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Evaluation of the Integrated Autism Service and Refreshed Autism Spectrum Disorder Strategic Action Plan

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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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Table of contents

Glossary of acronyms 6
Summary 7
1. Introduction 20
2. Approach and methodology 25
3. Context for the establishment of the Integrated Autism Service 29
4. Progress in delivering the integrated service model 37
5. The interface of the IAS with other services 71
6. The experiences of individuals and families accessing the IAS 90
7. Progress made in delivering the priorities for action set out in the refreshed ASD SAP……..... 105
8. Awareness raising, information and training resources 134
9. Conclusions and recommendations 150
9. Bibliography 168

List of tables

Table 1. Interviews, discussions and focus groups with autistic adults and families 26

Table 2: Number of survey responses from family members and carers and autistic adults 28

Table 3. The volume of support provided by IASs in quarters 1 and 2 of 2018 67

Table 4. Compliance with the national standards 68

List of figures

Graph 1: Responses from autistic adults to the statement “it was easy to see (meet) someone who could assess if I had autism or not.”……..46
Graph 2. Family members responses to the question “did getting a diagnosis make a difference your or your child’s life?”..... 108

Graph 3: Parents’ and carers’ responses to the question “how easy was it to see someone who could assess if your child/children had autism or not?” 112

Graph 4: Professionals’ response to the statement “children in my area have access to timely referral, assessment and post diagnostic services, which meets their needs.” 113

Graph 5. Parents’ and carers’ responses to the statement: “I am confident that I or my child/children can access advice and support services that meet his or her needs in education (e.g. in school)” 119

Graph 6. Professionals’ responses to the statement “in my area, children with autism can access education services that meet their needs” 120

Graph 7. Parents’ and carers’ responses to the statement “I am confident that my child/children will make a successful transition from school to, for example, college or employment.” 124

Graph 8. Responses from autistic adults to the statement “I can access advice and services to help meet my needs in education or training”..... 125

Graph 9. Responses from autistic adults to the statement “I can access advice and services to help meet my needs from employment services” 127

Graph 10. Professionals’ responses to the statement “in my area, adults with autism can access services that meet their needs in education or training” 127

Graph 11. Family members’ and carers’ confidence accessing advice and support from NHS and social services. 132

Graph 12. Autistic adults’ confidence accessing advice and services from mental health and social services 132

Graph 13. Professionals’ responses to questions about access to health and social services to meet children’s and adults’ needs 133

Graph 14. The number of ASDinfoWales Website Sessions (2011-2018) 137

Graph 15. Parents’ and carers’, autistic adults’ and professionals’ responses when asked if they “know about the ASD info Wales website” 138

Graph 16. Parents’ and carers’, autistic adults’and professionals’ responses to the question: “do you use the ASD info Wales Website to find information?”..... 140

Graph 17. Parents’ and carers’, autistic adults’ and professionals’ response to the question “do you find the information on ASDInfoWales website useful?” 141

Graph 18: Responses from autistic adults to the statement “I can access good quality information, advice and training that meets my needs…….....142
Graph 19. Professionals’ responses to questions about their and families’ access to good quality information and training..... 143
Table 6. Take up of the Learning with Autism programme 145
Graph 20. Take up of the Working with Autism programme (number completed, 2015-2018)..... 148

Glossary of acronyms

ALN	Additional Learning Needs
ALNET	Additional Learning Needs and Education Tribunal [Act]
ASCC	Autism Spectrum Connections Cymru
ASD	Autistic Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CMHT	Community Mental Health Team
IAS	Integrated Autism Service
ICF	Integrated Care Fund
IQ	Intelligence Quotient
LA	Local Authority/Authorities
LD	Learning Disability
LHB	Local Health Board
NAS	National Autistic Society
ND	Neurodevelopmental
NICE	National Institute of Care Excellence
PHW	Public Health Wales
PNA	Population Needs Assessments
PSB	Public Service Board
RPB	Regional Partnership Board
SAP	Strategic Action Plan
SCIE	Social Care Institute for Excellence
SEN	Special Educational Needs
T4CYP	Together for Children and Young People
WG	Welsh Government
WLGA	Welsh Local Government Association

The language to best describe autism is difficult, as different people prefer different terms. There is some evidence, drawn from consultation with autistic people, that there has been a shift toward more assertive language like “autistic adults” rather than “adults with autism” (NAS, n.d.) and we have chosen to use this where appropriate in this report. However, where for example, we directly quote someone or a report like the NICE guidelines that uses other descriptions, such as “adults with autism”, we use those.

Summary

Introduction

In March 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP), the Welsh Government announced that it would be funding a new national Integrated Autism Service (IAS) to provide:

- advice and training for families and carers of children, young people and autistic adults;
- advice, support and interventions for autistic people, to help them with their daily lives;
- training and support for professionals, to help them understand the needs of autistic people when they are delivering services, care and support;
- integrated provision of services and support across health authorities and local authorities;
- teams of professionals providing support in the local community, including psychology, occupational therapy, speech and language therapy, nursing and support workers from across health and social care; and
- diagnostic services and post-diagnostic support for adults (WG, 2016a, p.18).

The refreshed ASD SAP also outlined planned improvements to children's assessment and diagnosis, education, social care and employment support and information, advice and training.

This evaluation

The aim of this evaluation is to evaluate the refreshed ASD SAP and accompanying Delivery Plan, with specific focus on the implementation and impact of the IAS. This includes evaluating:

- progress in delivering the integrated service model across each Regional Partnership Board (RPB) area;

- assessing the impact of the IAS across health, social care, education and the third sector;
- assessing compliance with the agreed national service standards for the IAS and, where required, suggesting improvements to the standards;
- assessing progress towards achieving the key success factors [identified by the Welsh Government]; and
- assessing the interface of the IAS with other relevant services.

The evaluation is also required to take into account the experience of individuals, families and professionals in accessing the IAS and their views on the impact of the services delivered, and, as a secondary objective, to undertake an assessment of how the refreshed ASD SAP is meeting its aims; this included:

- undertaking a high level assessment of the progress made in delivering the priorities for action set out in the refreshed ASD SAP and accompanying delivery plan;
- assessing the impact of awareness raising, information and training resources developed and implemented through the ASD SAP; and
- assessing the use and impact of the ASDinfoWales website for individuals, families and professionals.

An interim report, focused upon the development of the IAS in Cardiff and Vale, Cwm Taf, Gwent and Powys, was published in March 2018 and, in September 2018, an extension to the contract was agreed to focus on investigating the reasons for continued long waiting times in children's neurodevelopmental (ND) services and the IAS, and also to explore the scope for greater alignment of ND services. This will be addressed in a forthcoming report.

Approach and methodology

This independent evaluation, which focuses upon the establishment and operation of the IAS and its impact, and also the refreshed ASD SAP, draws upon primarily qualitative data[1]. This was generated through interviews and discussions with autistic adults (n=43), some of whom were also parents of children with autism, and family members and carers (n=37); staff from all seven IASs (n=30), partner services, such as mental health and children's ND services (n=16), ASD Leads (n=13), the Welsh Government (n=4), the Welsh Local Government Association (WLGA) (n=6), Public Health Wales (PHW) (n= 2); and the voluntary sector (n=3). These were complemented by an online questionnaire completed by autistic adults (n=123), parents and carers (n=150) and professionals, mostly from Local Authorities (LAs) and Local Health Boards (LHBs) (n=60) and a review of programme data and documents.

Progress in establishing the IAS

The IAS was introduced on a rolling basis. Powys was the first service to become operational in June 2017, followed by Cardiff and Vale and Gwent, (both in September 2017), Cwm Taf (in March 2018) and North Wales (June 2018). It is expected that the services in Western Bay and West Wales will be operational by the spring of 2019.

The development of the IAS was not easy everywhere. In Powys the process was relatively smooth, although even here there were problems in recruiting the team, and there were significant difficulties and delays in establishing the IASs in the other six regions. As a consequence, the original timeline slipped, and even after some services were operational, there were delays before teams were fully staffed and services could deliver their full offer. The delays were initially caused by difficulties securing local "ownership" of the national IAS model, and once this was secured, by

[1] Problems with the IASs' plans for data collection, linked to IT and data governance challenges, limited the outcome data available for the evaluation.

problems inherent in establishing a new integrated service, such as difficulties with recruitment, IT and accommodation.

The first four services to be established: Cardiff and Vale, Cwm Taf, Gwent and Powys IASs, have all overcome initial teething troubles and made good progress in consolidating their teams, their approaches to assessment and diagnosis, post-diagnostic support, and work with other services. Feedback from service users has become increasingly positive over time, and the IAS has:

- markedly improved the capacity and quality of assessment and diagnosis services for adults, with the biggest impacts in areas like Cwm Taf, where adults' assessment services were limited;
- provided valuable support for adults whose needs cannot be met by learning disability or mental health services, filling a key gap in service provision;
- provided valuable information, advice and support for parents and carers, who often cannot access this from children's ND services, given the pressures ND services face; and
- provided a focal point for consolidating autism expertise and a resource for joint working, consultancy, advice and training to raise awareness and upskill other services, most notably mental health services.

Similar improvements are expected in North Wales (which, although operational and providing support from June 2018, was not able to offer assessment and diagnosis until 2019) and West Wales and Western Bay, which are expected to become operational in spring 2019.

However, Cardiff and Vale, Cwm Taf, Gwent and Powys have struggled to manage demand for their services and long waiting lists for assessment and diagnosis have developed. It is expected that the IASs in North Wales, West Wales and Western Bay will face similar problems. Although an important concern, this highlights the previously unmet or latent demand for assessment and diagnosis for adults.

The interface of the IAS with other services

All seven IASs have worked with a range of partners, in particular mental health services, to clarify referral pathways and ensure autistic adults were referred to the service best able to meet their needs. The IASs have also worked with partners:

- by providing information, advice and training to increase their capacity;
- by making referrals, signposting and supporting autistic adults and also family members and carers to access other services; and
- through joint working, to ensure that the sometimes complex needs of autistic adults are met.

So far, the integration of services and support has been most developed in relation to mental health and children's ND services, which were prioritised. It has been less developed with learning disability (LD) services, where there was seen to be less need[2], and social care services, where IASs have experienced difficulties in having referrals for assessment accepted, and in getting longer term needs, that the IASs cannot provide for, met.

Progress achieving the key success factors

Most of the key success factors identified (by the Welsh Government) for the IAS have been met; for example:

- the IASs in Cardiff and Vale, Cwm Taf, Gwent and Powys provide broadly the same model of support, supported by NICE guidelines, and it is expected that services in North Wales, West Wales and Western Bay will also do so. However, the differing speeds at which the services have developed, and differences in the capacity and responses of other services in each area, inevitably means the support the IASs offer is not identical;

[2] Given services' experience working with autistic people and a learning disability and clear boundaries between the IAS and LD services.

