellbeing and Autistic Experiences. The Team provided specific resources for autistic adults and parents/carers, e.g the Test, Trace and Protect advice sheet, to help them to navigate what was an incredibly unprecedented, stressful and confusing time for many autistic people and their families.

The NAT reviewed and adjusted its work plan to respond to the needs of autistic people and their families more proactively and created a Covid-19 hub of information on [AutismWales.org/en/news/latest-information-on-novel-coronavirus-covid-19/](https://www.autismwales.org/en/news/latest-information-on-novel-coronavirus-covid-19/). The Team also increased social media activity, as part of this response via their [Facebook](#) and [Twitter](#) accounts.

Chapter 2: Collaborative Working

Working with the autistic community

Autistic people are the core of our working groups, and help shape and inform our work, resources, training, and events. Autistic UK Wales have been commissioned to proof-read all our documents, and training to ensure that they are fit for purpose and is acceptable to the autistic community. As a principle we value the contribution of the autistic people who work with us and recognize the time, energy, expertise and commitment they give to our projects.



Working with Willow

The National Autism Team filmed a digital case study with Willow Holloway called **'Working with Willow'**, an inspirational autistic advocate and lived experience advisor. Willow is the Executive Chair and Strategic Lead for Autistic UK in North Wales, where she is now based, and has been Vice Chair for the Disability Wales Board since 2016. Willow received a late diagnosis of autism at the age of 44, and in the case study she talks about the impact receiving her diagnosis has had on her life.



Working with Willow is the second digital case study that the National Autism Team have produced. In the Digital Stories series, the National Autism Team ask autistic people what they would like parents/carers, professionals, and the general public to know about autism.

What's next?

The NAT intend to continue creating digital stories this year, to celebrate the achievements of autistic individuals across Wales. The National Autism Team also intend to expand the series to include digital stories with a professional focus, in order to amplify the voices of autistic individuals and their parents/carers and help them to communicate their needs to practitioners.

Online employment symposium

On 4th December 2020, the National Autism Team facilitated a Free Employment Symposium Webinar in partnership with Swansea University, the National Centre for Mental Health (NCMH) (Cardiff University) and Learning Disability Wales (LDW). The symposium was funded by Welsh Government and supported by the Welsh Local Government Association (WLGA) and Public Health Wales (PHW).



The event was held for employers, supported employment providers and key employment staff and provided guidance on support available to employers with autistic employees. The event was held in collaboration with Learning Disability Wales in order to ensure that the needs of autistic individuals with a co-occurring learning disability were also represented. The event hosted a range of

speakers, both neurodiverse and neurotypical, and provided attendees with resources to better support autistic employees.

Feedback from the event demonstrated that attendees developed a better understanding of autistic people's experience of the workplace and employment. Furthermore, attendees also reported improved knowledge and understanding of the reasonable adjustments that need to be put in place in order for autistic people to thrive in the workplace.



What's next?

The National Autism Team are in the beginning stages of developing an employment event for the autistic community which is being co-produced with autistic people in order to ensure it is shaped by the needs and views of the autistic community.

Autism Leads

The National Autism Team work closely with the 29 Autism Leads in local authorities across Wales. The National Autism Team have continued to facilitate the quarterly National Autism Leads network meetings virtually, and introduced regional “Hwb” meetings, to encourage strong engagement across the specialism and to provide an opportunity to share good practice on a national, regional and local level. The attendance levels have been record-breaking as more Leads are able to attend with the absence of travel time.

The Autism Leads played an essential role in disseminating information from the National Autism Team locally and informing national policy and guidance through local networks and engagement in a grass-roots approach. The network ‘sign-posted’ the people they support and professional colleagues to the National Autism Team’s Covid-19 Information webpage, and Facebook and Twitter pages.

Examples of innovative practice demonstrated by Autism Leads during this period are:

- Continued one-to-one ‘virtual’ support of vulnerable adults, or those with very high needs in Blaenau Gwent.
- A virtual VE Day party to keep the community connected in Wrexham.
- Storybooks explaining Covid-19 to young children, including autistic children provided in Flintshire.
- A “card” developed to provide autistic people with improved communication mechanisms with emergency services during lockdown in Denbighshire.
- A virtual “forum” for young autistic adults developing skills for life in Cardiff & Vale.
- A thorough “lessons learned” evaluation throughout the lockdown period, resulting in a re-designing and re-shaping of some services in Torfaen.
- Ten “hubs” opened during lockdown to support families in Pembrokeshire.
- Engagement with autistic adults and those with a learning disability through the lockdown period in Gwynedd.

Telehealth Workshop

Over the past year, the National Autism Team have worked closely with developers of telehealth services, which has been of increasing importance with much of the world moving online due to the Covid-19 pandemic. In September 2020, the National Autism Team held a workshop focused on telehealth services, which brought together those working in the Integrated Autism Services and Neurodevelopmental services to identify the key issues in telehealth care.

The workshop speakers included Professor Alka Ahuja, who provided information about the developments of telehealth services in Wales so far; Dr. Catherine Norton, who reflected on telehealth services from a neurodevelopmental services perspective; and Simon Moseley, clinical psychologist in North Wales IAS and Bethan Roberts, clinical psychologist in West Wales IAS, who reflected on the strengths and challenges of telehealth services in their regions, with particular reference to diagnostic assessments and virtual support.

The workshop provided an opportunity for attendees to share best practice and reflect on the opportunities and challenges involved in the use of telehealth services to support autistic individuals, and to identify what needs to be done to overcome these challenges moving forward.

Regional Partnership Boards (RPBs)

The National Autism Team, IAS Leads and Welsh Government colleagues continued to attend the Regional Partnership Boards (RPBs) throughout Wales to raise awareness of autism, and the work being undertaken locally, regionally, and nationally. There was particular emphasis upon the increased role of the RPB, outlined in the Code of Practice for autism, which will have a significant impact on how autism services are monitored and delivered.

Online diagnostic assessments and support

The year 2020/21 has been a difficult year for many and the pandemic has had an unprecedented impact on many public services, including all seven Integrated Autism Services (IAS) in Wales. However, all seven IASs have shown resilience and innovation by amending policies and procedures in order to provide a service to those seeking diagnostic assessment and support in difficult circumstances.



During 2020-21 most training providers adapted their courses to be able to deliver them remotely. ADIR and ADOS diagnostic assessment courses were adapted and rolled out to IAS staff throughout this period to ensure that staff were equipped with the knowledge and skills to continue providing assessments remotely.

In addition, several of the IASs adapted their courses and support services so that they could be delivered to autistic people and their families remotely e.g. a virtual post diagnostic support course and virtual support hubs. These proved to be extremely popular and ensured that many people could continue to be effectively supported throughout the pandemic.

Covid-19 Response: Online Hwb Meetings

The National Autism Team have continued to facilitate regular virtual meetings between IAS staff members to share examples of good practice and positive solutions to meet the demands of Covid-19 restrictions. The meetings have focused on issues such as online diagnostic assessments and offering virtual support.

