# Integrated Autism Service 2019/20 Data Report

## 1. Executive Summary

During 2019/20 a new data framework was put in place to capture Integrated Autism Service (IAS) data. This first year is seen as a 'development year' and therefore the accuracy of all data may not be absolute but gives a good indication of service demand across Wales. Each IAS is at a differing stage of maturity and therefore service data varies (for example, one IAS was operational in September 2017, another in April 2019). This report therefore looks at the high-level national data across all IASs across Wales and should be considered as a 'first attempt' to capture data about the services

The following data headlines were observed.

- **5,651** interactions were made with autistic adults
- **3,337** referrals to the service were made for autistic adults with 36% of these self-referrals from adults
- **65%** of referrals for autistic adults were requesting autism diagnostic assessments and **35%** were requesting support
- **840** adults received a diagnostic assessment
- **639** adults received a positive diagnosis of autism (76%)
- **2,338** interactions were made with parents/ carers
- **680** referrals to the service were made for parents/ carers with 82% of these self-referrals
- **41%** of referrals were for parent/ carers of autistic adults and **35%** were for parent/ carers of autistic children
- **4,651** interactions were made with professionals
- **2,901** new contacts with professionals
- **53%** of contacts were from health professionals, **25%** were professionals from local authorities and **13%** were from the voluntary sector

## 2. Introduction

There are 7 Integrated Autism Services 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 NAT which is hosted by the WLGA together with PHW has been committed from the outset, together with the IAS Leads and the Community of Practise for Adult Diagnosis to ensure that the impact of the new Integrated Autism Service be measured. After discussions with the IAS Leads themselves, it became clear that the data capture should be both quantitative (how many?) and qualitative (how much?) because every individual's experience of the service is unique and every autistic individual, or carer is also unique. The data set took many months to agree and to finalise, which needed to be translated into a mechanism that was both practical and informative.

The data 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 Autistic Adult Data, Parent Carer Data and Professional Data. To enrich the data, qualitative data is capture through the Outcomes Star an outcomes measurement tool and case studies.

## 3. Autistic Adult Data

For autistic 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. Below is data related to this provided by the IASs in 2019/20. Please note that not all data was captured as services were established, therefore some of the data totals will not add up to referral numbers.

Below are the number of interactions and referrals relating to autistic 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 autistic individuals to the IASs

| Interactions with autistic individuals | 5,651 |
|---|---|
| Referrals for autistic individuals | 3,337* |
|     Referred by professionals | 1,876 |
|     Self-referred | 1,200 |
|     Referred by parents/ carers | 252 |

*note that nine referrals were not initially categorised and are not included in the breakdown of referrals

Graph 3.1: The break-down of referrals for autistic individuals



Referrals for autistic individuals

8% 36% 56%

■ Referred by professionals  ■ Self-referred  ■ Referred by parents/ carers
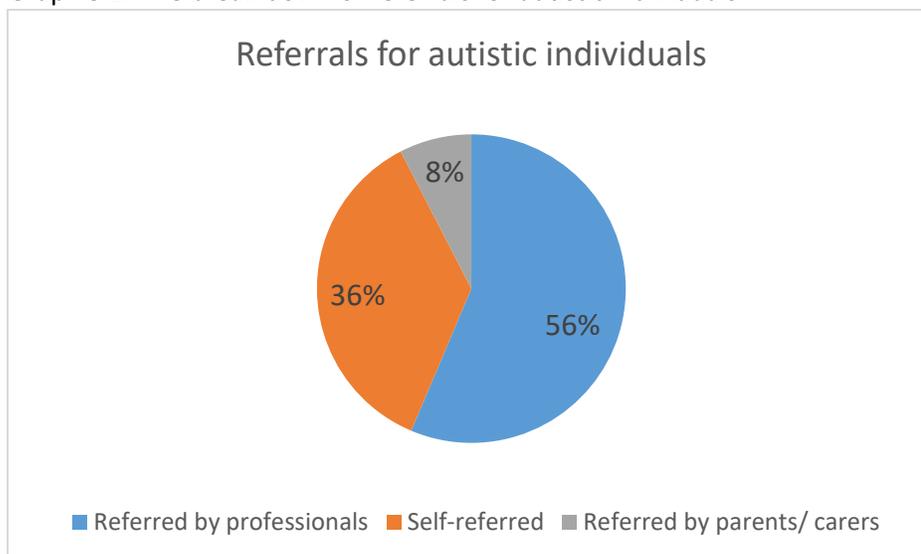
Referral requests can be split into two categories, individuals already with a diagnosis of autism but seeking support and adults seeking a diagnostic assessment. Below is a table and graph showing the nature of the referrals to the IASs.