- there are now consistent diagnostic pathways for adults to the IAS, although some work needs to be done to clarify diagnostic pathways to other services, such as mental health;
- although it took time, and although the involvement of autistic adults and family members in developing the services has been mixed, there are now clear governance arrangements for the IAS in each area and key stakeholders from LHBs and LAs have been engaged;
- the services link to existing autism provision, where available, the integration of voluntary sector services (e.g. by commissioning services from the sector) is limited by the IAS staffing and funding model; and
- there is now effective national implementation, oversight and support.

However, two other success factors have not yet been met: there are concerns about the adequacy of resources, given the level of demand, and also the differing needs of each region (which led to criticism of the apportionment of funding across regions), and long term sustainability plans have not yet been developed.

The experience of adults and families accessing the IAS

Service users contributing to the study most valued the way the IAS understood and accepted them; for example, as one adult described the first time he talked with an IAS staff member: “where have you been all my life?” Many talked about the relief of finding the IAS after a lifetime of “masking” their condition, hiding their concerns and not talking about them.

Many of the adults who contributed to the study were not diagnosed until they had experienced a period of crisis leading to acute anxiety or, as many people described it, a “meltdown”. Some were diagnosed by the IAS, others had been diagnosed in the past and were coming to the IAS for support, often following a referral from mental health services. The impact of getting a diagnosis was mixed. For most it was a relief and helped them understand and make sense of their lives, but a minority found it: “challenged their self-identity”.

It was clear that, for some people, partners and family were absolutely crucial in enabling them to function and there was appreciation that this was recognised by the IAS, who could work with and support parents, carers and partners.

There were examples of autistic adults and family members who were very frustrated that the IAS could not meet their expectations to, for example, work directly with children (which is not part of the IASs' role) or offer more support. However, interviewees generally became more positive about the IAS as the evaluation progressed, reflecting how the service has developed over the course of 2018. They praised the one to one support provided by support workers, and the groups and training offered, often in glowing terms. This is consistent with the feedback IASs have collected from service users.

Progress in delivering the priorities for action set out in the refreshed ASD SAP

Improvements to the capacity and quality of children's assessment and diagnosis services have been made, through the establishment of new children's ND services. However, like the IAS, the new services have struggled to cope with demand and long waiting lists have developed (or continued, where existing waiting lists were carried over to the new service).

The early evidence from the Additional Learning Needs (ALN) transformation programme is encouraging. However, it is too early to judge if it will improve identification of needs and educational provision and also parents and carers' relationships with schools and LAs, which are often adversarial.

The Engage to Change programme, which supports young people with disabilities like autism, looks promising, but the impact of other actions to promote employment is likely to be limited, given the limited scope of activity. It is still too early to judge what impact the new Employability Programme will have.

Despite the Social Services and Well-being Act, access to social care remains difficult, and a new Autism Code of Practice is being developed.

Information, advice and training

The evidence suggests that awareness and use of the revamped ASDInfoWales website is relatively high and its resources are well-regarded. The resources are often most effectively promoted by workers who encourage and support autistic adults to use them, rather than relying upon independent or self-directed use. Similarly, IASs report that they have been able to use the training resources developed by the National Autism Team to build awareness and understanding in other key services.

Take up of the Learning with Autism programme has increased, but remains patchy, with a low take up in many LAs, reflecting differing degrees of interest and engagement by LAs and schools in the programme. Take up of other programmes, such as Working with Autism, which have not been as heavily promoted, has been more modest.

Conclusions

There was a strong case for creating a national Integrated Autism Service, given gaps and weakness in provision, with almost universal support amongst the stakeholders interviewed for this study, for the aspirations of the new service. Where well established, as in Cardiff and Vale, Cwm Taf, Gwent and Powys, the IAS is delivering what it set out to do; the services:

- have increased the capacity and quality of assessment and diagnosis services for adults, although they have struggled to cope with demand;
- support autistic adults, through one to one to and group based work (including training) by a multi-disciplinary team of clinicians and support workers, and referrals, signposting, information and advice;
- support family members and carers through group based work (including training) and signposting, information and advice; and

- have worked with and delivered training and support to others, to help ensure a more integrated provision of services and support across LHBs and LAs.

There is confidence that the other IASs in North Wales, Western Bay and West Wales will also deliver this as they become established.

Although the IAS is a national service, working to agreed and prescribed national standards, the support each IAS offers inevitably differs due to differences in the pace of development, funding[3], partners, and the staffing, structure and ethos of each IAS.

The concerns that were raised by some stakeholders about the IAS were generally either that the IAS did not meet their expectations, due, for example, to the delays establishing the service, or that they wanted the IAS to do more, most notably working directly with children (which is not part of the IAS's remit). In some cases, the initial announcements about the IAS raised expectations which could not be met, as people projected their hopes upon the vision of a new service, and managing people's expectations continues to be a key challenge for the IAS. This reflects the often very negative impact of autism upon people's and their families' lives. As one interviewee put it, life with autism in a neuro-typical world can be "bloody hard", and many family members talked about a constant "battle" to access the services and support needed. There were also concerns about the long-term sustainability of the programme, given uncertainty about a future for the service after the initial funding period ends in March 2021. It is understood that the outcome of this review will inform decisions about future funding for the service.

Therefore, while the IAS has made important contributions to improving the lives of autistic adults and also their family members and carers, it cannot meet all needs, nor can it work directly or indirectly with all autistic people. To be effective, the IAS needs to be an integral part of a broader approach to supporting autistic people, including, but not limited to, learning disability mental health, employment, leisure,

[3] For example, some services like Cardiff and Vale benefit from additional funding from the LHB and LA, and some services, such as Western Bay, complained that the apportionment of funding across areas is inequitable and does not adequately reflect differing levels of demand.

education and housing services, and raising awareness and understanding of autism across society. These concerns are reflected in the current delivery plan, separate to the delivery of the IAS and it is important that they have greater priority once the IAS is fully established.

Recommendations

Recommendation 1. The Welsh Government and the National Autism Team should review the communication strategy, to provide clarity about the IAS role and remit.

Recommendation 2. The Welsh Government and the National Autism Team should identify how more information about the progress in establishing the IAS, the challenges encountered, and its performance, can be appropriately shared with (i) stakeholders involved in the development and establishment of the IAS (e.g. through the National Advisory Implementation Group and the community of practice) and (ii) autistic adults, children and young people and their families, and the general public through, for example, ASDInfoWales and local ASD steering groups.

Recommendation 3. The Welsh Government, National Autism Team and RPB ASD Champions[4] should continue to monitor the development and performance of the first five IASs (Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales) and the establishment of the two remaining services (Western Bay and West Wales).

Recommendation 4. The National Autism Team should ensure that monitoring consistency through compliance with the IAS's national standards is complemented by a benchmarking of outcomes across IASs. This should be done intelligently and the reasons for differences in outcomes explored; for example, differences in resources and context are likely to impact upon outcomes. Improvements in the measurement and reporting of outcomes using Outcome Stars will be crucial to enable this.

[4] In the draft Autism Code of Practice, the role of Regional ASD Champions includes "Reporting to the regional partnership board on the delivery of autism services" (p. 37, WG, 2018a).

Recommendation 5. IASs should continue to monitor the profile of autistic adults accessing the service in order to assess how well suited the IASs' support offer is to the needs of different groups, such as men and women with autism those with mental health difficulties and those with sensory needs. This should be informed by analysis of data on outcomes. This analysis should then inform Population Assessments, which under the draft Autism Code of Practice (WG, 2018a), must include autism as a core theme.

Recommendation 6. IASs should assess the capacity of the service to respond to changes in people's circumstances and needs; for example, this could include monitoring the numbers of autistic adults who receive a short term, outcome focused intervention, and who subsequently re-engage with the IAS at a later point, when their circumstances or needs change.

Recommendation 7. The National Autism Team and IASs should continue to monitor and evaluate the extent to which the interventions and support they offer for adults and parents and carers meets their needs. Where gaps in support are identified, consideration should be given to whether IASs should develop their offer and/or work with others services to meet the need.

Recommendation 8. Each IAS should periodically review its work with other services to ensure that a strategic approach is taken, and that engagement with different services is prioritised (e.g. which services are engaged with as a priority) and planned. Opportunities to involve autistic adults and also family members in this review should be taken.

Recommendation 9. The Welsh Government, National Autism Team and RPB ASD Champions should examine how the interface between the IAS and other services develops, including, in particular, its impact upon access to mental health services and social care and upon outcomes for autistic adults and parents and carers.

Recommendation 10. The National Autism Team should work with IASs, RPBs, voluntary sector and service users, to consider the scope and ambition of the IAS; for example, should the IAS (i) focus its work upon a small number of services such

as mental health, learning disability and social care services, or (ii) should it seek to take on a more ambitious agenda, to also work systematically with other services such as leisure, employment and housing services? This should consider both which organisation/s are best placed to deliver this, and their capacity to do so.

Recommendation 11. IAS should work with the National Autism Team and RPB ASD Champions to ensure the evidence needed to inform decisions about long term funding is available.

Recommendation 12. LHBs and LAs hosting IASs should monitor staffing and the impact of decisions about terms, conditions and pay upon services' budgets and their ability to recruit and retain staff.

Recommendation 13. The Welsh Government, National Autism Team and RPBs should review the adequacy of overall funding for the IAS, given the demand for assessment and diagnosis, support and collaborative work with other services.

Recommendation 14. The Welsh Government and National Autism Team should review the apportionment of funding for each IAS in the light of the evidence of the demand for each service.

Recommendation 15. The Welsh Government should make its expectations about long term funding of the IAS clear; for example, whether the expectation is that if the model is proved cost effective, it will continue to be funded through the ICF, or if, for example, LHBs and LAs will be expected to fund the service after March 2021.

Recommendation 16. As outlined in the draft Autism Code of Practice: "Local Health Boards must ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles". As part of this, LHBs should review assessment and diagnosis practice in adult mental health and learning disability services and, where needed, invest in workforce development to address confidence and skill gaps.

Recommendation 17. The Welsh Government and National Autism Team should work with other stakeholders to explore where responsibility for regional and local ASD policy development should lie.

Recommendation 18. As the IAS becomes firmly established, the Welsh Government, National Autism Team, RPB ASD Champions , PSBs and Local ASD Leads should work with autistic adults and their families, and the voluntary sector, to identify the next priorities for action; for example, support in education, for transitions and employment appear to be key unmet needs, but is too early to judge if actions in the refreshed autism strategy are sufficient to address this.

Recommendation 19. The Welsh Government should ensure that the impact of the new Autism Code of Practice is evaluated and that, for example, the impact upon access to social care is considered. This should include assessing the extent to which Information, Advice and Assistance Services have the appropriate skills to assist autistic people; assessors have the knowledge, skills and understanding of autism necessary to identify care and support needs; and the extent to which eligible care and support needs are felt to be identified (in assessments) and provided for.

Recommendation 20. As far as possible, future evaluations of other key elements of the autism strategy, such as the Employability Programme and ALN Transformation Programme, should be required to identify and report on their impact upon autistic people.