Data collection

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 headlines were observed this year:

- **7,032** interactions were made with adults
- **2,344** referrals to the service were made for adults with **43%** of these self-referrals
- **50%** of referrals for adults requesting autism diagnostic assessments and **50%** were requesting support
- **662** adults received a diagnostic assessment
- **479** adults received a positive diagnosis of autism (**72%**)
- **275** support group sessions for autistic adults
- **1,258** interactions were made with parents/ carers
- **324** referrals to the service were made for parents/ carers with **83%** of these self-referrals
- **63%** of referrals were for parent/ carers of autistic adults and **33%** were for parent/ carers of autistic children
- **36** support group sessions for parent/ carers
- **6,364** interactions were made with professionals
- **2,500** new contacts with professionals
- **54%** of contacts were from health professionals, **27%** were professionals from local authorities and **7%** were professionals from the voluntary sector

For the full 2020/21 IAS data report, see Appendix 1.

Demand and Capacity review

Welsh Government were planning to commission a demand and capacity review of neurodevelopmental services in Wales in April 2020. However, due to Covid 19 demands this work was delayed. The National Autism Team and IAS Leads had undergone training in readiness for the review. Therefore, it was decided that some initial work would be undertaken to supplement the information that was already available via the IAS reporting data set. This work was undertaken in April – September 2020.

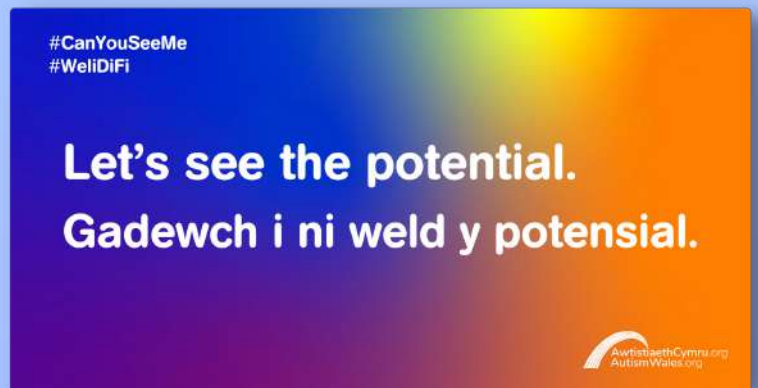
Individual reports for each IAS were created jointly between the National Autism Team and IASs and included chapters on the referral process, demand, service data, team structure and barriers to service both current and anticipated.

World Autism Awareness Week 2021

World Autism Awareness Week is a key event for increasing awareness, understanding and acceptance of autism and is celebrated in the last week of March. Like last year, World Autism Awareness Week 2021 was celebrated virtually in accordance with Welsh Government Covid-19 regulations. The National Autism Team responded creatively to the situation, to ensure that the week was used to raise awareness to the prevalent issues facing autistic people and their parent/carers across Wales. 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 awareness on the Autism Wales website.

Can You See Me II

World Autism Awareness Week 2021 also fell within the National Autism Team's 4-week 'Can You See Me? II' campaign, which began on 10th March 2021. The campaign was supported by external marketing company **Cowshed Ltd.** and was a relaunch of the original 2017 **Can You See Me?** campaign.



The Can You See Me II campaign focused on employment and its aim was to encourage businesses to see the potential of autistic people in the workplace. The campaign touched on an incredibly relevant issue, with only 15% of autistic people in full-time employment. This figure is likely to be even lower when including those who are undiagnosed, or those have lost employment as a result of the Covid-19 pandemic.

The Team worked closely with Cardiff-based communications and marketing company, Cowshed Ltd. Together, the project team produced a **campaign video**, narrated by Amara Tamblyn, an autistic young woman who has just completed a law degree. The project team also produced a bilingual stakeholder toolkit, which provided social media graphics that outlined the campaign's key message which were shared widely on social media.

The Campaign video received 8,050 views across Facebook and Twitter and 53 organisations from across Wales shared campaign messages, including Gwent Police, Transport for Wales, National Theatre Wales, Principality Stadium and 13 local authorities. The campaign also received 5 pieces of coverage across TV, radio and online, including a TV interview with Amara Tamblyn on ITV Wales and features on BBC Radio Cymru, **The National**, **News From Wales**, **Business Live** and **Western Mail**.



Cowshed took control of Autism Wales' Twitter and Facebook social media channels for the duration of the campaign. In total 125 campaign related posts were made on Twitter and 82 were made on Facebook across the duration of the campaign. Can You See Me II was an important contribution to the conversation surrounding autism and employment and the social media presence of the campaign intended to communicate to the autistic community that they are valued by employers.

One of the central aims of the campaign was to encourage organisations to complete the **Autism Aware Certification Scheme**, available on AutismWales.org, which provides general training about what autism is. So far over 3,500 people have taken the first step and completed the Autism Awareness questionnaire, and 9 businesses have become autism aware. This number is increasing by the day, with the National Autism Team supporting a number of local authorities to become autism aware and therefore better equipped to support autistic employees.

Developing Virtual Training

In response to the Covid-19 pandemic and teams across Wales working from home, developing bespoke training packages, utilising digital platforms, and creating virtual training programs were key priorities for the National Autism Team in 2020/21. The Team also collaborated with Autism Wellbeing to fund online courses for autistic people, parent carers and professionals.



Emergency Services Training

North Wales Police

The Team adapted the existing Train the Trainer resources to an online package, holding virtual sessions for North Wales Police. Face to face Autism Awareness sessions also took place as part of the Mental Health and Suicide prevention training. The National Autism Team will continue to work with North Wales Police this year to roll out the Emergency Services Train the Trainer package further.

"The training was detailed and interesting".

"A big thank you for an excellent session, it was well received by all".

Children and Family Court Advisory and Support Service (CAFCASS) Cymru

The National Autism Team also provided virtual Understanding Autism Training autism for Cafcass Cymru.



"It was really helpful to know how to contact an organisation with specialism in this area for advice/support/assessment. The trainers were very good at communicating the issues and happy to respond to any questions or queries".

"Having worked in a Children with Disabilities Team, I was very impressed, again, with the high standard of your work!"

Department for Work and Pensions (DWP) Training

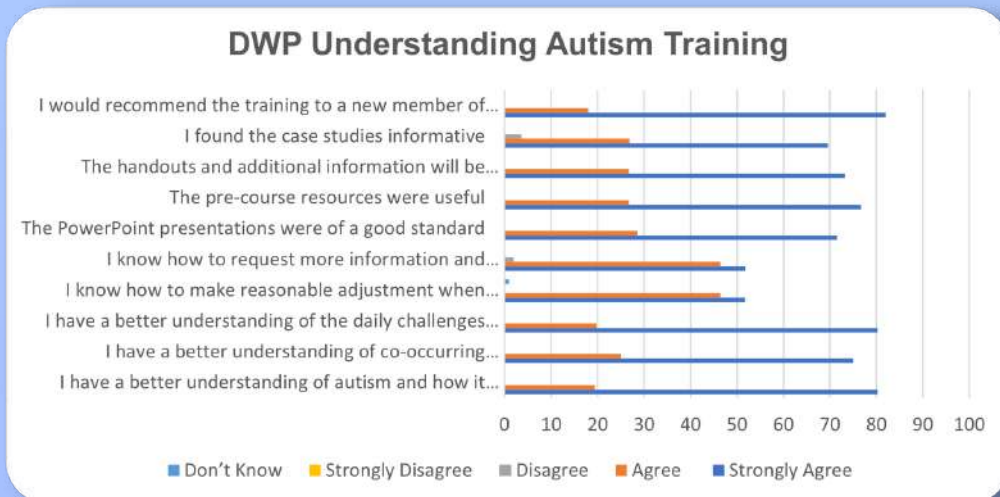
This year, the National Autism Team have worked closely with DWP nationally alongside local Integrated Autism Services. The long-term aim of this work is to make the organisation autism aware and increase their understanding of autism, so that the process of applying for Personal Independence Payments (PIP) is less onerous and stressful for autistic people.