Table 3.2: The nature of referrals for autistic adults

| Service Users | |
| --- | --- |
| Autistic adults requesting support | 1,151 |
| Autistic adults seeking diagnosis | 2,092 |

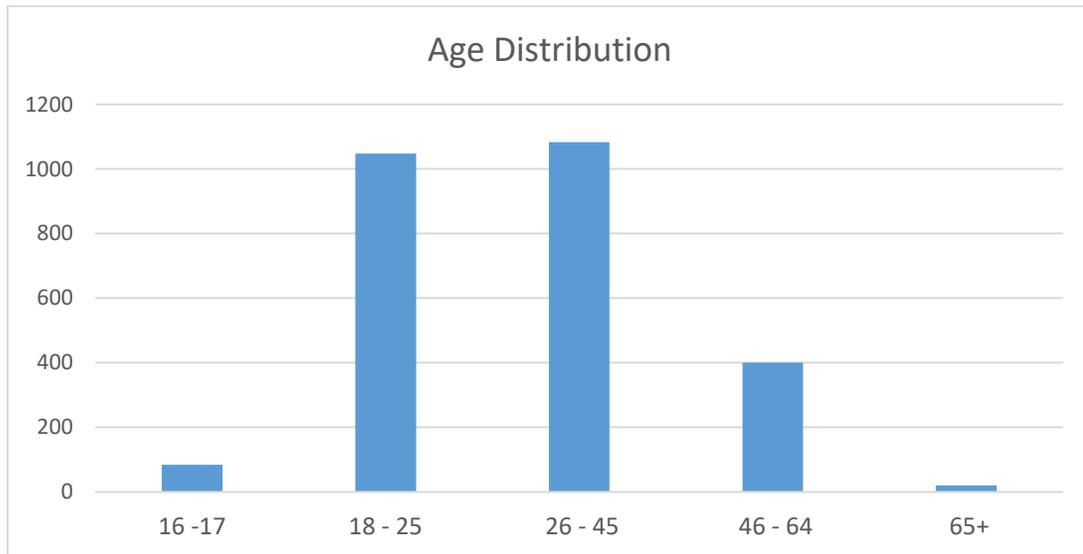Graph 3.2: The nature of services requested by autistic adults
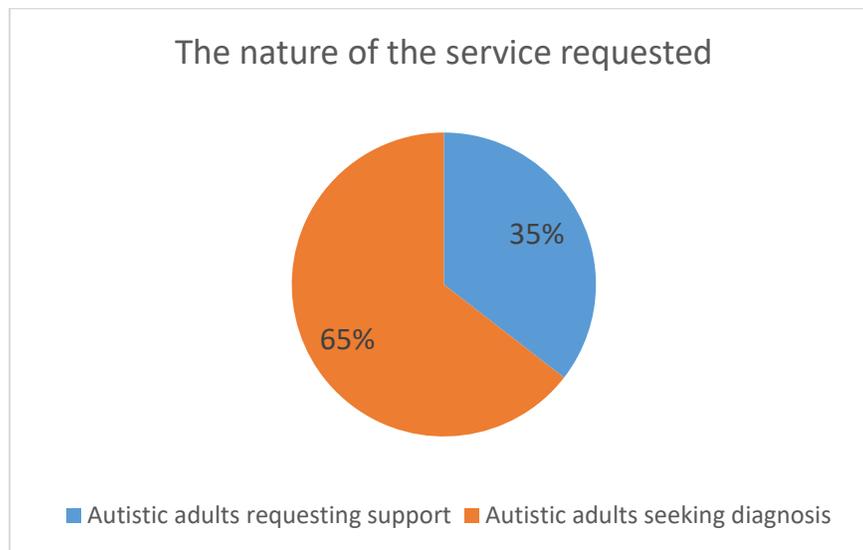


The age distribution of autistic adults accessing the service is depicted in the following table and graph. The 'prefer not to say' option represents those for whom it would not be appropriate to automatically collect this data. This may include people seen in drop-in sessions or enquiry referrals.

Table 3.3: The age distribution of autistic adults accessing services

| Age Distribution | |
| --- | --- |
| 16 -17 | 84 |
| 18 - 25 | 1048 |
| 26 - 45 | 1083 |
| 46 - 64 | 400 |
| 65+ | 20 |
| Prefer not to say | 145 |

Graph 3.3: The age distribution of autistic adults accessing services

## Age Distribution

| Age range | Count (approx) |
|-----------|----------------|
| 16 -17 | ~85 |
| 18 - 25 | ~1050 |
| 26 - 45 | ~1085 |
| 46 - 64 | ~400 |
| 65+ | ~20 |

The gender of autistic 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 autistic adults accessing services

| Gender | |
|--------|------|
| Male | 1811 |
| Female | 1223 |
| Prefer not to say | 69 |
| Other | 57 |