1. Introduction

1.1. Autism is a lifelong developmental condition that affects: "how a person communicates with and relates to other people, and how they experience the world around them"[5].

Assessment and diagnosis

1.2. Timely access to assessment and diagnostic services can help ensure that an individual's needs are understood and appropriate services are put in place to support them to lead fulfilling lives. It can also help autistic people, and their families and friends, better understand their lives and experiences (WG, 2016a). Although autism can (and should) be identified and diagnosed at a young age, some people do not receive a diagnosis until adulthood, either because opportunities for diagnosis were not available when they were young, or because the impact of their autism increased as they became adult.

Meeting support needs

1.3. Individuals with autism, and their families, have a range of needs. This reflects both differences in the impact of autism (which is a "spectrum" condition) (Baron-Cohen, 2008), and in their circumstances (for example, differences in the capacity of families and support services), which shape their needs[6]. This has led to the expression: "if you have met one person who has autism, you have simply met one person who has autism" (SCIE, 2017). While autism is a lifelong condition, levels of disability are not fixed and, if needs are not met, individuals with autism and their families can struggle to live fulfilling lives.

[5] What is autism? National Autistic Society
[6] This means needs are dynamic, and as a person's circumstances change, and they, for example, make a transition from school to further education or employment, their needs can also change.

Wales's Autism Strategy

1.4. In order to improve outcomes for autistic people and their families, in 2008 the ASD SAP for Wales was published (WAG, 2008). Consultation with stakeholders and evaluation of the strategy identified that, although the ground-breaking strategy achieved a great deal, there was a need for greater focus. In 2016, a refreshed ASD SAP and Delivery Plan, which included proposals for a national Integrated Autism Service, were published (WG, 2016a, 2016b).

1.5. The refreshed ASD SAP included proposals for an Integrated Autism Service (discussed below) and also actions to improve children's assessment and diagnosis, access to education, health and social care, employment and information, awareness raising and training.

The Integrated Autism Service

1.6. The IAS was introduced on a three year rolling basis. The original timeline envisaged the first four IASs (Cwm Taf, Cardiff and Vale, Gwent and Powys) operating by October 2017, followed by West Wales in October 2018, Western Bay in January 2019 and North Wales in July 2019.

1.7. The IAS is intended to offer:

- "advice and training for families and carers of children, young people and adults;
- advice, support and interventions for people with autism[7] to help them with their daily lives;
- training and support for professionals to help them understand the needs of people with autism when they are delivering services, care and support;

[7] The term "people with autism' was used throughout the ASD Strategic Action Plan. Consultation with autistic adults since has led to "autistic adults" or "autistic people" being the preferred term used throughout this report (unless otherwise stated).

- integrated provision of services and support across health and local authorities;
- teams of professionals providing support in the local community, including psychology, occupational therapy, speech and language therapy, nursing and support workers from across health and social care; and
- diagnostic services and post-diagnostic support for adults"[8] (WG, 2016a, p.18).

1.8. Although described as a: "national service to provide lifetime support to children and adults with autism, and their families"[9] the IAS is not intended to replace existing services, but to address gaps in service provision; for example, as the revised guidance makes clear:

> "the service has been developed to meet the needs of autistic individuals (and their family and carers) who do not meet the eligibility criteria for statutory services due to absence of a moderate to severe mental health need or moderate to severe learning disability. Those who do meet eligibility criteria for statutory services should be supported by the service that addresses the most significant need and not the Integrated Autism Service" (WLGA, n.d.b, p.5).

1.9. Alongside the IAS:

- assessment and diagnosis of children will continue to be undertaken by ND services, with the support of the Together for Children and Young People (T4CYP) programme (discussed in section 6)[10];

[8] Diagnosis and assessment for children is provided through the T4CYP programme.
[9] Extra £7 million for innovative all-Wales autism service
[10] The revised Guidance (WLGA, n.d b) makes it clear that: "the service will provide diagnostic assessment for those aged 18 and over who are not accessing appropriate support from learning disability or mental health services due to eligibility exclusion. Local flexibility between the IAS and ND service in relation to those bordering the age cut off for services will be employed, with the focus on the most appropriate approach for the young person" and: "the service provides advice and supportive interventions for individuals of all ages. The decision about how this is delivered will be based on the individual's developmental age. For children, this will likely be via family members/carers and adults directly. Older children/young people may need a combination of approaches. Age should not be the only factor used to make decisions about the way an individual is supported" (ibid, p.5).

- specialist post-diagnostic support for children will be provided by existing services (e.g. SEN specialist services such as educational psychologists and children's disability teams); and
- assessment and diagnosis and post-diagnostic support for adults with moderate to severe mental health or learning disabilities will be through existing mental health and learning disability services.

Aim and objectives of the evaluation

1.10. The aim of the evaluation is to evaluate the refreshed ASD SAP and accompanying Delivery Plan, with specific focus on the implementation and impact of the IAS. The evaluation has two main objectives; the primary objective is to undertake an assessment of the delivery and impact of the national Integrated Autism Service; this includes evaluating:

- progress in delivering the integrated service model across each RPB area;
- assessing the impact of the IAS across health, social care, education and the third sector;
- assessing compliance with the agreed national service standards for the IAS and, where required, suggesting improvements to the standards;
- assessing progress towards achieving the key success factors [as identified by Welsh Government]; and
- assessing the interface of the IAS with other relevant services.

1.11. The evaluation is also required to take into account the experience of individuals, families and professionals in accessing the IAS and their views on the impact of the services delivered, and, as a secondary objective, to undertake an assessment of how the refreshed ASD SAP is meeting its aims.

This report

1.12. This report focuses upon the progress made in establishing the IAS in each region (section 4) and its interface with and impact upon other services (section 5) and service users (section 6). It also provides an assessment of how the refreshed ASD SAP is meeting its aims in relation to children's assessment and diagnosis, access to education, health and social care and employment (section 8) and awareness raising information and training (section 9). The report does not include the full detail provided in the Interim Report (Holtom and Lloyd-Jones, 2018)[11] about the early stages of the development of the IAS in Cardiff and Vale, Cwm Taf Gwent and Powys. It will also be complemented by a forthcoming report focused upon examining waiting times for assessment and diagnosis for children and adults.

[11] Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan

2. Approach and methodology

2.1. A primarily qualitative approach was taken to identify how the IASs were established in each area and their interface with and impact upon other services; this included semi-structured interviews and discussions with:

- the Welsh Government's Adult Social Services Lead (who leads on autism policy in the Welsh Government);
- staff involved in developing and delivering each of the seven IASs (n= n=30);
- staff in the key services the IAS interfaces with, most notably mental health and children's ND services (n=16);
- current and former members of the National Autism Team (n=6);
- ASD leads (n=13);
- Public Health Wales (n=2);
- representatives from the NAS Cymru and Autistic Spectrum Connections Cymru (key voluntary sector organisations) (n=3).

2.2. Stakeholders' responses and views were triangulated and enriched by a desk-based review of documents[12] and service monitoring data, to ensure that as complete a picture as possible of progress and impact could be generated.

2.3. A similarly qualitative approach was taken to explore and identify the experience of autistic adults and of the family members and carers of children with autism; this included:

- semi-structured interviews or in small number of cases (n=5), discussion by email, with autistic adults and family members or partners (n=1) of autistic adults accessing services, who were recruited with the help of the

[12] Key Welsh Government and WLGA policy documents were reviewed, such as the ASD SAP and national guidance for the IAS and Integrated Care Fund (ICF) returns.

five operational IASs (Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales) or who approached the evaluation team and who were interviewed on an ad hoc basis;

- five group discussions with autistic adults and/or family members and carers in Cardiff and Vale[13], Gwent and North Wales;
- online questionnaires, distributed by National Autistic Society (NAS) Cymru, Autism Spectrum Connections Cymru (ASSC) and five ASD Leads, which generated 150 responses from family members and carers and 123 responses from autistic adults (see table 2 below).

2.4. As table 1 illustrates, the number of people who came forward in each region differed, creating an uneven distribution across Wales. This was partially offset by responses from the online survey (discussed below).

Table 1. Interviews, discussions and focus groups with adults and autism and families

Region	# of autistic adults*	# of family members
Cardiff and Vale	23	7
Cwm Taf	1	1
Gwent	4	23
Powys	2	0
North Wales	14	5
West Wales	0	0
Western Bay	0	1
Total (all Wales)	**43**	**37**

* Some of the autistic adults were also parents of children with autism. Where they spoke principally about their own experiences, we counted them as adults in Table 1.

[13] The evaluation team was invited to observe a focus group that ASSC organised to provide evidence for the Health and Social Care Committee.

2.5. The assessment of how the refreshed ASD SAP is meeting its aims drew upon evidence from research with the stakeholders outlined above, and:

- interviews with representatives of the Children's Mental Health Division (n=2) (responsible for children's ND services); ALN Reform Branch (n=2) and Employability programme (n=1) in the Welsh Government;
- the Engage to Change programme (n=1)
- a desk-based review of documents and data[14];
- an online questionnaire, distributed by five ASD Leads, which generated 60 responses from professionals.

The online survey

2.6. As table 2 Illustrates, although there were responses from all regions, around half of all autistic adults, family members and carers who responded came from the Gwent area. As this could have skewed the responses, a separate analysis of those from the Gwent area compared with the rest was done. There was no marked difference in their responses. In addition, some of the written comments on the questionnaire indicated that a carer had completed the questionnaire on behalf of an adult. This appears to explain why the number of responses to questions about how and when the respondent was diagnosed (n=42) were markedly lower than responses to other questions (which typically ranged from 75 to 122 responses).

[14] Such as WLGA data on the ASDInfoWales website and the Learning with Autism programme.

Table 2: Number of survey responses from family members and carers and autistic adults

Region	# Family members and carers	# Autistic adults
Cardiff & Vale	4	12
Cwm Taf	8	4
Gwent	72	68
Powys	5	4
North Wales	12	9
Western Bay	24	14
West Wales	24	13
Total	**149**	**124**

Sources: People and Work survey

2.7. There were 59 responses from professionals to the online survey. The majority represented either LAs (n=30) or LHBs (n=14). There was also a smaller number of responses from the voluntary sector (n=9).

Triangulating data

2.8. The total size of the sample of autistic adults and family members is small and it is not possible to assess how representative the views of each sample are of the populations (i.e. all autistic adults and family members). Therefore, data from the interviews, focus groups, emails and questionnaires was triangulated with other sources to provide an indication of how representative the responses were likely to be. Responses of adults and also family members and carers were also compared with those of professionals. Where both adults or family members and carers share similar views as professionals, and this is also consistent with other evidence (such as other research like the national consultation that informed the development of the IAS (WLGA, 2015), we can be more confident that the findings have external validity.