A bespoke training package was created for the organisation. The package included pre-course materials and a resource toolkit that assessors can refer to when working with autistic people, to help them to better understand the underlying co-occurring conditions that affect so many in the autistic community.

The training was provided to DWP Tier 1 and Tier 2 staff. The training shared the vast range of resources available on our website and assisted Job Coaches not only to better understand autism, but to better understand the challenges faced by other neurodiverse job seekers.

DWP Tiers 1



DWP Tiers 2



“Over the past year DWP PIP Reconsiderations Team in Wales have been working in partnership with the National Autism Team for Wales to raise Autism Awareness. This has been an invaluable partnership.

Delivery of the training sessions highlighted their expertise and professionalism. The sessions were highly beneficial in raising awareness of Autism and providing deeper understanding and insight into the daily challenges faced by those living with autistic characteristics.

The impact has been powerful, opening up discussion and providing a thorough insight. Colleagues report the training had a transformative effect which they have made use of both inside and outside of work in how best to support claimants, make informed decisions on benefit entitlement, and in supporting colleagues and friends and family members who have autistic characteristics.

As a department we are pleased this training has run across all areas of PIP within Wales; First Tier and Reconsideration. We are delighted to hear that this training will be launching across CAPITA to all assessors in Wales later this year.

I am extremely proud to have heard feedback from claimants and from Frances that DWP are getting it right and they have had smooth and pleasant journeys through the claim process.

The training has left a lasting impression and we look forward to continuing our partnership with the National Autism Team and strive to continuously improve customer experience for our claimants”.

- Sianny Wynter, PIP Disputes Leader

Autism Wellbeing

Making Sense of Autism



The National Autism Team supported Autism Wellbeing to deliver an online training course for autistic people and their caregivers. Funded by Welsh Government, ‘Making Sense of Autism’, created by a team of autistic and non-autistic trainers, comprised a range of learning resources; a series of short films complemented by a set of written learning materials (PDFs). The films and learning resources together provided attendees a clear understanding of the sensory processing difficulties that many autistic people experience.

Find out more information about the training course [here](#).

“It was all useful but particularly the lived experience examples to back up the theoretical aspects. I will be far more sensory aware”.

"Although I have worked for many years with autistic children, I feel I now have a better understanding of how the world looks from their perspective”.

Sensory Trauma

Welsh Government also funded 'Sensory Trauma and Autism' an online training course shining a light on this neglected and often misunderstood dimension of autistic experience. A series of short films setting out the different aspects of Sensory Trauma as well as the impact that Sensory Trauma can have on the lives of autistic people. The course materials included extensive use of the first-person testimony of autistic individuals and included written learning materials (PDFs) as well as a reading/resources list for course participants who wanted to explore Sensory Trauma in greater depth.

Find out more information about the training course [here](#).

"It was all thought provoking. I particularly found the section relating to the parasympathetic nervous system interesting and the impact of sensory trauma from so young and the impact of that going forward on social interaction and relationships".

"The course was insightful and inspiring. Thank you".

Chapter 6: Learning about Autism

The Learning about Autism programmes adopts a whole setting or school approach to improve awareness and understanding of the needs of autistic children. The training is designed to stimulate 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, **2,262 staff** have undertaken the training programme and **96** Early Year Settings have received their LaA award, **25 of these were during 2020/21**.



In the last year, feedback from the post-training evaluation forms from these settings have shown that **100% agree** that 'the LaA programme increased their understanding of autism' and **100%** agreed that 'the programme has had a positive impact on children.'

The following quote was received by a setting who completed the programme in 2020/21:

"I believe it has had a really positive impact on all of the children, it is developing their understanding that we are all different and those qualities should be respected and celebrated."

- *Alphabet Playgroup Ltd*

The Primary Schools Programme

The Primary Schools Programme was launched in March 2016. Since its launch, **213 schools across Wales** have achieved their LaA award. During 2020/21 a further **28 schools** achieved their LaA award – a huge achievement during the pandemic.



Over the past year, LaA training has been undertaken by **789 Teaching staff** (7,702 in total) and **1,005 Learning support Staff** (7,997 in total). Furthermore, **1,174 children have completed the Autism Superheroes scheme**. (42,801 in total).

The evaluation forms completed by the schools who have undertaken the programme demonstrate that: **100% agreed** that the programme has 'increased their ability to recognise particular signs of autism that they might have missed before'; **94% agreed** that 'the Learning About Autism programme led to changes being made to a child's IEP?'; and **100% agreed** that they 'would recommend the Learning About Autism Programme to other schools.'

The following quote was received by a primary school who completed the programme in 2020/21 shared how they will adapt their day to day practice.

"By recognising that no two autistic children are the same. Gaining a holistic view of the child and adapt practice to individual learning styles, sensory needs and by placing learning last in respect of importance. The child's surroundings are of great importance and once this is correct, learning will follow."

- Capcoch Primary School

The Secondary Schools Programme



Since its launch at the beginning of September 2017, **4,627 staff** have undertaken the training programme, and **22,026 pupils** have received the Sgilti lesson and taken their pledge. A further **4 schools** across Wales have received their LaA award this past year, resulting in **20 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 LaA programmes, which contributed to the 7,623 that were awarded during 2020/21.

The feedback from the evaluation forms from these settings have shown that **100% agree** that 'the LaA programme increased their understanding of autism', and **100% also agreed** that 'the programme has increased their ability to recognise any particular signs of autism that you might have missed before'. Moreover, **all schools** have stated that they would recommend the programme to other schools.

Feedback from Milford Haven School perfectly captures why the Learning about Autism programme is essential to the wellbeing of autistic pupils and those with autistic family members.

'We had very good reactions to the lesson, including one pupil personally thanking us for showing the video because his younger sibling is due with us in September and he has autism and he was worried about people understanding. We have also had a number of our autistic pupils asking if we could show more videos to include a female perspective, celebrities and other successful autistic people.'

- *Milford Haven School*

Integrated Autism Services 2020/21 Data Report

1. Executive Summary

The year 2020/21 has been a difficult year for many and the pandemic has had an unprecedented impact on many public services including all seven Integrated Autism Services (IAS) in Wales. However, all seven IASs have shown resilience and innovation by amending policies and procedures in order to provide a service to those seeking diagnostic assessment and support in difficult circumstances. This report shows key high-level data from all seven IASs across Wales and reflects the hard work and dedication of staff to ensure that the impact of the pandemic was kept to a minimum.

The following data headlines were observed.