Graph 3.4: The gender of autistic adults accessing services

Gender

- Male 57%
- Female 39%
- Prefer not to say 2%
- Other 2%
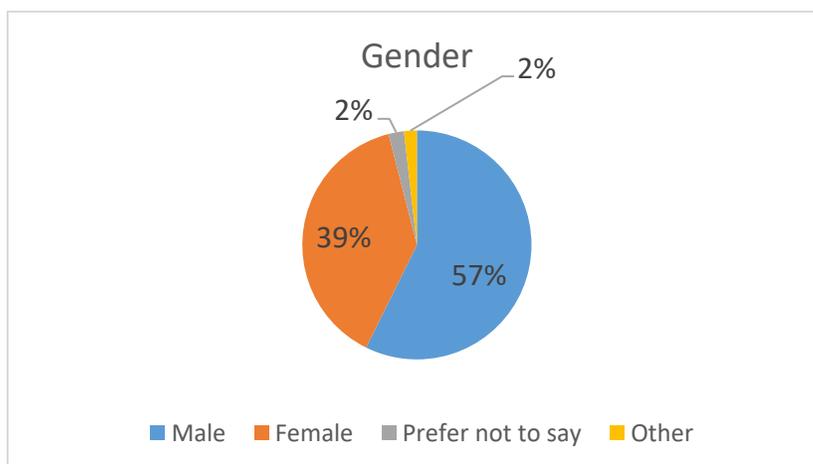
The table and graph below depict the primary reason that adults are referred into the service. This may change through initial discussions with the service but gives an idea of some of the difficulties that are identified by autistic adults.

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

| Primary reason for referral | |
|---|---|
| Post diagnostic support / advice | 615 |
| Employment support | 54 |
| Daily living skills | 94 |
| Challenging behaviour | 6 |
| Leisure / recreation | 45 |
| Social skills | 74 |
| Diagnostic assessment | 1862 |
| Emotional dysregulation | 14 |
| Anxiety | 58 |
| Depression | 8 |
| Sleep / diet | 17 |
| Access to other services | 20 |
| Parenting support | 63 |
| Other | 168 |

Graph 3.5: The initial primary reason for referral into the service
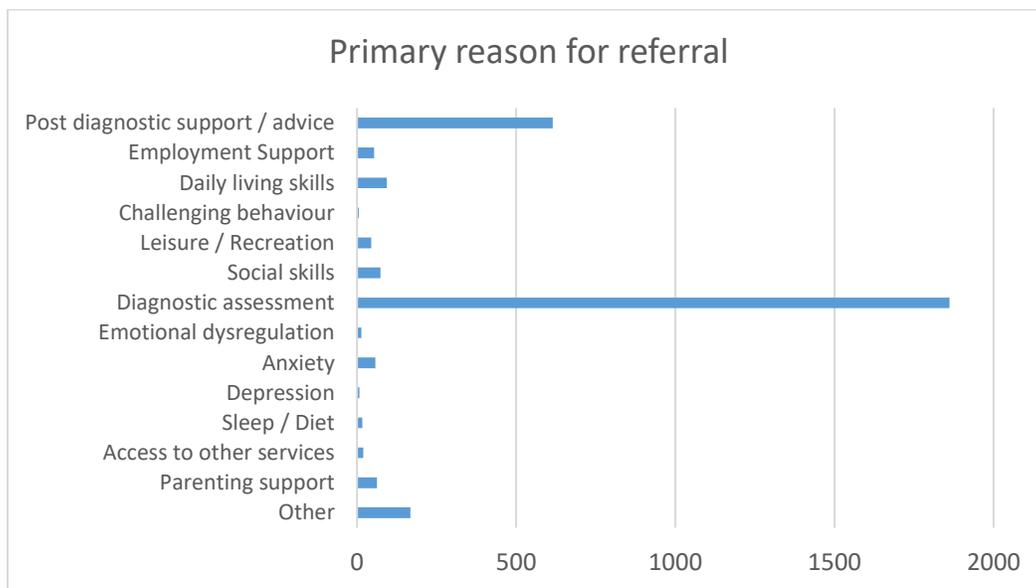
Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 3.6: The outcome of referrals into the service

| Referral Outcomes | |
| --- | --- |
| Decisions | |
| Accepted | 2,389 |
| Not accepted | 284 |
| Pending more information | 237 |

Graph 3.6: The outcome of referrals into the service
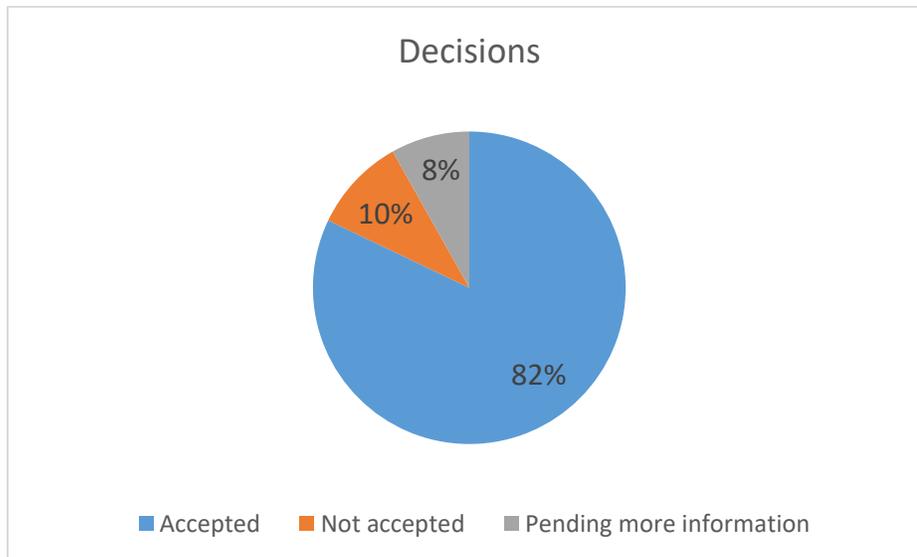