3. Context for the establishment of the Integrated Autism Service

Health and care services

3.1. Health and social care services face a very challenging context, with rising demand as a result of demographic changes and increasing expectations, alongside cuts or freezes in their budgets. Consequently, many services are under pressure and access can be rationed through waiting lists and/or increasingly strict eligibility criteria. There are also concerns that pressures may lead to "cost shunting" where cuts or restrictions in access to one service increases demand upon other services.

3.2. A focus upon co-production, prevention and integration of services is seen as a key part of the response to this challenge (see e.g. the Well-being of Future Generations and Social Services and Well-being Acts). RPBs[15] and the ICF[16] are key vehicles for advancing this agenda. RPBs are responsible for undertaking Population Needs Assessments (PNAs), which include the needs of autistic people, and which should inform regional planning and priorities.

3.3. The focus upon co-production and prevention is expected to help improve effectiveness and reduce demand (e.g. by preventing escalation of needs) and integration is expected to help maximise synergies and create more seamless services for users/citizens (Parliamentary Review, 2017; Williams, 2014). However, evidence of the impact and efficiencies generated by integration remains weak (Cameron et al., 2012).

[15] Regional Partnership Boards were established in response to the Social Services and Well-being (Wales) Act 2014. They bring together health, social services, the third sector and other partners to take forward the effective delivery of integrated services in Wales[15]. RPBs administer the ICF, which supports delivery of the Social Services and Well-Being Act (2014).

[16] Established in 2014 as the Intermediate Care Fund to: "support initiatives which prevent unnecessary hospital admission, inappropriate admission to residential care, and delayed discharges from hospital", in April 2017 it was rebranded as the Integrated Care Fund to better reflect an expanded scope (WG, 2017).

NICE Guidelines

3.4. In 2012 the National Institute of Care Excellence (NICE) published clinical guidelines on: "autism spectrum disorder in adults: diagnosis and management" (NICE, 2012), outlining best practice advice on the care of autistic adults. The guideline recommendations included establishing a local autism multi-agency strategy group and a specialist community-based multi-disciplinary team for autistic adults (the specialist autism team)[17] (ibid., p.14). The guidelines suggest that this team: "should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services;
- specialist care and interventions;
- advice and training to other health and social care professionals on the diagnosis;
- assessment, care and interventions for adults with autism[18] (as not all may be in the care of a specialist team);
- support in accessing, and maintaining contact with, housing, educational and employment services;
- support to families, partners and carers where appropriate;
- care and interventions for adults with autism living in specialist residential accommodation; and
- training, support and consultation for staff who care for adults with autism in residential and community settings" (ibid, p.15).

3.5. However, the guidance also identifies that:

> "there is little evidence to guide the establishment and development of these teams. There is uncertainty about the precise nature of the population to be served (all people with autism or only those who have an

[17]The membership should include: clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists, support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

[18] The term "adults with autism" is used in the NICE guidelines and as such remains unchanged for the purpose of this reference: Autism spectrum disorder in adults: diagnosis and management

IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship
with regard to non-statutory care providers. Therefore, it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism" (ibid., p.40).

Autism policy and practice

3.6. As outlined in section 1, in 2008, Wales's first autism strategy was published (WAG, 2008). A new ASD infrastructure was established, based around local ASD leads in each LA, to help drive improvements and deliver the strategy. In 2010, in order to address continuing weaknesses in assessment and diagnosis for adults, and to address the NICE guidelines, an All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults was launched[19]. Community monitoring and support projects were also established[20] in order to address the continuing gap between mental health and learning disability services. In 2012 a commitment was given to refresh the ASD SAP, stakeholder consultation events were held and an ASD Stakeholder Advisory Group was established.

3.7. The All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults contributed to important improvements. However, in the absence of strategic leadership, whilst "islands" of practice and expertise developed, in some areas services struggled to develop, or

[19]The three primary functions of the network were to: "agree and facilitate a standardised process of assessment and diagnosis, interpreted and described within each Local Health Board, building on existing knowledge and structures; to develop and deliver training to increase the number of clinicians skilled in the field and to prove the quality and consistency of diagnostic practice; [and] to enable the development of local improvements and sharing of best practice by maintaining an expert reference group" (Betsi Cadwaladr, 2011, p.3).

[20] The community monitoring and support(CMS) worker posts were intended to provide a signposting service for adults with ASD and, by providing low-level support, were intended to help stop problems escalating. In practice, some CMS workers have taken a more interventionist role, in response to the lack of services to which to signpost people (Holtom & Lloyd-Jones, 2016).

collapsed after key people left[21]. As a consequence, in some parts of Wales, adults struggled to access assessment and diagnostic services, creating inequalities in access and provision, and contributing to long waiting lists (Holtom & Lloyd-Jones, 2016).

3.8. Given the problems, in 2015 the ASD Diagnosis Task and Finish Group was established to review assessment, diagnosis and support services. It identified the need for:

- improvements in assessment and diagnosis (including reductions in waiting times);
- clearer pathways and more information, advice and support at the point of diagnosis; and
- more effective post-diagnostic support around areas such as emotional and behavioural issues; ASD specific issues; social skills and life skills; information and advice; access to services, and support in relation to employment (WG, 2016c).

3.9. In April 2015 an Interim [Autism Strategy] Delivery Plan was published[22] and included proposals for scoping an Integrated Autism Service (WG, 2015a). To support this work, the ASD National Development Lead undertook a consultation with family members, carers and individuals with an ASD, through surveys and workshops. This consultation identified similar issues to those highlighted by the Task and Finish Group (outlined above). Subsequently, in parallel to the work of the Task and Finish Group, the ASD National Development Lead undertook a scoping study to consider options for establishing an Integrated Autism Service. This was presented to the Welsh Government in September 2015.

[21] As the Task and Finish Group identified: "improvements were only being driven by clinicians engaged with the network, as there has been an absence of strategic direction for autism services across health boards."

[22] An "interim", rather than full strategy was published: "to enable further policy development and to provide some time to ensure that future priorities took into account new legislation", which included the Social Services and Well-being Wales Act 2014 and the Well-being of Future Generations (Wales) Act 2015 (WG, 2015a).

3.10. In March 2016, the Minister for Health and Social Services announced a £6 million investment in the development of an Integrated Autism Service for Wales. A 12-week consultation on the proposals was undertaken and confirmed strong support for the proposals for an IAS, albeit with questions about detail (which were not outlined in the consultation document) (WG, 2016c).

3.11. Following the Minister's announcement, in March 2016, ICF funding for 2016/17 was announced. £188,000 was allocated to Powys, £204,000 to Cardiff and Vale, £204,000 to Cwm Taf and £249,000 to Gwent, to support the development of an IAS. The ICF Guidance for 2016/17 (published in April 2016) included the objective to:

> "develop an integrated autism service, focusing on a multidisciplinary team to support autism in adults and enhancing existing children's neuro-developmental services" (2016d, p.4).

3.12. In March 2017 it was announced that initial funding of £6 million for three years would be increased to £13 million over five years. This helped address concerns about the sustainability of the service over the medium term. Funding for RPBs for the IAS in 2017/18 totalled £2,674,400[23], with a further £80,000 for the WLGA (which was in addition to the ICF funding allocated to the IAS) with £245,600 retained by the Welsh Government (WG, 2017).

3.13. Proposals were required from RPBs on the use of ICF, to demonstrate how they intend to meet both the objectives of the grant (such as developing an integrated autism service) and the criteria for funding[24], because: "needs vary within regions" and it is up to:

[23] This comprised £367,000 for Cardiff and Vale; 367,000 for Cwm Taf; £458,400 for Gwent; £508,800 for North Wales; £336,800 for Powys; £318,200 for West Wales and £318,200 for West Wales (WG, 2017).

[24] i.e. proposals should encourage integrated working, be "strategic" and "transformational", "new/additional", "deliver benefits" and be "fair" and "equitable" (WG, 2017, pp 9-10).

"each region, with their partners, to develop proposals and determine the most appropriate model of delivery to best meet the specific needs within their area" (WG, 2016d, p.10).

3.14. In July 2017 the initial guidance for the IAS (WLGA, n.d. a) was revised, to provide additional detail on the national model and approach (WLGA, n.d. b)

Establishing a national service

3.15. Previous initiatives in this area, such as the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults and the community monitoring and support projects, relied upon a mix of "extrinsic levers"[25], most notably additional funding and targets, and "intrinsic levers"[26] such as the development of networks of practice. As outlined above, these contributed to important improvements, but also to unjustified inconsistencies in practice across Wales[27].

3.16. In response, a different approach has been taken to establishing the IAS. Primarily extrinsic levers would encourage and enable each RPB to establish an IAS, most notably:

- additional resources, allocated through the ICF;
- national standards (WLGA, n.d. a, b) based upon the NICE Guidelines (NICE, 2012); and
- support and challenge from the WLGA's ASD national team.

[25] These "…tend to 'direct' health and social care organisations to do specific things that can create added focus and momentum for delivery. Regulation, targets, national performance management, national contracts and nationally designed financial incentives are examples" (Parliamentary Review, 2017, p.54).
[26] These: "rely on supporting key individuals to do the right thing. This includes developing leaders to manage staff better to instil more effective cultures and behaviours within an organisation and providing professionals with information and analysis to allow them to review their performance and that of their peers" (ibid.).
[27] While some differences in provision: "reflect different challenges, contexts and priorities", too many people: "receive markedly worse service simply because of where they live" (Williams, 2014, p. 66).

It was intended that:

> The national approach will ensure consistency, enabling people with autism[28] to access comparable services across Wales, whilst taking into account differing regional or local circumstances (ibid.).

The Autism Bill and the Autism Code of Practice

3.17. Despite the progress made since 2008, concerns about inconsistency in provision across Wales and the sustainability of services have driven calls by individuals and groups, such as NAS, for an Autism Bill. In June 2017, a private members' bill to establish specific autism legislation[29] was introduced by Paul Davies AM to the National Assembly for Wales. In response, the Welsh Government pointed to the refreshed ASD SAP, including the commitment to establish the IAS and argued that the legislation needed to improve autism services, including the Social Services and Well-being Act, the Well-being of Future Generations Act, and the National Health Service Act, was already in place and announced plans to introduce an Autism Code of Practice; statutory guidance on autism under the Social Services and Well-being Act to underpin delivery of the ASD SAP.

3.18. The draft Bill created additional pressure to get the IAS established in Wales. It passed to committee stage one in September 2018. The Health, Social Care and Sport Committee could not reach consensus about whether to support the Bill, with some members of the Committee supporting the Bill, but others making the judgment that more time was needed to see if existing initiatives, like the IAS, would meet the needs the Bill seeks to address. However, there was agreement amongst members on the: "pressing need to improve support services for people with ASD

[28] The term "people with autism" is drawn from a direct quote and, as such remains unchanged in this report.