- **7,032** interactions were made with adults
- **2,344** referrals to the service were made for adults with **43%** of these self-referrals
- **50%** of referrals for adults requesting autism diagnostic assessments and **50%** were requesting support
- **662** adults received a diagnostic assessment
- **479** adults received a positive diagnosis of autism (**72%**)
- **1,258** interactions were made with parents/ carers
- **324** referrals to the service were made for parents/ carers with **83%** of these self-referrals
- **63%** of referrals were for parent/ carers of autistic adults and **33%** were for parent/ carers of autistic children
- **6,364** interactions were made with professionals
- **2,500** new contacts with professionals
- **54%** of contacts were from health professionals, **27%** 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

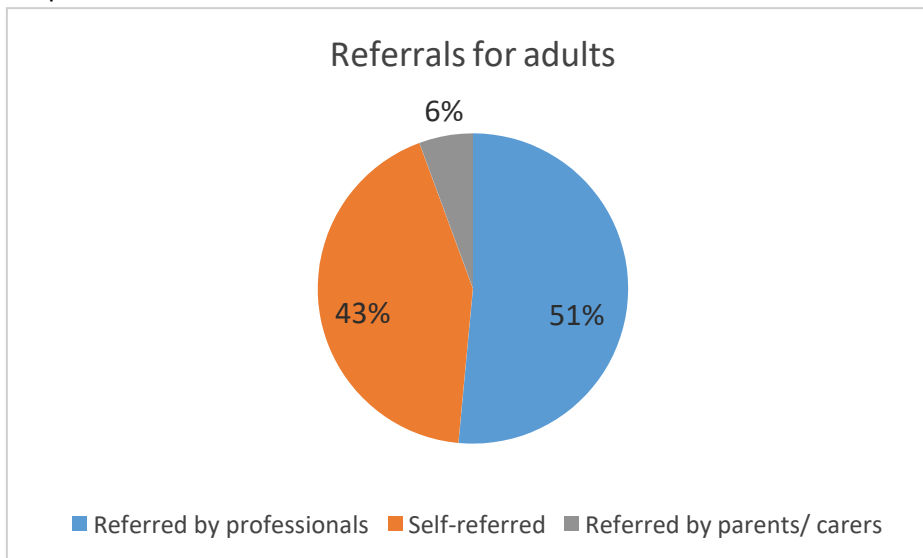
For adults who are unable to access advice or support from statutory services due to eligibility exclusion, and where the provision is not available elsewhere, the IAS provides diagnostic assessment and post diagnostic information and support for autistic adults. Below is data related to this provided by the IASs in 2020/21.

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	7032
Referrals for adults	2344
Referred by professionals	1193
Self-referred	994
Referred by parents/ carers	130

Graph 3.1: The break-down of referrals for adults

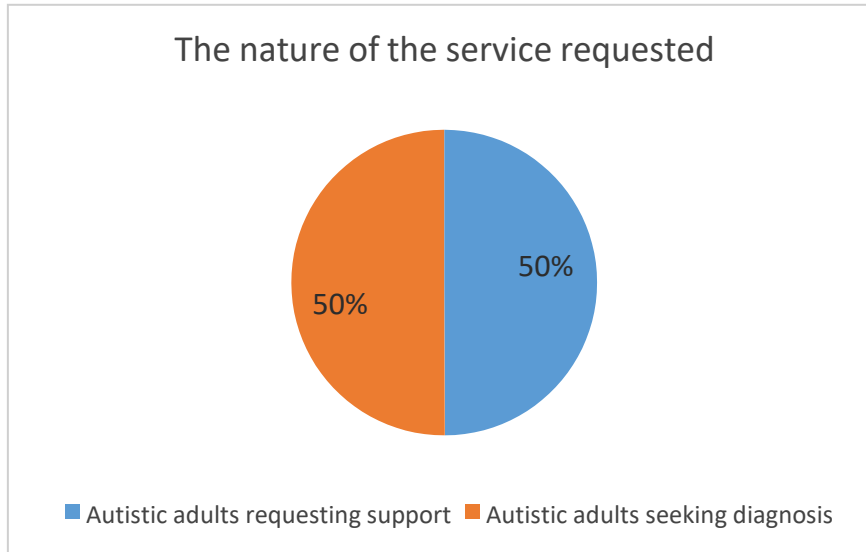


Referral requests can be split into two categories, individuals already with a diagnosis of autism but seeking support and adults seeking a diagnostic assessment. Below is a table and graph showing the nature of the referrals to the IASs.

Table 3.2: The nature of referrals for autistic adults

Service Users	
Autistic adults requesting support	1157
Autistic adults seeking diagnosis	1160

Graph 3.2: The nature of services requested by autistic adults

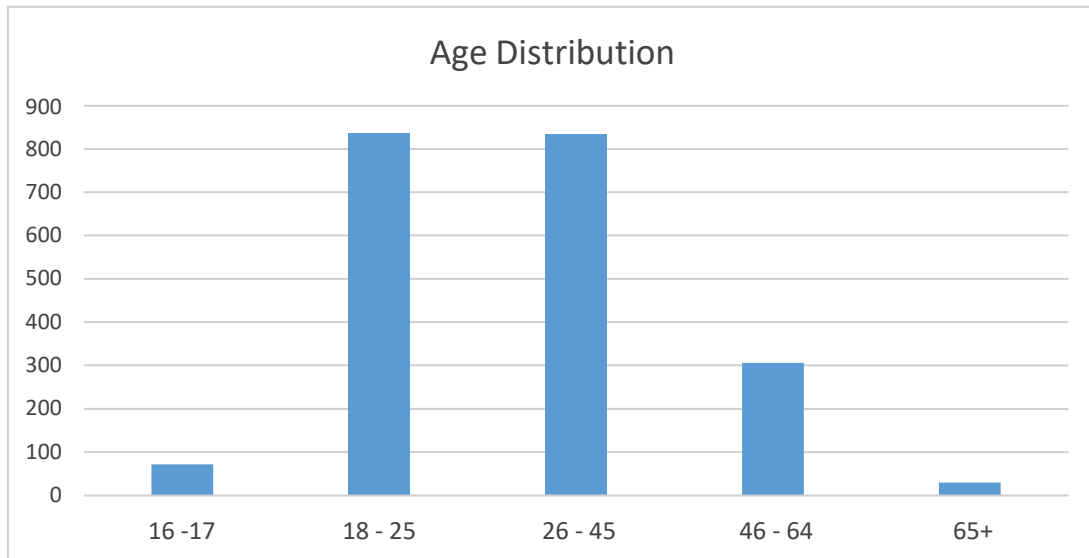


The age distribution of adults accessing the service is depicted in the following table and graph. The 'prefer not to say' option represents those for whom it would not be appropriate to automatically collect this data. This may include people seen in drop-in sessions or enquiry referrals.

Table 3.3: The age distribution of adults accessing services

Age Distribution	
16 -17	72
18 - 25	837
26 - 45	833
46 - 64	306
65+	30
Prefer not to say	239

Graph 3.3: The age distribution of adults accessing services

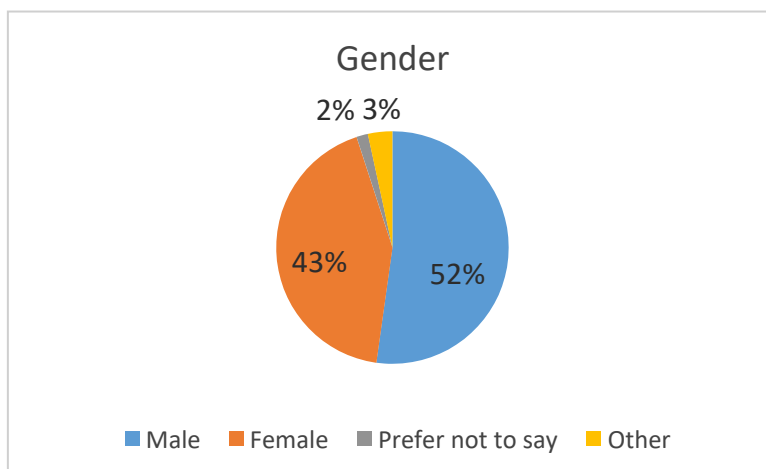


The gender of adults accessing the service is depicted in the following table and graph. The ‘Other’ section includes people who identify as alternative genders or for whom the data was not easily collated or identify.