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including someone who is receiving support from other services such as learning disability services or mental health services, or not appropriate due to age.

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

| Reason for not accepting the referral | |
| --- | --- |
| Out of area | 12 |
| Not appropriate | 131 |
| Insufficient information | 155 |

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

**Reason for not accepting the referral**



- Out of area
- Not appropriate
- Insufficient information
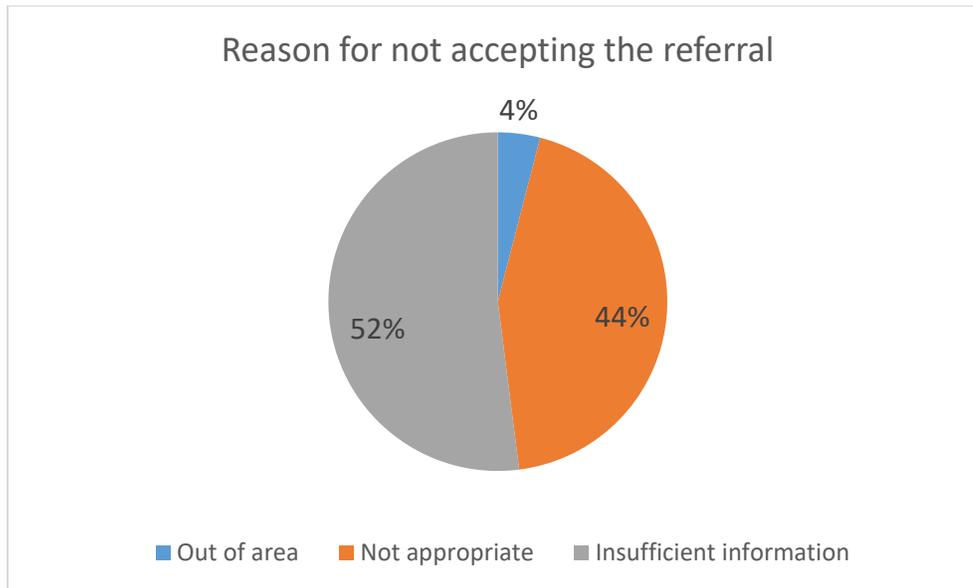
The table and graph below depict the interventions received by adults accessing the service. This gives an idea of what kind of services autistic adults need.

Table 3.8: The interventions received by autistic adults by the service

| Intervention Received | |
|---|---|
| Diagnostic assessment | 910 |
| IAS psychology staff | 175 |
| IAS Speech and Language Therapy staff | 52 |
| IAS Occupational Therapy staff | 134 |
| IAS dieticians | 20 |
| IAS support workers | 1297 |
| Access support group | 669 |
| Refer to other service | 66 |
| No further action | 32 |
| Signpost to other service | 40 |
| Information provided | 524 |
| ASD practitioner | 202 |
| Social Worker | 16 |
| Registered nurse | 45 |
| IAS team managers | 67 |
| Other | 43 |