[29] If enacted, the draft Autism Bill could include: a duty on every local area in Wales to have a pathway to diagnosis of autism; duties on LAs and LHBs about the way they organise local services and support for autistic people and their families in Wales; a requirement on key staff working with autistic people to receive autism training; duties around ensuring that LAs and LHBs publish information on the services they provide for autistic people in their areas; and a duty on Welsh Government to regularly review progress.

and their families across Wales" (NAfW, 2018). In January 2018, following the Stage One General Principles Debate, the Bill was rejected by the National Assembly for Wales and the Welsh Government is now focused upon developing an Autism Code of Practice[30] .

[30] The draft Code of Practice was published in 2018

4. Progress in delivering the integrated service model

4.1. In this section we consider progress in establishing the IAS in each region, including compliance with the agreed national service standards and the key success factors initially identified for the IAS. We draw primarily upon interviews with professionals and services' data. We discuss service users' perspectives on the IAS in section 6. We distinguish between progress in the first wave of IASs - Cardiff and Vale, Cwm Taf, Gwent, Powys, which were established in early 2018, and the second wave of IASs, Western Bay, West Wales and North Wales, established later. We then consider the cross-cutting themes for all seven IASs.

Cardiff and Vale, Cwm Taf, Gwent, Powys IASs

4.2. As outlined in the interim report (Holtom and Lloyd-Jones, 2018), while the process in Powys was relatively smooth, there were difficulties and delays in establishing IASs in the other three regions. These reflected weaknesses in communication and leadership and practical problems associated with the integration of services and recruitment (ibid). Cardiff and Vale, Cwm Taf and Gwent have all overcome these initial teething troubles. As we outline below, all four IASs have made good progress in consolidating their teams, and their approaches to assessment and diagnosis, post-diagnostic support, and work with other services.

Establishing the IAS

4.3. IASs consulted autistic adults and family members and carers through events and groups; for example, Cwm Taf and Powys worked with local parent support groups and Powys also worked with children's integrated disability services and has established an adult autism focus

group. Cardiff and Vale and Gwent also worked with autistic adults to develop more bespoke provision for different groups.

4.4. However, the scope for co-production of the IASs was constrained by the focus on adopting a common prescribed service model across Wales. This has limited IASs' scope to respond to people's wants from the service and caused frustration and, for example, in Gwent, family members attending a launch event expressed unhappiness that the service would not directly support children. The delays in establishing the service also contributed to discontent amongst some stakeholders in Cwm Taf who wanted to engage with the development of the service, but were unable to do so, as it was reported that the delays in, for example, agreeing the service model and staffing, limited the scope for stakeholder engagement about what the service would and could do. Nevertheless, after a somewhat rocky start, engagement in Gwent was reported to have improved markedly, with autistic adults, carers and family members reporting subsequently very positive experiences of the Gwent IAS and, as we outline in section 7, engagement at an individual level with service users was generally reported to be working very well.

4.5. Recruitment of staff was difficult in Powys and Cwm Taf in particular, reflecting the small size of the workforce with the skills needed, and more general difficulties recruiting staff in more rural areas, slowing the establishment of teams. Integrating clinical and support staff was difficult in Cardiff and Vale, Cwm Taf and Gwent[31]. The challenges included differing terms and conditions for health services and LA staff and different line management of health and LA staff in some areas. It has taken time for IAS staff, LAs and LHBs to work out how to work

[31] Integration of health and social care staff in Powys, which has a number of integrated teams, was relatively straightforward.

together. While there are concerns in some areas like Cardiff and Vale, that risks remain[32], the teams are now all reported to be working well.

4.6. Nevertheless, none of the four services is finalised. Assessment, diagnosis and support arrangements (both discussed below) are well established now, but work with other agencies, as we discuss in section 5, is still developing. As some interviewees said: "it's a work in progress", and: "a year into a new service is not that long". In addition, services recognised the need to continue to test new approaches and to evolve, given the growing demand for their services (which is stretching capacity) and the need to respond to the differing needs and interests of autistic people.

4.7. Moreover, even where services were established and running well, there are concerns about their long-term sustainability. In the medium term, these concerns centre upon managing demand for assessment and diagnosis in particular, (which we discuss below) and staffing, including:

- retention of staff given, for example, pressure upon services (which might lead to staff moving on), and differing terms and conditions across IASs (for example, Gwent's staff are either on secondment or fixed term contracts, while Powys' staff are on permanent contracts);
- covering staff absences, for example, due to sickness or maternity leave, which could be challenging (as was the case in Cwm Taf and Powys); and

[32] For example, as one interviewee put it, when describing managing the service: "it's a structural challenge." They described how at the moment there are very good working relationships with the team and the line manager for each team member, but that there are potential difficulties if, for example, capability and disciplinary procedures became necessary. They also noted that the dual management structure takes more time and means more paperwork as, for example, decisions on annual leave and TOIL need to be approved by two people.

- covering the cost of increases in pay (as budgets were already stretched and some staff were expected to move up pay scales over time).

4.8. In the longer term, challenges centred upon the end of the current funding for the IAS in March 2021, and a lack of clarity about if it would continue, and if so, who would provide funding for the service at this point. This is why some felt that, while services were working well, they were somewhat “fragile”.

Assessment and diagnosis for adults

4.9. Interviews and written responses from autistic adults confirmed the value and importance of diagnosis; for example, as one adult put it:

> It is hard to put into words what a difference getting a diagnosis has made to me, it explains so many things, has made me more accepting of myself, improved my mental health and is the start of a journey which has made the world seem a brighter place full of other people like me.

4.10. As another put it:

> I now know why my life experiences have been so difficult. I have always pushed myself to do better; expected more from myself, yet have not achieved the life experiences of my peers in my age group, and that has caused me a great deal of anxiety through masking in order to avoid awkward and embarrassing questions.

4.11. As outlined in section 1, the evaluation of Wales’s first autism strategy highlighted important improvements in assessment and diagnosis for adults in some areas (Holtom and Lloyd-Jones, 2014). However, it also identified considerable inconsistency in practice across Wales, with long waiting lists in some areas, an excessive reliance upon individuals

with an interest and commitment to the area (which contributed to the fragility of services) and, in some areas, a lack of clarity about referral pathways (ibid.).

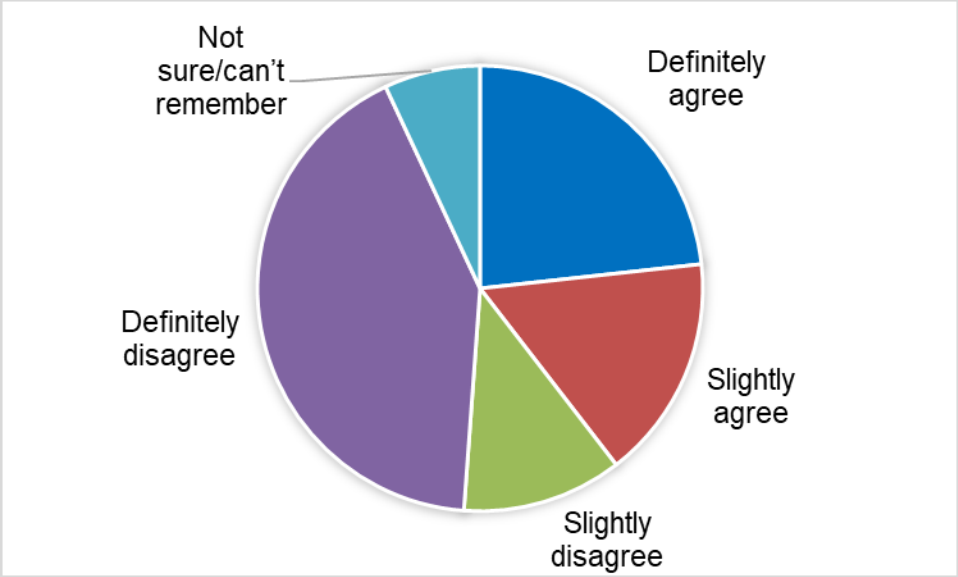
4.12. The long-standing weaknesses in assessment and diagnosis services for adults were reflected in responses from adults to the online survey, with less than half of adult respondents (n=16) who answered the question, agreeing that it was easy to access an assessment for diagnosis. Written responses to the questionnaire elaborated upon this; for example, as one adult pithily put it, after diagnosis there was: “no support or help afterwards” and as another put it, he had a:

> 4 year wait, after referral, for a diagnosis. Diagnostic report recommended numerous actions/interventions that there is no provision for. There has been no follow up, and no services for autistic adults exist in my area. I feel abandoned in a strange and scary new world without either guide, map, or compass.

4.13. Another described:

> feeling I was going to get some help [after diagnosis] and that I wasn't just feeling self loathing, lonely depressed all the time. But there is no help for adults, just NAS volunteers.

Graph 1: Responses from autistic adults to the statement "it was easy to see (meet) someone who could assess if I had autism or not"



Source: People and Work survey of Autistic adults (n=43)

4.14. Similarly, many of the adults interviewed for the study described the difficulties they had experienced in the past accessing an assessment and diagnosis and post diagnostic support. For example, a number of adults in North Wales reported having to go to England and pay for private assessments.

4.15. Improving the quality and consistency of assessment and diagnosis and post-diagnostic support for adults was therefore a key priority for the IAS. All four services have established referral pathways and what they consider to be robust and NICE-compliant assessment and diagnosis processes. In Cardiff and Vale, Powys and Gwent, elements of existing adult assessment and diagnosis services have been aligned and, to differing degrees, integrated in the IASs[33]. As we discuss in section 5, diagnostic pathways to other services, most notably mental health services, have also been worked on. While these are now

[33] In Cardiff and Vale one of the specialist nurse practitioner posts in the IAS in Cardiff and Vale is funded by mental health services; in Gwent a psychiatrist is a de facto member of the IAS (Psychiatrists are not part of the IAS model, limiting the scope for full integration); and in Powys, a Clinical Psychologist, a role which was not part of the original model, is a key member of the IAS. - Revised 13 May 2019

clearer, in Cardiff and Vale and Cwm Taf, IAS report that they have not yet been finalised.

4.16. In all four areas the changes have improved access to assessment and diagnosis. The impact of this has been greatest in areas like Cwm Taf, where the pre-existing arrangements were weakest[34]. The processes are reported to be working well, but the new services have had to deal with a high level of demand, meaning waiting times for assessment and diagnosis have increased sharply; for example, in late 2018:

- in Cardiff and Vale, there was a six to eight month wait for assessment and diagnosis;
- in Cwm Taf there was a four to six month wait for assessment and diagnosis;
- in Powys there was an 11 to 15 month wait for assessment and diagnosis; and
- in Gwent there was a 12-month wait, but there were fears that it could rise to 18 or even 24 months, if there were to be no change in demand or capacity.