Table 3.4: The gender of adults accessing services

Gender	
Male	1210
Female	991
Prefer not to say	37
Other	79

Graph 3.4: The gender of adults accessing services

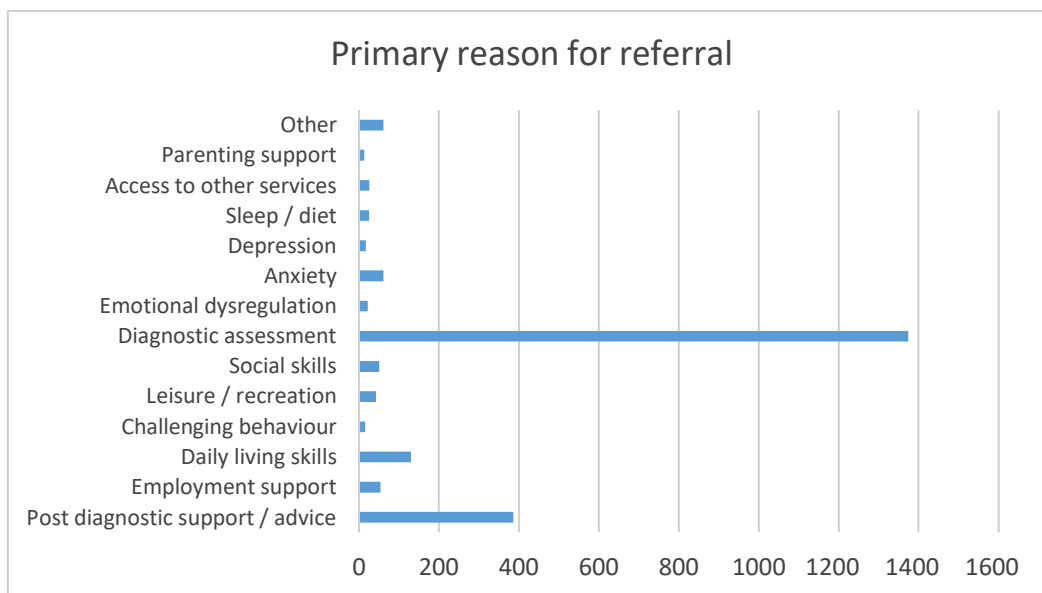


The table and graph below depict the primary reason that adults are referred into the service. This may change through initial discussions with the service but gives an idea of some of the difficulties that are identified by autistic adults.

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

Primary reason for referral	
Post diagnostic support / advice	386
Employment support	54
Daily living skills	130
Challenging behaviour	16
Leisure / recreation	43
Social skills	51
Diagnostic assessment	1374
Emotional dysregulation	22
Anxiety	61
Depression	17
Sleep / diet	25
Access to other services	26
Parenting support	13
Other	61

Graph 3.5: The primary reason for referral into the service

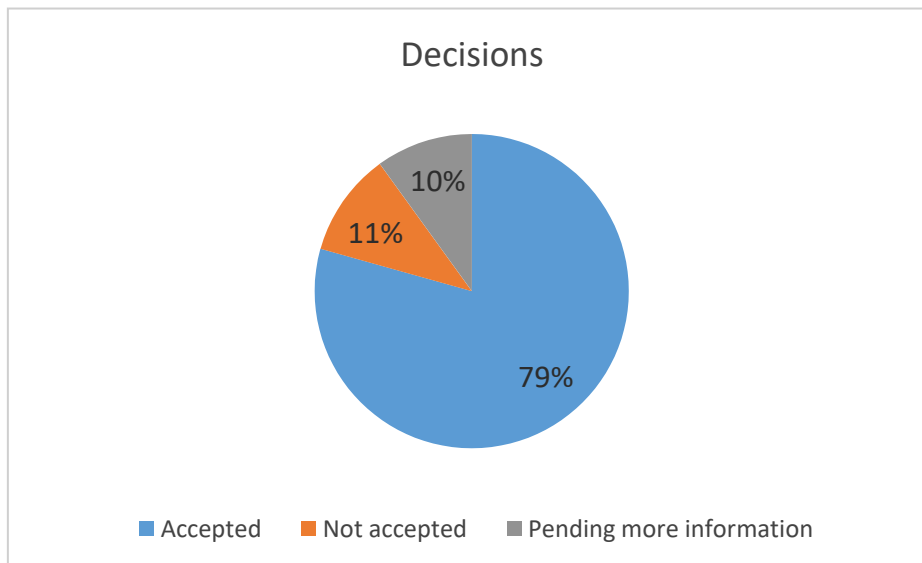


Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 3.6: The outcome of referrals into the service

Referral Outcomes	
Decisions	
Accepted	1768
Not accepted	238
Pending more information	222

Graph 3.6: The outcome of referrals into the service

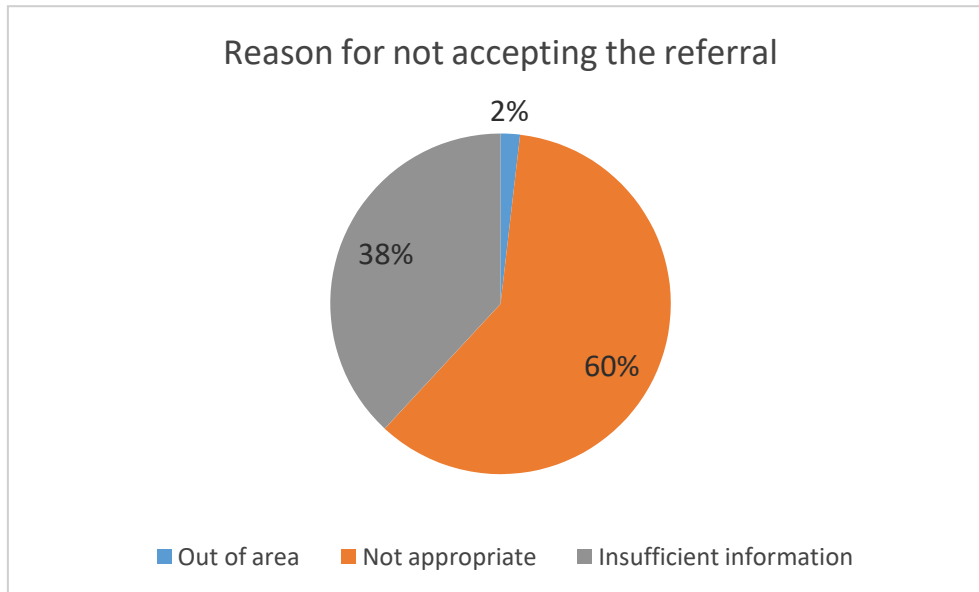


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including someone who is receiving support from other services such as learning disability services or mental health services, or not appropriate due to age.