Graph 3.8: The interventions received by autistic adults by the service
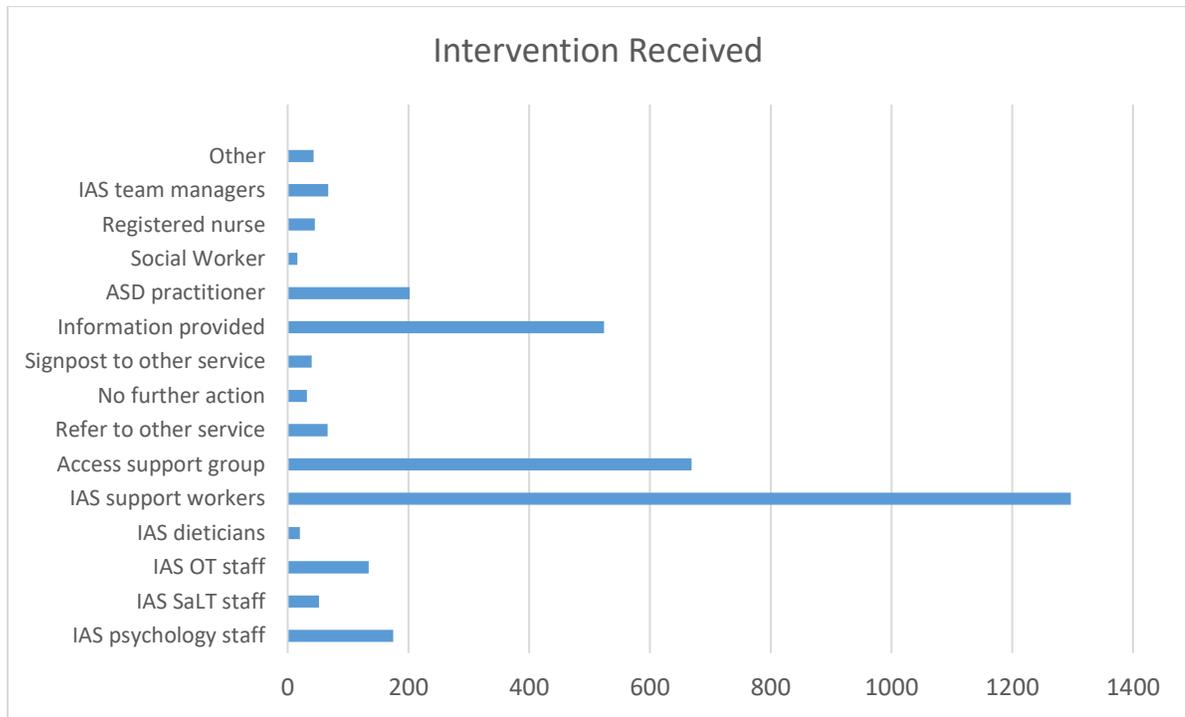


The timeliness of support and diagnostic assessment are shown in weeks in the table below. The data is based on quarter 4 of 2019/20 only as it shows a more accurate picture of the current situation.

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

| Timeliness of support | |
|---|---|
| Average weeks from point of referral received to accepted | 2.2 |
| Average weeks from referral accepted to start of intervention | 13.0 |
| Timeliness of diagnostic assessment | |
| Average weeks from point of referral received to accepted | 3.0 |
| Average weeks from referral accepted to start of intervention | 48.7 |
| Average weeks from initial appointment to diagnosis / outcome | 5.2 |

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 | **840** |
| Number of assessments that lead to a positive diagnosis | 639 |
| Percentage positive diagnosis | 76% |

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 | 342 |
| Number of formal complaints received | 16 |
| Number of compliments received | 269 |

## 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 2019/20.

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 | **2,338** |
|---|---|
| Referrals for parents/ carers | **680** |
| Referred from professionals | 122 |
| Self-referred | 558 |

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

## Referrals for parents/ carers

18%

82%

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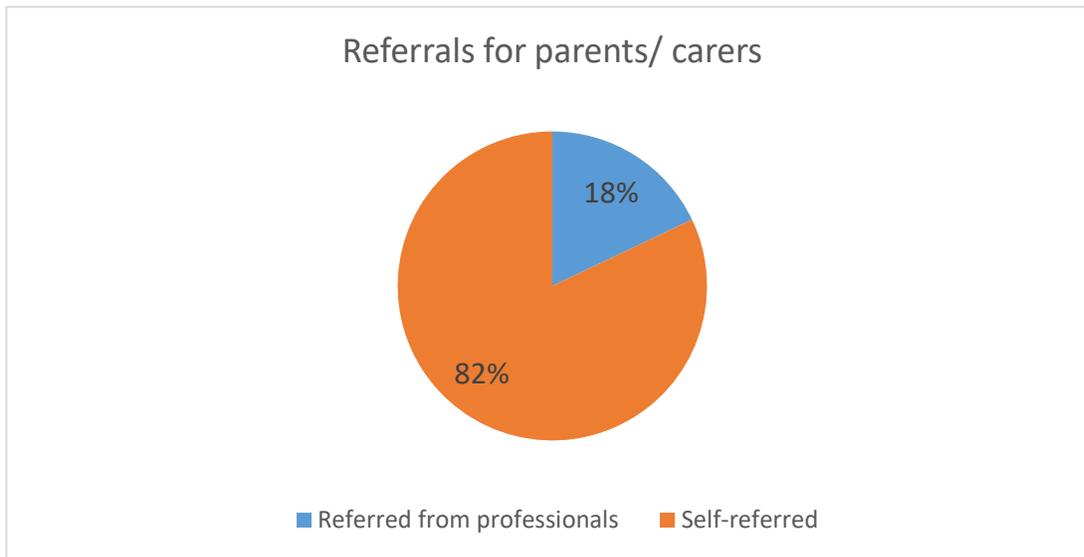
The table and graph below show whether service users are parents and carers of autistic adults or children. The 'other' category includes parents/carers who care for both those over and under 18 and instances where the data was unavailable.