4.17. Gwent and Powys reported that current demand exceeded capacity, particularly in relation to assessment and diagnosis, whilst Cardiff and Vale, which benefits from additional funding[35], and Cwm Taf were only just coping. Demand profiling during the planning stage of the IAS was felt to have been weak, and it was unclear if current levels of demand represented a spike in demand (supply induced demand), following the establishment of a new service, or were indicative of an ongoing trend

[34] In Cwm Taf, assessment and diagnosis were reliant upon a single clinician and referral pathways were unclear and unpublished. Provision was somewhat stronger in the other areas; for example, in Cardiff and Vale services, which had been reliant upon a specialist nurse, things were improving, with an experienced clinician undertaking assessments, clearer pathways being established and some post-diagnostic counselling and support being provided; in Gwent, assessment and diagnosis was reliant upon a single, albeit very experienced, clinician with support from a specialist nurse (rather than multi-disciplinary team); and in Powys, an adult diagnostic pathway, including pre- and post-diagnostic support was in place.

[35] The service receives an additional £155,000 (over and above its annual ICF allocation of £367,000) composed of £40,000 from Cardiff and £40,000 from the Vale of Glamorgan council and £75,000 from Cardiff and Vale University Health Board.

in demand. Some areas such as Gwent (and also Western Bay) felt that the funding for the IAS was neither proportional nor equitably distributed across IASs, given the demands upon their services.

4.18. Where the IAS inherited an existing waiting list, as in Gwent and Powys, this increased the pressure upon services and waiting times. In response, Powys commissioned additional assessments and diagnosis from the Dyscovery Centre to tackle some of this backlog and estimates that it will take another 20 months to get through the rest, alongside new referrals. Gwent reported that it is constantly reviewing its processes to maximise the efficiency of the assessment and diagnosis process without compromising its quality. Assessment was described as a "clinician intensive" process, requiring at least two clinicians to be involved over a period of a couple of weeks. There is a basic mismatch between the number of referrals and the capacity of services to carry out assessments. We discuss the demand for services and causes for waiting times in detail, in a forthcoming paper.

4.19. A common concern across all four IASs was that the pressure to prioritise diagnosis would draw in staff time and energy, undermining the post -diagnostic support that services could offer (discussed below). It was observed that this had happened to other integrated autism services in the UK and, as one interviewee put it, it was: "pointless to have a diagnostic service if there is no resource to support that" (by providing post-diagnostic services).

Support for autistic adults, their partners and family members and carers

4.20. Support following diagnosis is a key part of early intervention. The right support can make a huge difference to adults and their families' and carers' quality of life and independence. (SCIE, 2017). In response, all four services described offering a mix of:

- one to one support;

- joint work with other services;
- group based work, including training; and
- referrals and signposting to other services.

4.21. All four services offer one to one support to autistic adults, and in a few cases, to family members and carers. The one to one support is provided by clinical staff, such as psychologists, occupational therapists (OTs) and dieticians, and by community support workers (CSWs).

4.22. Clinical staff have important expertise; for example, a number of services described how often sensory issues came up, issues that were often addressed by OTs and were seen as critical in enabling other interventions[36]. Similarly, where they were part of the team, as in Cardiff and Vale, dieticians might focus upon issues like restricted eating and, in North Wales, a psychologist described developing Dialectical Behaviour Therapy (DBT). However, clinical staff's time is limited, given their role in assessment and diagnosis, and the one to one support clinical staff offer was usually underpinned and complemented by one to one work delivered by support workers and group-based work.

4.23. Community support staff were seen as vital in continuing and following up interventions and strategies developed by clinical staff and, as the case study below illustrates, also in addressing more day to day issues. Examples were given during interviews and focus groups with adults and also family members and carers, of the stress and difficulties they experienced in dealing with services. In response, community support workers focus on helping people to manage their anxiety, referring them to opportunities in the community and running courses, such as Skills for Life. Workers may also convene and facilitate support groups.

[36] It was observed that if sensory issues were not addressed, service users could struggle to access other types of support (such as that offered by community support workers).

There were also examples of community support workers doing “soft handovers”, accompanying people to appointments or new activities, until they were confident to go alone. They were also sometimes involved in helping people with practical financial, housing or self-care issues. The effectiveness of clinical and support staff roles was therefore mutually dependent.

Roger

Roger (not his real name) is 22 years old and lives with his family members. Roger has previously attended college courses, but reported that his anxiety increased when he was at university. This led to his experiencing physical discomfort and becoming overly fixated on his physical health. Symptoms had reduced since he stopped going to university and with the introduction of medication.

Roger was referred to IAS by Primary mental health services for input around management of anxiety symptoms, leisure and recreation opportunities and employment support. The input required was identified as being for a short, focused intervention.

Roger was initially assessed by an IAS clinician and support worker. The clinician defined anxiety and described the possible physical effects it could have. This helped Roger identify how stress physically affects his body and Roger was able to list situations which might cause him to experience increased anxiety. The IAS used tools to develop a personalised anxiety management plan with Roger, identifying strategies to help manage his anxiety.

Alongside this, the family support worker discussed and provided information about sport and leisure activities in the area and also provided information about the local Job Centre and the additional support he could access there (as Roger was not working, but wanted

to).

Adapted from the National Autism Team Case Studies Library

4.24. As the next case study below illustrates, the expertise and skills of community support staff were valued in their own right and, in some cases, the only contact people had with the IAS was through support workers. Support workers established relationships with adults and family members and carers, which, as we outline in section 6, were often described as very good. In Gwent and Cardiff and Vale, support workers were the first point of contact in the IAS, helping free up clinicians' time, and enabling a swifter, more responsive service.

Charlie

Charlie's referral came about after meeting with a parent and carer group and me telling group members about the new service. The foster mother of Charlie (not his real name) came along to the meeting to find out what support the IAS offers. The referral came via the Multi-Disciplinary Team (MDT) and a support worker went to visit Charlie to see what support he feels he needs.

The support worker reports that initially Charlie was very quiet and would share very little with me. In the beginning they spent a lot of time trying to build a good rapport, showing interest in Charlie's interests and using "person-centred thinking" to help Charlie to see others' points of view and to recognise and take responsibility for how he spends his time.

The intervention has been deemed a success by Charlie and the family members. Charlie went from spending all his time in his room except for meals and only leaving the house for college via his taxi, to attending a social group on two occasions, walking the dog regularly,

going into the village to purchase items and asking for forms at the post office, and travelling on the bus alone to local towns.

Adapted from the National Autism Team Case Studies Library

4.25. One to one support was described by all services as outcome focused, offering short-term interventions to provide people with practical help and skills and insights into autism. Nevertheless, services described some flexibility in how long support could be provided for, and some staff and IAS users described it as a life-long service[37]. This was not about open caseloads, but rather that people could come back to the IAS if facing new problems. Most one to one support was offered face to face through appointments, and in some areas, drop in sessions, or by phone. Some areas such as Gwent were exploring alternative ways to provide advice and support, such as Skype.

4.26. As outlined in section 6, feedback from services users about the support they received was generally positive and sometimes very positive. This is consistent with the feedback, where available, from IASs. For example, in Cardiff and Vale, 61 people completed questionnaires in the second quarter of 2018. Over two thirds were "extremely likely" to recommend the service to a family or friend if they need similar care or treatment and around a further fifth were "likely" to do so. Written comments included "very helpful and informative", "made me feel very comfortable when discussing difficult things" and "fantastic service", "very supportive friendly staff and very informative". However, as we also outline in section 6, in a small number of cases, service users were unhappy that they were not offered more support.

[37] When launched in March 2016, it was described as offering a lifelong long service. This has caused some confusion, as the service does not work directly with children and is not intended to provide long-term on-going support.

4.27. As outlined in section 5, in a small number of cases, services provide one to one support by working jointly with another service. This is still being developed and was most common in relation to mental health services. Cardiff and Vale offer joint assessments and appointments with mental health services. One area (Powys) is experimenting with a Team around the Individual (TATI) approach, drawing from Team Around the Family approaches. The idea is to get all useful agencies around the table to tackle the complex or multi-faceted difficulties many adults accessing the service face.

4.28. All four services offer group based support to autistic adults and, in some cases, family members and carers of children and autistic adults. Services' "offer" was developed in consultation with service users and included:

- post- diagnostic programmes (in all areas);
- structured group based training for adults such as NAS's SocialEyes (see boxed text) course and Skills for Life and, for family members and carers, courses such as the Incredible Years ASD – parenting programme[38], NAS's Early Bird, Early Bird Plus and Teen Life[39] (in Cardiff and Vale and Gwent, with plans to develop this in Cwm Taf[40]);
- more bespoke group based training sessions agreed with participants, which can cover issues such as budgeting and managing money, routines and scheduling, and skills for life and independence, like laundry and house maintenance (in Cardiff and Vale and Gwent); and

[38] The programme is offered to parents of young children (aged 2-5) on the autism spectrum or with language delays: "in order to promote children's emotional regulation, social competence, language skills, school readiness, and relationships with others". Incredible Years ASD – parenting programme

[39] Teen Life is an NAS programme that: "aims to empower parents and support professionals to understand more about how autism is experienced by autistic teenagers."

[40] In Powys, parenting support is delivered by children's services rather than the IAS. In Cwm Taf a Positive Behaviour Support (PBS) course for family members / carers of children with ASD and a Skills for Life course for adults with ASD are being developed.

- more informal social groups and forums (in Cardiff and Vale, Gwent and Powys)

The Socialeyes Course - Case Study provided by Cardiff and Vale

Socialeyes is a learning resource developed by NAS with and for autistic people. The workshops provide an opportunity to focus on the unwritten rules of social communication which often can be ambiguous, confusing and sometimes lead to miscommunication.

Feedback from group members has consistently shown positive outcomes for most participants, including increased social confidence, reduced anxiety and improved self-esteem. One participant of a recent group said:

> "I have to admit I wasn't looking forward to a course full of people I've never met before. In fact, on the first day of being there I had a mini anxiety attack. I was sitting too close to people, the room seemed too small. It didn't take me long to settle down and become more relaxed with my group, and environment. It actually became a part of my weekly routine I enjoyed. A place where I didn't need to hide myself from the world. I could be myself without having to play the role of someone I wasn't. It's one of the reasons I wanted to go on the course. To learn how to use the social strategies offered, while at the same time, being myself. The discussions allowed the group to connect and share personal experiences without being judged."

Adapted from the National Autism Team Case Studies Library

4.29. Group based work was seen as more efficient than one to one work, as it enabled one clinical or support worker to support more people. Social groups and forums (as distinct from more structured group based training) were also used to provide access to ongoing support over the medium to long term. Group based support was also seen to be more effective in some ways than one to one support; for example, group

based work provided opportunities for autistic people to share their experiences, which could help them socialise and feel less alone (and see that their experiences were not singular).

4.30. Where feedback was collected from those accessing groups, it was very positive. For example, in Gwent, 11 evaluation forms were completed by participants in group sessions. All rated the sessions as "good" or "excellent" and written comments included: "very enthusiastic and delivered with genuine interest by the tutors who clearly want to help people. They want to make a difference to autistic people and clearly care", and: "the agency seems to be doing a great job catering for recently diagnosed." Feedback on social groups in Cardiff and Vale was similarly positive, stressing the opportunities to socialise and share experiences as key positives.