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

Reason for not accepting the referral	
Out of area	5
Not appropriate	164
Insufficient information	104

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

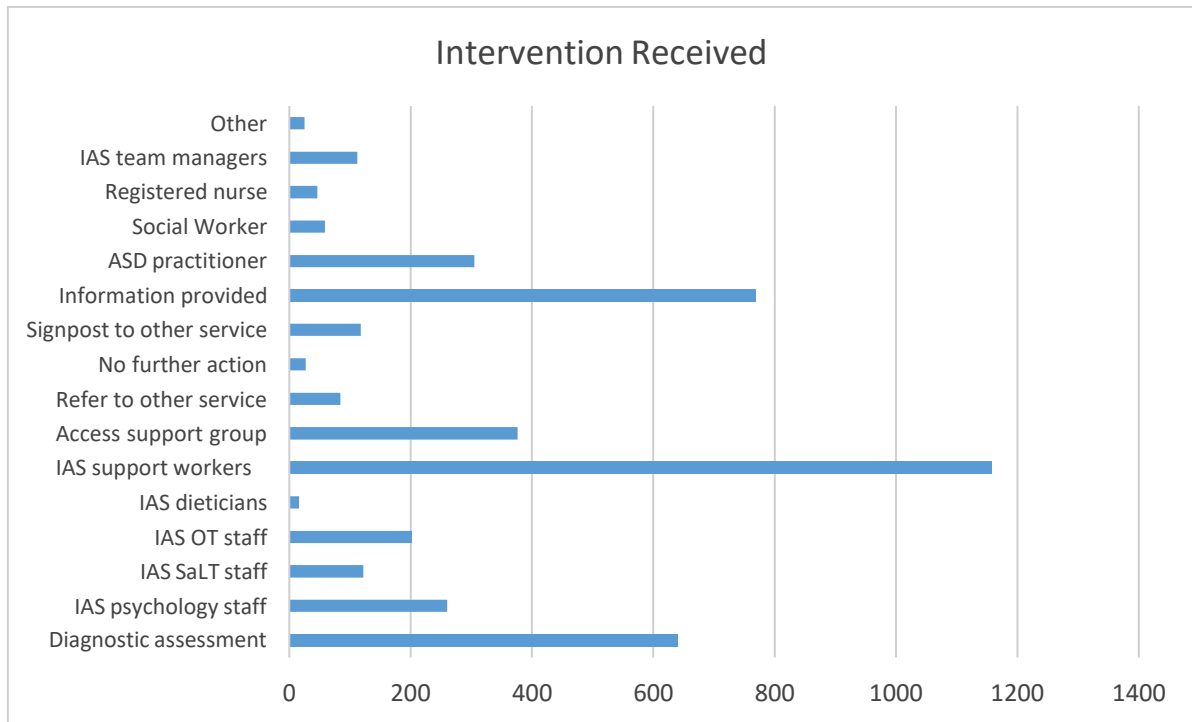


The table and graph below depict the interventions received by adults accessing the service. This gives an idea of what kind of services autistic adults need.

Table 3.8: The interventions received by adults within the service

Intervention Received	
Diagnostic assessment	640
IAS psychology staff	260
IAS Speech and Language Therapy staff	122
IAS Occupational Therapy staff	202
IAS dieticians	16
IAS support workers	1158
Access support group	376
Refer to other service	84
No further action	27
Signpost to other service	118
Information provided	768
ASD practitioner	305
Social Worker	59
Registered nurse	46
IAS team managers	112
Other	25

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 2020/21 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	1.7
Average weeks from referral accepted to start of intervention	5.4
Timeliness of diagnostic assessment	
Average weeks from point of referral received to accepted	2.6
Average weeks from referral accepted to start of intervention	78.3
Average weeks from initial appointment to diagnosis / outcome	2.4

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	662
Number of assessments that lead to a positive diagnosis	479
Percentage positive diagnosis	72%

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	275
Number of formal complaints received	7
Number of compliments received	226

4. Parent/ Carer Data

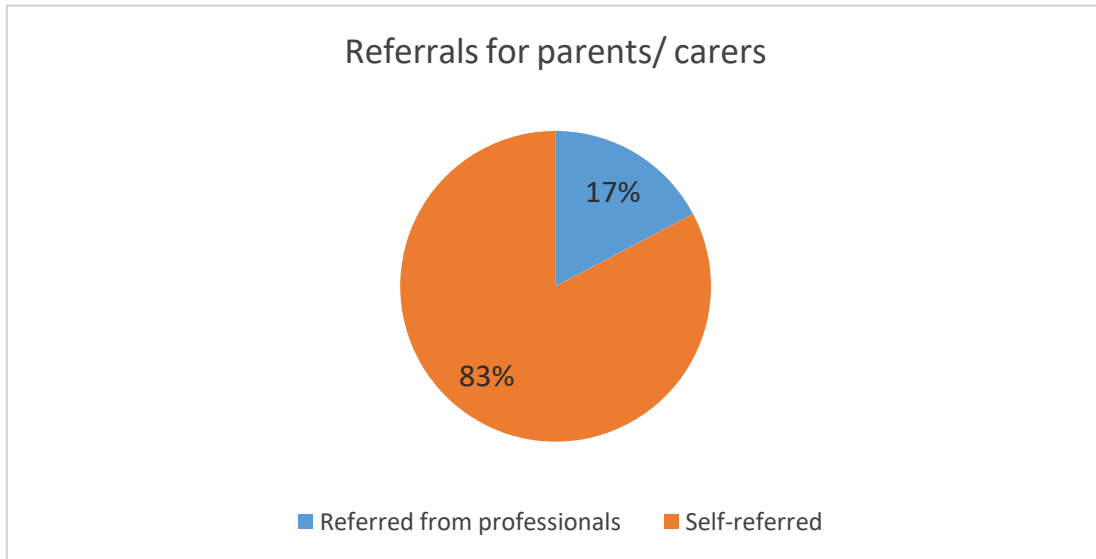
Whilst not working directly with children and young people, the service works in partnership with other organisations to support parents and carers. Below is data related to this provided by the IASs in 2020/21.

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	1258
Referrals for parents/ carers	324
Referred from professionals	56
Self-referred	268

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

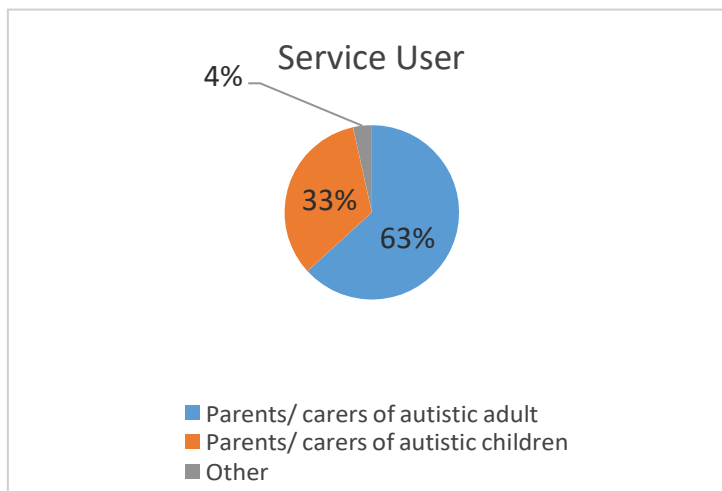


The table and graph below show whether service users are parents and carers of autistic adults or children. The 'other' category includes parents/carers who care for both those over and under 18 and instances where the data was unavailable.