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

| Service User | |
|---|---|
| Parents/ carers of autistic adult | 211 |
| Parents/ carers of autistic children | 184 |
| Other | 125 |

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

## Service User

24% 41%

35%

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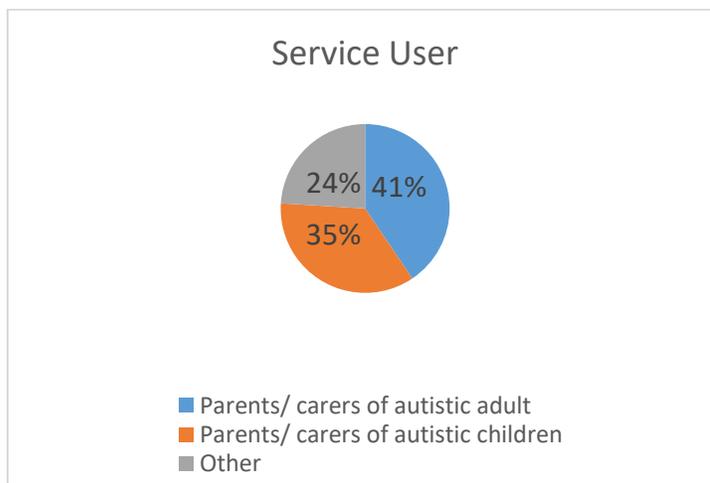
The table and graph below depict the primary reason that parent/ carers are referred into the service. This may change through initial discussions with the service but gives an idea of the support that parent/ carers are seeking.

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

| Primary Reason for referral | |
|---|---|
| Post diagnostic support / advice | 142 |
| Education support | 34 |
| Daily living skills | 12 |
| Challenging behaviour | 30 |
| Leisure / Recreation | 7 |
| Social skills | 8 |
| Parent / Carer support | 271 |
| Emotional dysregulation | 4 |
| Anxiety | 5 |
| Depression | 2 |
| Sleep / Diet | 3 |
| Access to other services | 13 |
| Parenting support (programmes) | 51 |
| Other | 28 |

Table 4.3: The initial primary reason for referral into the service
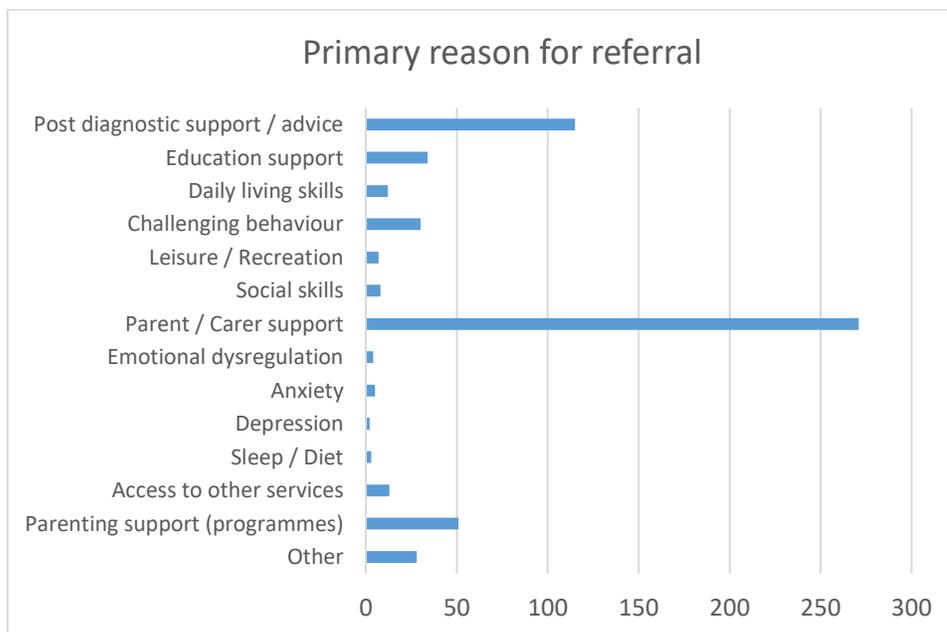
Below is the outcome of referrals into the service. This information helps the services identify patterns in referrals that cannot be accepted and those needing further information.

Table 4.4: The outcome of referrals into the service

| Referral Outcomes | |
|---|---|
| Decisions | |
| Accepted | 728 |
| Not accepted | 35 |
| Pending more information | 42 |