4.31. Group based work was therefore seen as adding value to one to one work, although it was recognised that it did not meet everyone's needs; for example:

- some people struggled with the social demands of even small groups;
- it can be difficult to "pitch" a group to meet the wide range of support needs autistic people have; some high functioning people, for example, felt groups they had attended were more appropriate to people with greater needs than themselves; and
- in some cases, it was difficult find the critical mass of people with the same needs or interests necessary to make it viable to establish a group focused upon that specific issue or interest.

4.32. Training courses were a core part of each service's offer to family members and carers. As section 5 outlines, working with partners, Cardiff and Vale Gwent IASs offered Early Bird, for parents and carers of young children and Early Bird Plus, Cygnet and Teen Life, for

parents and carers of older children[41]. As one interviewee described it: "IASs find a lot of family members or carers are struggling", and the training was reported to be effective in, for example, providing reassurance that they would be supported, and helping them set boundaries, define what is acceptable behaviour and better understand their children and their emotions.

4.33. Despite the criticism of "signposting" raised by the Health and Social committee (N/AFW, 2018) signposting and more formal referrals were seen as a valuable and often essential part of services' offer to autistic adults, their family members and carers; for example, it was observed that the capacity of the IAS was limited and that:

- other statutory services are funded to meet different types of need and there is a range of voluntary sector provision, including that offered by autism specific services like NAS Cymru and mental health charities like Mind, Gofal and Hafal. Therefore, it was seen as more efficient to refer people to those services, rather than seeking to duplicate them. This was also seen as a more inclusive approach, helping ensure that autistic people were not excluded from services they were entitled to;
- some services have expertise that IASs do not have. As one dietician observed: "I don't have expertise with type 1 diabetes", so a referral to the diabetes team was appropriate. Similarly, voluntary sector organisations like ASSC were seen as having particular expertise in supporting benefits claims.

4.34. Effective signposting and referrals require a good local knowledge of services and one interviewee described part of their vision for the service as being "like a library". It was recognised that some people and some services needed support to enable signposting to work

[41] Cwm Taf is developing its training offer and Powys accesses courses delivered by children's services.

effectively. As outlined above, this could include support workers accompanying people to access services and the IAS working with services to build their understanding and awareness through training and advice; for example, one clinician observed that it can be difficult for autistic people to "navigate" health systems so: "I make it easier". Before making a referral, they: "contact the team, explain, meet the team, give relevant information and advice to smooth the hand over." As we discuss below, in some cases this meant working jointly with services, such as mental health, to support autistic adults. Given the communication difficulties associated with autism and the particular difficulties those whose "behaviour challenges services" face in accessing services (SCIE, 2017), this role can be vital. Autistic adults and family members and carers in North Wales were particularly keen for the service to develop an advocacy role on their behalf to help them access services[42].

4.35. IAS's reliance upon other services means that inevitably the support that autistic adults and family members and carers can access differs. As one interviewee observed: "where there is a pathway to support we use it", but these pathways vary by area; for example:

- people in South Torfaen can access a range of children's services at the Serrenu Integrated Children's Centre, whilst those in North Torfaen have a more limited offer from Neville Hall Hospital; and
- in some cases, there is no service or support to which to signpost people. Cardiff and Vale has identified that there is a gap for clients in accessing psychological therapy where their needs are too great for Primary Mental Health Services (PMHS) to meet, but not severe enough to reach Secondary Mental Health Services' criteria.

[42] In a focus group participants reported that an advocacy scheme exists in North East Wales, but it was felt that the staff were not adequately trained in autism and its co-occurring conditions. There was a worry about those families who cannot turn up to meetings and who cannot advocate for themselves. It was therefore hoped that the service would take on an advocacy role.

Similarly, there are no transgender autism support groups that the service can refer people to in Wales (the closest is in Bristol).

4.36. The differing access to services and support reflects both different decisions by LAs and LHBs about service provision in their area, and also greater access to services, including those provided by the voluntary sector, in urban areas. The impact of cuts to some voluntary sector organisations was also highlighted as constraining the capacity of the IAS to meet needs.

4.37. As the case study below illustrates, in some cases IASs have been able to set up new groups to fill gaps, but their capacity to do so is constrained by the heavy demand for assessment and diagnosis and support.

Olivia

A sub-group of referrals received in the IAS demonstrated a need to support young, autistic women with understanding relationships as well as keeping safe online. In many cases, these women were recognised to be vulnerable to potential abuse and/or exploitation.

Olivia (not her real name) self-identified difficulties in managing inter-personal relationships as well as traumatic experiences related to sex. The IAS responded to this demand by connecting with a third sector partner which could deliver support to these young women. The SAFE (Sexual Awareness for Everyone) Project has been commissioned (by the Big Lottery) to deliver peer led sessions that support disabled young women to understand friendships, relationships and keeping safe online. This was delivered jointly with SAFE and the IAS in April/May 2018.

Olivia attended three out of the four delivered sessions and responded

positively to the peer led approach. Olivia said that she would like to share what she had learned with other young women. The SAFE project offered Olivia a volunteering position and Olivia will help to deliver an upcoming group. Olivia will also be working towards achieving an accredited Millennium Volunteering award.

Adapted from the National Autism Team Case Studies Library

Managing demand

4.38. All four services have struggled to meet demand. All four services have experienced large increases in referrals for diagnosis and for support. As outlined above, this has increased waiting times for assessment and diagnosis in particular, and although waiting times for access to support are considerably shorter they are slowly creeping up in some areas; for example, in late 2018 waiting times for support or intervention for adults was around five weeks in Cardiff and Vale, rising to up to three months in Gwent and four months in Cwm Taf and Powys. Services like Cardiff and Vale and Gwent also offer telephone and email contact, with an expectation that a response within 24 hours will be provided and are developing drop in sessions to offer responsive low level face to face support.

The Western Bay, West Wales and North Wales IASs

Establishing the IAS

4.39. There was a slow initial start in all three areas and, at the time of writing (January 2019), only the North Wales IAS was operational, and even here, support work was established in mid-2018, before assessment and diagnostic processes began. Consequently, as one adult with autism described it in January 2019, "it is a fledgling service that is still being developed". In each area, it took time for strong leadership to emerge to develop the service; for example:

- in North Wales “no one took hold of it” initially, until a project manager was appointed and Flintshire stepped forward to host the new service;
- in Western Bay there was some hesitancy, attributed to the health board having “had their fingers burnt” with the establishment of the ND service, which had been difficult; and
- in West Wales there were delays until Ceredigion agreed to host the service and resources for a project manager were approved.

4.40. Moreover, in Western Bay and West Wales, even after leadership emerged, progress stalled. Despite senior leaders in LHBs and LAs (on RPBs) committing to the IAS, and putting pressure upon teams to get established, blockages were reported at lower levels; for example, in finance, estates and human resource departments; blockages that were largely beyond the control of IASs. In addition, in Western Bay there were disagreements with the national team over governance of the service, and proposals for the third sector to host support staff[43]. Once this was resolved, progress again stalled, due to the planned disaggregation of Bridgend from Western Bay into Cwm Taf in April 2019, which meant that the service’s budget could not be agreed[44], and recruitment to the service was put on hold.

[43] The Western Bay board proposed that, given the expertise in the third sector, they could host support staff through a Service Level Agreement (SLA), but this was rejected by the National Autism Team.

[44] It was proposed by the Welsh Government and Western Bay that the disaggregation would be managed through a Service Level Agreement (SLA) so that Western Bay would continue to provide an assessment and diagnosis service for Bridgend up until 2021. However, Bridgend and Cwm Taf resisted this and it was therefore not clear how much of the funding allocated to Western Bay would be reallocated to Cwm Taf, with the Western Bay service facing the prospect of a 27per cent cut in funding.

4.41. The blockages in middle management that services experienced feature in the literature on integration (Personal Communication; Sara Harvey). The difficulties overcoming them reflect a number of factors, including:

- the size and complexity of LHBs and RPBs' agendas, for which autism is only a very small part, which limited the time, attention and energy devoted to the development of IASs;
- the lack of ownership of autism services, which may have been compounded by the grant funding and prescribed model (which limited the time and energy invested by leaders in developing a service in their area), and difficulties identifying where the IAS belongs in LAs and LHBs; and
- the financial pressures on all LHBs and the additional scrutiny Hywel Dda and Betsi Cadwaladr face, given Welsh Government concerns about their performance.

4.42. The problems were not easily resolved and, as one interviewee from an IAS put it: "I feel powerless: a very small cog in a big wheel". In some cases, the National Autism Team was able to intervene and help free up blockages, but the blockages have delayed the recruitment of staff and the establishment of services in each area. Interviewees described it as "incredibly frustrating", and: "it shouldn't be this hard for a service we've got funding for."

4.43. Once posts were approved, staff recruitment was a challenge for all three IASs – as it had been for Powys and Cwm Taf. In both Western Bay and West Wales, business cases for the new posts had to be prepared and scrutinised by several layers of management before posts were approved and recruitment could start. In West Wales, the LHB was only prepared to approve the posts as secondments, as the funding was time limited.

4.44. It was observed that: “autism is a specialism in itself” and that the workforce with autism skills was small in size, with staff typically gaining skills through experience, rather than formal training. This challenge has been compounded by the prescriptive requirements of the IAS staffing model, which limited the scope to take on more junior staff[45], and by differences in terms and conditions across LAs and LHBs, which can mean that the pay of an occupational therapist (OT) employed by the LA is lower than one employed by an LHB. Recruiting so many posts in Wales at the same time was always going to be hard and, for example, in West Wales the OT post was advertised three times without success. There has also been some “cannibalisation”, with experienced staff either moving between IASs, or into IASs, from services such as mental health or learning disabilities, and thus weakening them.

4.45. A number of other challenges were identified; these included:

- the sequencing of recruitment with, for example, support staff recruited before the team leader was in post in West Wales and delays recruiting clinical staff in North Wales, which meant that although operational, the service could not, at first, offer assessment and diagnosis;
- integration of clinical and support workers, given differences in pay, conditions and line management; and
- delays associated with getting people into post and trained, so in the first wave of IASs, as one interviewee put it, even after staff recruitment was completed, it was likely to take the: “best part of a year before services really got going.”

[45] The IAS staffing model stipulates a Band 8 Psychologist and Band 7 Speech and Language Therapist, Occupational Therapist and Specialist Practitioner.

4.46. The challenges were not insurmountable, but they absorbed a lot of time and caused frustration and delays. As one interviewee put it, the "people skills" of IAS services and team leaders were critical in establishing and then integrating and managing the teams. The delays also meant the IASs had "slippage" money. This was used in different ways; for example:

- in West Wales the money was used to equip a clinical space and also to support a waiting list initiative for adults in the pre-existing assessment and diagnosis service; and
- Western Bay was looking to use the funding to support a waiting list initiative for young people aged 16-18 and also potentially an initiative in PMHS.