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

Service User	
Parents/ carers of autistic adult	165
Parents/ carers of autistic children	87
Other	9

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

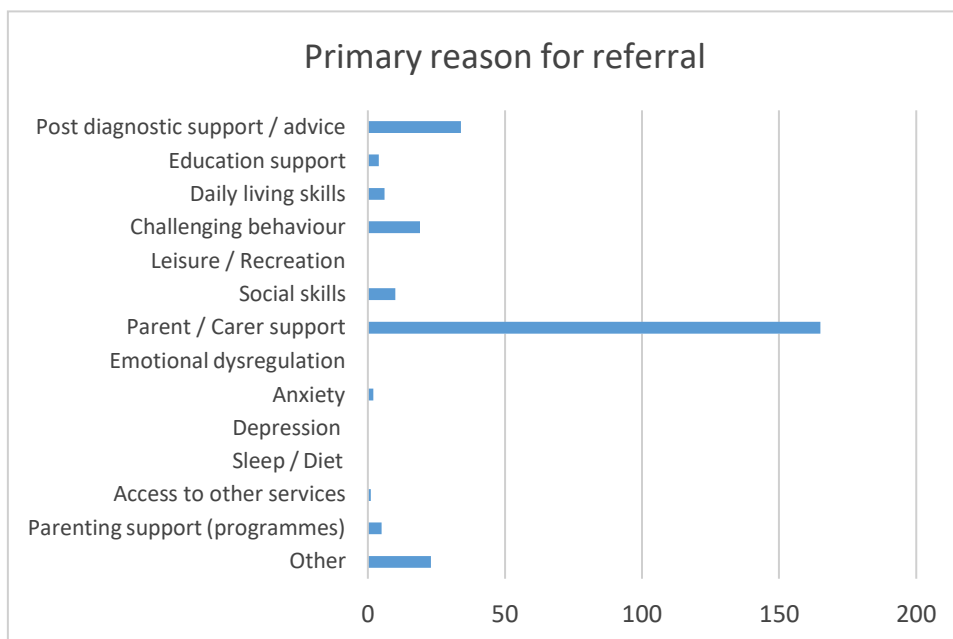


The table and graph below depict the primary reason that parent/ carers are referred into the service. This may change through initial discussions with the service but gives an idea of the support that parent/ carers are seeking.

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

Primary Reason for referral	
Post diagnostic support / advice	34
Education support	4
Daily living skills	6
Challenging behaviour	19
Leisure / Recreation	0
Social skills	10
Parent / Carer support	165
Emotional dysregulation	0
Anxiety	2
Depression	0
Sleep / Diet	0
Access to other services	1
Parenting support (programmes)	5
Other	23

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

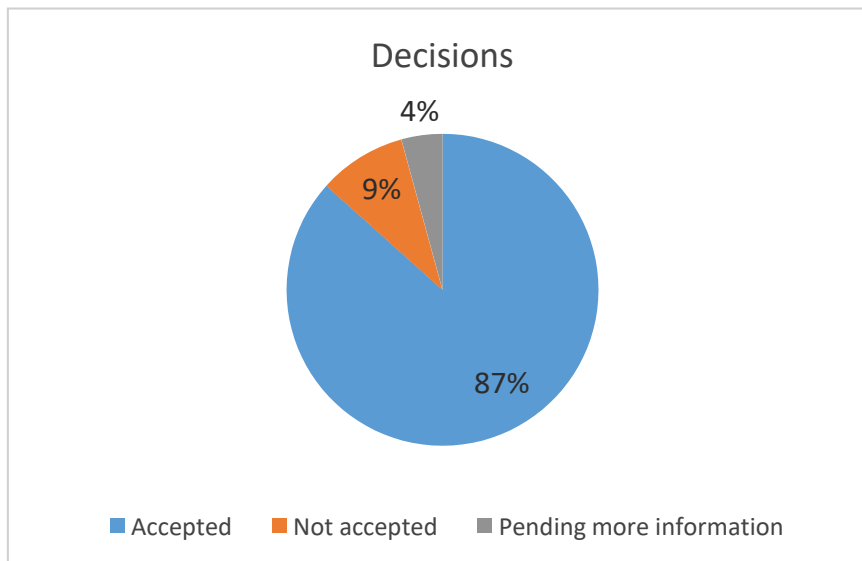


Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 4.4: The outcome of referrals into the service

Referral Outcomes	
Decisions	
Accepted	285
Not accepted	30
Pending more information	14

Graph 4.4: The outcome of referrals into the service

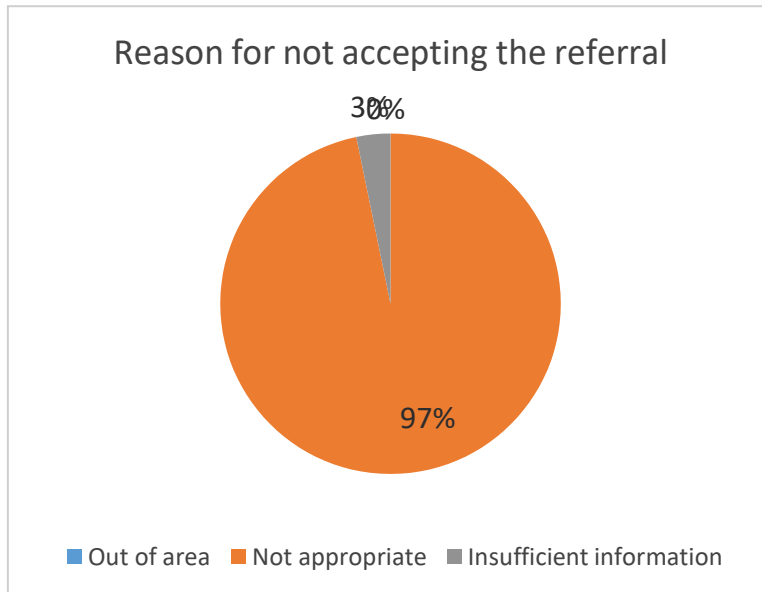


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including those who are receiving support from other services.

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

Reason for not accepting the referral	
Out of area	0
Not appropriate	30
Insufficient information	1

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

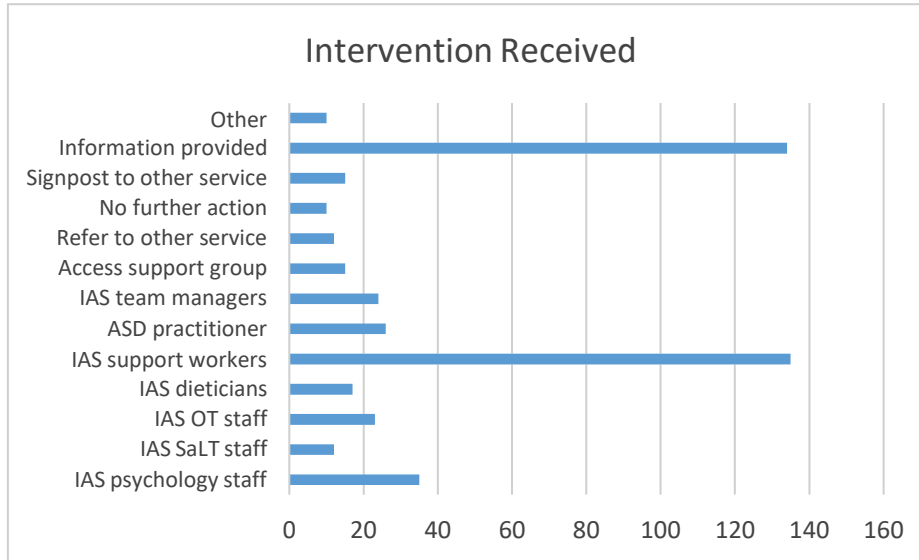


The table and graph below depict the interventions received by parent/ carers accessing the service. This gives an idea of what kind of services parent/ carers need.