Graph 4.4: The outcome of referrals into the service
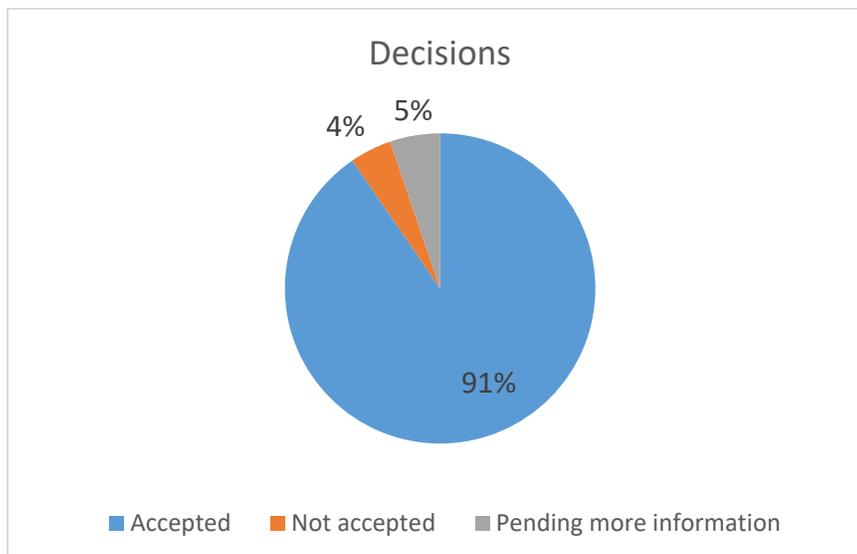


Below is the breakdown of referrals not accepted into services. There are several reasons that referrals may not be appropriate, including those who are receiving support from other services.

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

| Reason for not accepting the referral | |
|---|---|
| Out of area | 0 |
| Not appropriate | 31 |
| Insufficient information | 6 |

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



Reason for not accepting the referral

0%

16%

84%

■ Out of area ■ Not appropriate ■ Insufficient information
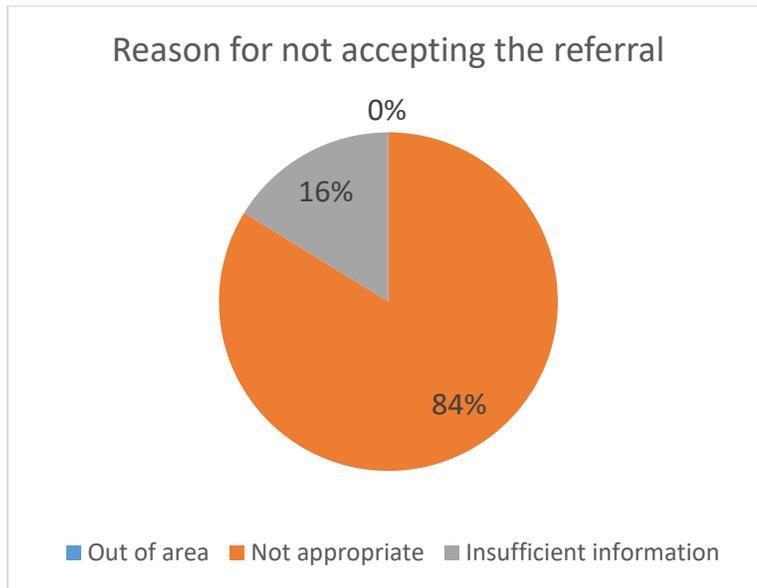
The table and graph below depict the interventions received by parent/ carers accessing the service. This gives an idea of what kind of services parent/ carers need.

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

| Intervention Received | |
|---|---|
| IAS psychology staff | 64 |
| IAS SaLT staff | 45 |
| IAS OT staff | 93 |
| IAS dieticians | 21 |
| IAS support workers | 317 |
| 1:1 support provided | 114 |
| Access support group | 98 |
| Refer to other service | 43 |
| No further action | 6 |
| Signpost to other service | 58 |
| Information provided | 504 |
| Other | 43 |

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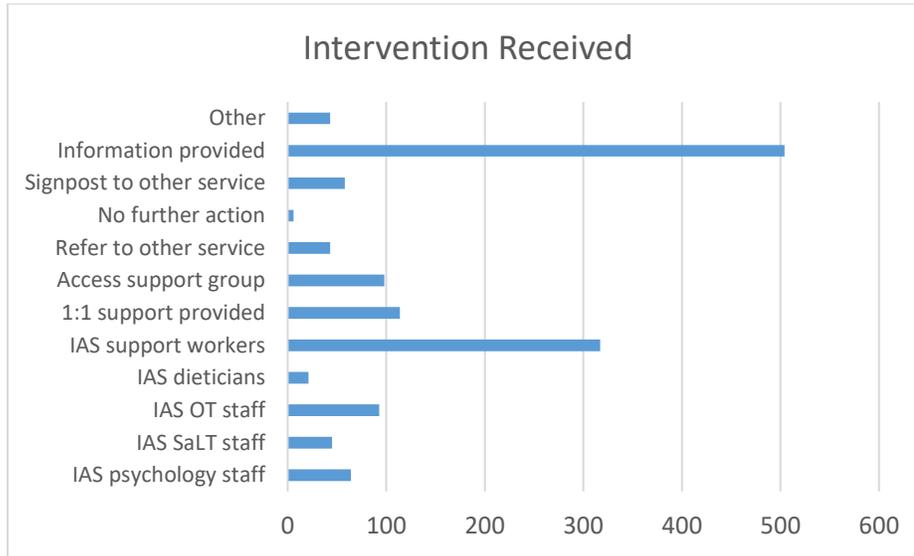


The timeliness of support for parent/ carers is shown in weeks in the table below. The data is based on quarter 4 of 2019/20 only as it shows a more accurate picture of the current situation. The table also includes additional information of the number of group sessions held and the number of formal complaints and compliments received over the 2019/20 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 | 2.2 |
| Average weeks from referral accepted to start of intervention | 17.3 |
| Additional Information | |
| Number of support group sessions held | 120 |
| Number of formal complaints received | 3 |
| Number of compliments received | 93 |

## 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 2019/20.

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 | **4,651** |
| New contact with professionals | 2,901 |

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 | 909 |
| Request joint work/ consultation for a client | 599 |
| Request support to work with a client(s) | 503 |
| Request for training | 370 |
| Other general enquiry | 758 |
| Referral for parent/ carer support | 85 |

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



Primary reason for contact by professionals

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 | 627 |
| Health | 1,326 |
| Private Sector | 125 |
| Voluntary / Third Sector | 322 |
| Criminal Justice | 64 |
| Other | 37 |

Graph 5.3: The sector professionals contacting the service are from



Sector

- Local Authority
- Health
- Private Sector
- Voluntary Sector
- Criminal Justice
- Other

25%, 53%, 5%, 13%, 3%, 1%
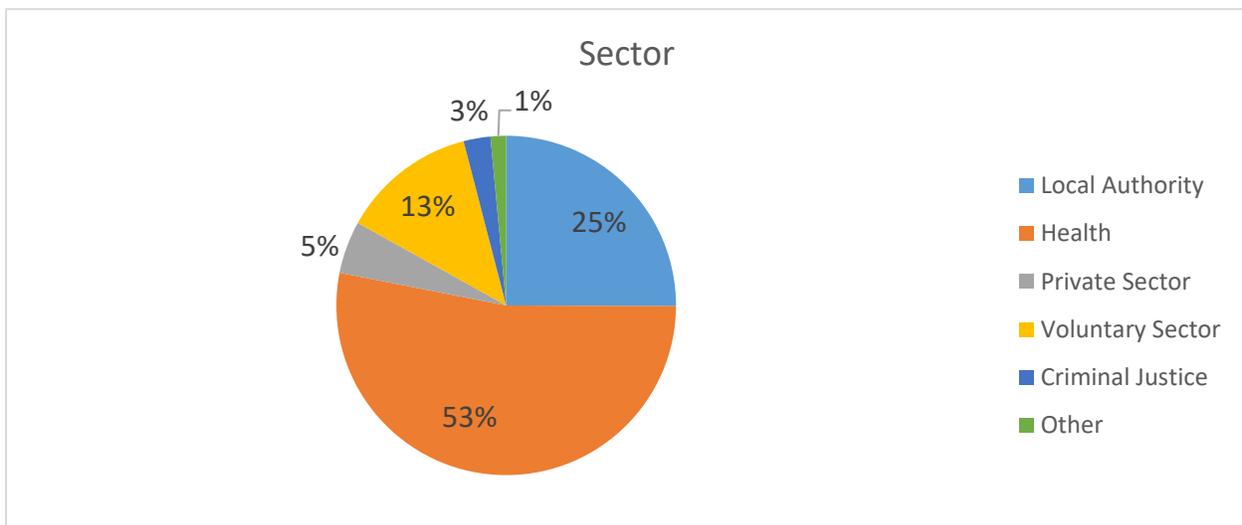
## 6. Conclusion

It is important to reiterate that this first year is seen as a 'development year' with regards to the data and therefore the accuracy of all data may not be absolute. However, it does give a good indication of service demand across Wales.

The data demonstrates that the IASs have been working with a large number of individuals and responding to a number of different needs.

For services provided to autistic adults 36% of referrals were self-referrals from adults themselves. Sixty five percent of the referrals were for diagnostic assessment and 35% for support. Most of the age distribution of autistic adults accessing the service is between 18-45. The most frequently accessed interventions were support from IAS support workers, diagnostic assessment, accessing support groups and providing information.

For services provided to parent/ carers 82% of referrals were self-referrals. Forty one percent of the referrals were from parent and carers of adults and 35% were from parent and carers of children. The primary reason for referrals were for parent/ carer support, post diagnostic support/ advice, parenting support and educational support. The most frequently accessed interventions were support from IAS support workers, diagnostic assessment, accessing support groups and providing information.

The data shows that a significant part of the services' work is engaging with professionals. The primary reason for referrals were referrals for diagnostic assessment, general enquiries, request joint work/ consultation with client and request support to work with a client. In addition, 53% were professionals from the health board, 25% were from local authorities and 13% from the voluntary sector.

As the first year of firm data collection the data presented can be used to shape services for the future.