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

Intervention Received	
IAS psychology staff	35
IAS SaLT staff	12
IAS OT staff	23
IAS dieticians	17
IAS support workers	135
1:1 support provided	26
Access support group	24
Refer to other service	15
No further action	12
Signpost to other service	10
Information provided	15
Other	134

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 2020/21 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 2020/21 year.

Table 4.5: The timeliness of support and additional information for parents and carers

Timeliness of support	
Average weeks from point of referral received to accepted	1.1
Average weeks from referral accepted to start of intervention	5.1
Additional Information	
Number of support group sessions held	36
Number of formal complaints received	3
Number of compliments received	89

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 2020/21.

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

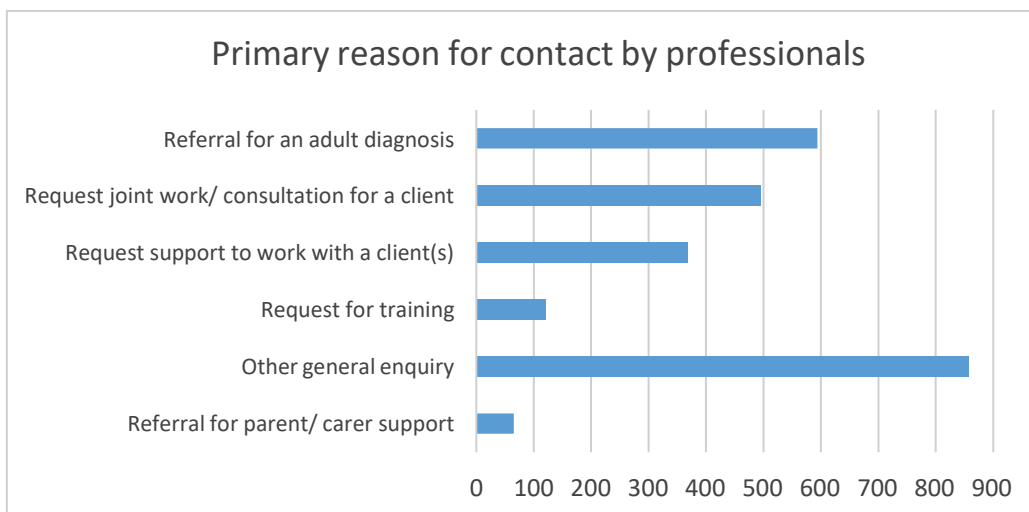
Interactions with professionals	6,364
New contact with professionals	2,500

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	
Referral for an adult diagnosis	594
Request joint work/ consultation for a client	495
Request support to work with a client(s)	369
Request for training	120
Other general enquiry	857
Referral for parent/ carer support	65

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

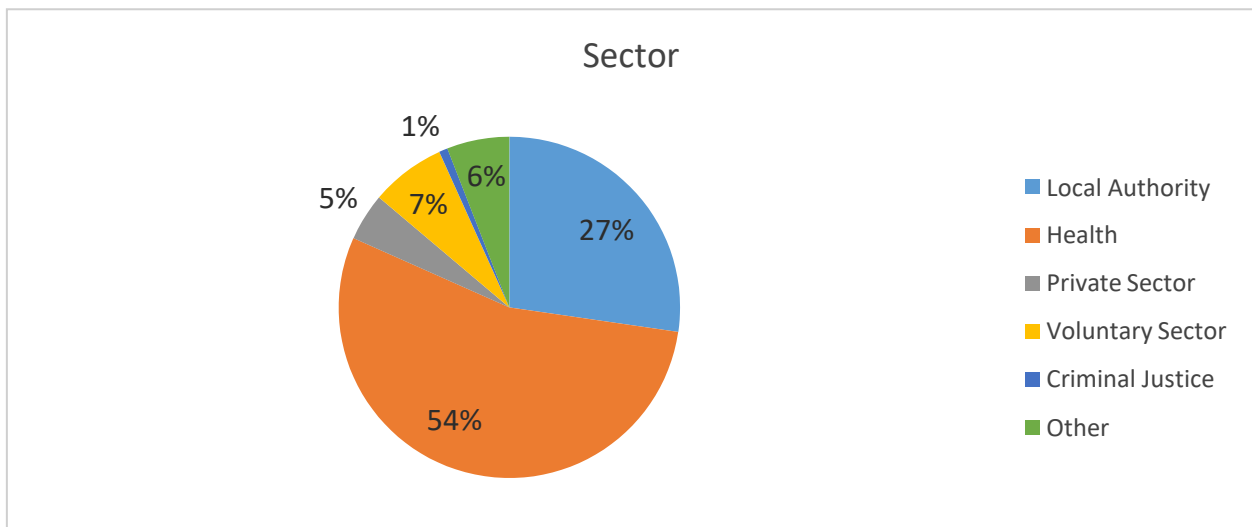


The following table and graph show the sector which professionals contacting the services are from. The 'other' category may include professionals working in the civil services such as DWP employees or the information may not be available to include.

Table 5.3: The sector professionals contacting the service are from

Sector	
Local Authority	631
Health	1257
Private Sector	104
Voluntary / Third Sector	164
Criminal Justice	19
Other	137

Graph 5.3: The sector professionals contacting the service are from



6. Conclusion

It is important to reiterate that this has been a challenging year for the IASs, but as can be seen from the data, services have continued as much as possible in a safe manner. The data demonstrates that the IASs have continued to work with a large number of individuals and responding to a number of different needs.

For services provided to adults 43% of referrals were self-referrals from adults themselves. Fifty percent of the referrals were for diagnostic assessment and 50% for support. Most of the age distribution of autistic adults accessing the service is between 18-45. The most frequently accessed interventions were support from IAS support workers, providing information, diagnostic assessment and accessing support groups. It can also be noted that there was a 30% decrease in referrals to the service from adults in 2020/21 in comparison with 2019/20 figures. In addition, there was a 21% decrease in diagnostic assessments undertaken in 2020/21 in comparison to 2019/20.

For services provided to parent/ carers 83% of referrals were self-referrals. Sixty three percent of the referrals were from parent and carers of adults and 33% were from parent and carers of children. The primary reason for referrals were for parent/ carer support, post diagnostic support/ advice, behaviour that challenges and social skills. The most frequently accessed interventions were support from IAS support workers, IAS psychology staff, 1:1 support and accessing support groups. It can also be noted that there was a 52% decrease in referrals to the service from parent/ carers in 2020/21 in comparison with 2019/20 figures.

The data shows that a significant part of the services' work is engaging with professionals. The primary reason for referrals were general enquiries, referrals for diagnostic assessment, request joint work/ consultation with client and request support to work with a client. In addition, 54% were professionals from the health board, 27% were from local authorities and 7% from the voluntary sector. It can also be noted that there was a 14% decrease in contacts with the service from professionals in 2020/21 in comparison with 2019/20 figures.