4.47. The perceived lack of transparency about how ICF monies, including slippage monies, were used, was a cause for some concern amongst some autistic adults, some family members and some voluntary sector organisations. Although the evaluation found no evidence that slippage monies had been used inappropriately, the lack of transparency led some interviewees to question whether the funding for the IAS had been used efficiently and effectively.

Stakeholder Engagement

4.48. Engagement with stakeholders was identified as important by all three services, but as it had been in Cwm Taf, was described as challenging during the development phase in all three areas. The model was initially developed from the top down by RPBs and, as a number of interviewees in Western Bay and West Wales observed, even when IAS service managers were recruited, the lack of clarity about what the service would and could offer, made it difficult to engage with services and service users.

4.49. Of the three services, North Wales was most strongly committed to developing the service co-productively, recruiting “experts by experience” and involving service users in key decisions like recruitment. The importance of being person-centred, to avoid the risk of: “setting up systems and expecting others to fit into them” was stressed by the service. This was seen as particularly important for autistic people who might otherwise struggle to access services. It may also have reflected the political context in North Wales where there is a small established group of highly vocal and politicised family members.

4.50. Nevertheless, even in North Wales there was frustration amongst some autistic adults, family members and carers, and advocates for autistic people, that they had not been able to engage in shaping the service earlier. There were also hopes and expectations of the service that would not or could not be met; for example, in a focus group, participants described how they had hoped the service would work with children, including helping parents who were fighting for services for their child, only to learn later that it will not. They felt that the IAS’s remit in this area was not clear. Negative past experiences also clouded some people’s expectations and initial interactions with the IAS. As one interviewee put it: “some people have had really bad past experiences – by the time they get to us, [they’re] really disgruntled, cheesed off.”

4.51. In Western Bay a gap analysis was undertaken (with the support of the Regional Officer) and stakeholders were consulted, but the scope for consultation was constrained by the delays in agreeing the service’s budget and staffing. This meant that service users wanted to engage and attend the operational group but that: “there was nothing to discuss”. It also made it difficult to describe what the service would do and could offer (given the uncertainties about its size and staffing). Consequently, as one interviewee summed it up: “we can’t co-produce until we know what we can do.” It was also observed, for example, that consultation often identified a desire (as in North Wales) for the service

to work with children and young people, which is not part of the IAS model. Equally, it was observed that the prescribed nature of the model could be helpful, as it reduced the scope for local debate and disagreement over what the service should do.

4.52. In West Wales, consultation with stakeholders was reported to have gone well. Although, as in Western Bay, the consultation highlighted concerns about services for children, which are not part of the IASs' remit, it was reported that stakeholders "felt listened to". The process also created opportunities to involve people as volunteers or to help set up peer support networks and consult on specific aspects of the service's offer, such as the type of social skills support offered.

Cross cutting themes

Accommodation

4.53. There was no allocation in the budget for the IAS for accommodation and LAs and LHBs struggled to find suitable[46] and accessible accommodation. All services now have a base, using either health service or LA buildings, but Western Bay does not yet have a permanent one[47]. Moreover, as one interviewee put it: "all we want is two clinical rooms, with a waiting room, and somewhere to park….and ideally a bigger room for training", but of all the IASs, only Cardiff and Vale was felt to have this space. The larger regions like Powys, West and North Wales and, to a lesser degree, Gwent, face particular problems given the size of the geographical areas they cover and sometimes poor public transport links, particularly in rural areas. In response, Powys is working from two bases[48] while Gwent and North Wales are making extensive use of community venues, which it is

[46] Access to appropriate clinical spaces was a key challenge.
[47] Western Bay is refurbishing a disused ward in Tonna Hospital using ICF capital funding, but it will not be ready until spring 2019.
[48] In Powys, the main base is at Erwood on the Bronllys Hospital site with a northern base in Newtown Hospital.

hoped will also help address some service users' negative preconceptions about health and social services.

Managing expectations

4.54. Some interviewees observed that the way the IAS was initially announced and 'sold' by the Welsh Government raised people's expectations too high. For example, as one put it, "when the Welsh Government announced it was going to roll out an Integrated Autism Service expectations went through the roof". Political pressure, given the Autism Bill (outlined in section 1), and a temptation to point to the IAS as the answer to people's criticism of weakness in support and services, was reported to have exacerbated this. The failure to manage expectations was therefore seen by some as key failure – as the IAS could never be the 'silver bullet' that meets all needs. Some also observed that what they felt was the lack of transparency and openness about the funding for the service, its outcomes and the reasons for the slower than anticipated roll out (outlined above), had fuelled suspicion, frustration and sometimes incomprehension; for example, as one autistic adult vividly put it when discussing the IAS's accommodation: if the "brownies can find a room [in Cwmbran]…[why] can't a professional organisation [the IAS] with a sodding amount of money find a room?!"

National implementation, oversight and support

4.55. In the second phase of the roll out, the IASs' relationship with the National Autism Team was consistently described as much more collaborative than in the first phase. Many of those interviewed praised the work of the two national ASD Leads currently in post. They highlighted the way the national leads had taken time to understand IASs and involve them in developing aspects for the model, such as data collection and revising the national IAS guidance. In both West Wales and North Wales (where the Western Bay, West Wales and

North Wales IASs were developing), the support of regional ASD officers who knew the area and key people, and who could help share learning from the first phase (Cardiff and Vale, Cwm Taf, Gwent and Powys), was consistently praised.

4.56. With the support of the National Autism Team collaboration between IASs has also strengthened, illustrated by the joint evidence IASs gave to the Health and Social Care Committee on the proposed Autism Bill. The community of practice (facilitated by the national team) was also valued, albeit seen as a work in progress; for example, a speech and language therapist (SLT) talked about the value of meeting with the other four appointed so far to IASs (another two are to be appointed). This was particularly valuable as none had ever worked in adult autism before and they have been able to share resources and materials.

Data collection

4.57. The original proposals for data collection[49] foundered upon a range of problems, including IT and General Data Protection Regulation (GDPR) difficulties, and had to be abandoned. Services developed interim solutions to enable them to meet ICF reporting requirements, although these were felt to be inefficient and time consuming and as table 4 on page 70 illustrates, limited the data available on outcomes for service users. There was optimism that the new approach, developed with IASs and currently being piloted, would resolve the problems and provide robust data on both process (e.g. numbers of assessments and waiting times) and outcomes (to be measured using Outcome Stars).

[49] These included collection of data using a range of structured tools such as the WHO Quality of Life assessments and recording and reporting on SYML, an online system developed as a temporary system until the Wales Community Care Information System (WCCIS) was rolled out.

Discussion

4.58. Despite the challenge which slowed progress, IASs in Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales have been established. The foundations for IASs in Western Bay and West Wales have been laid, with an expectation that services will be operational by Spring 2019. Moreover, most of the key success factors identified for the service have been met; for example:

- the IASs in Cardiff and Vale, Cwm Taf, Gwent and Powys provide broadly the same model of support, supported by NICE guidelines, and it is expected that services in North Wales, West Wales and Western Bay will also do so. The differing speeds at which the services have developed inevitably means the support they offer at this stage also differs. Moreover, users' access to other services that the IAS works with and signposts to differs and is, for example, generally more limited in rural areas, creating inconsistences in access to support. Finally, although the guidance is intended to be black and white about what services should and should not do, grey areas have emerged in a small number of cases, and services have responded to these in different ways [50];
- there are now consistent diagnostic pathways for adults to the IAS, although some work needs to be done to clarify diagnostic pathways to other services, such as mental health, in Cwm Taf and North Wales (and also Western Bay and West Wales which are not yet operational);
- there are clear governance arrangements for the IAS in each area, senior management buy-in was secured and key partners from health and social care were engaged, although this sometimes involved a lengthy process delaying progress, and the involvement of autistic adults and family members and carers in developing the services has been mixed, but is improving;

[50] For example, while the service is intended for people with a diagnosis, access to those awaiting diagnosis, who are judged in crisis, has been allowed.

- the services include, or link to, existing autism provision where available through sign posting and, to a lesser degree, joint work and training. However, it is only in Cardiff and Vale and Powys that existing assessment and diagnostic and autism support services have been formally integrated into the IAS and the integration of voluntary sector services (e.g. by commissioning services from the sector) is limited by the IAS staffing and funding model; and
- there is effective national implementation oversight and support. Although, as we outline in our interim report, the very prescriptive approach taken in the first phase, together with miscommunication, initially slowed progress, communication by the National Autism Team was reported to have improved markedly. The national team has also increased its focus upon engaging with stakeholders[51] and established two new boards for professionals and service users to oversee and inform its work. Nevertheless, there were some concerns raised - within some voluntary sector groups that the national team was too close to the Welsh Government and bodies like the National Implementation Advisory Group had not been able to play a more active role.

4.59. However, two other success factors have not yet been met: there are concerns about the adequacy of resources, given the level of demand, and also the differing needs of each region (which led to criticism of the apportionment of funding across regions), and long term sustainability plans have not yet been developed. Consequently, some stakeholders were very concerned about what would happen to the IAS once the current funding ends in 2021.

[51] For example, in April 2019, the National team will be running a conference to promote wellbeing among autistic adults aged 16+. The Conference is being co produced by a Task and Finish Group of lived experience advisors including autistic people, parents and carers together with health and local government professionals and third sector partners from across Wales. (Personal Communication, Sara Harvey).

4.60. The national guidance has been revised to better describe expectations of the IAS[52] and, as table 5 illustrates[53], most of the agreed standards in relation to support have been met by the five operational IASs. The key exceptions have been in relation to work to support children, which is constrained, as the IAS can only work indirectly with children (e.g. by working with their parents and carers), and in relation to "functional analysis" which has been the subject of debate and discussion with the national team.. In addition, not all standards may be relevant. For example, an IAS would only offer "anger management interventions"[54] when needed by an individual service user and unless or until this need presented itself, the standard would not be met.

[52] The original guidance was also felt by some to be too negative (focusing too much upon what the IAS could/should not do) and has been revised to, for example, better describe expectations about the IAS "lifelong" service remit.
[53] The table is based upon data provided by IASs in their ICF returns, augmented, where appropriate with additional data from interviews with IASs.
[54] One standard is "The Integrated Autism Service has provided anger management interventions, adjusted to the needs of autistic adults."

Table 3. The volume of support provided by IASs in Quarter 1 and 2 of 2018

	Gwent		North Wales	Cardiff and Vale		Cwm Taf		West Wales*		Powys***
	Q1	Q2	Q1/Q2**	Q1**	Q2	Q1	Q2	Q1	Q2	Q1/Q2
Number of professionals provided with advice or support	N/A	N/A	N/A	N/A	10	180*	120 *	220	82	N/A
Number of adults supported by the service	86	85	N/A	0	110	143	204	3	16	N/A
Number of children / parents or carers supported by the service	23	14	N/A	0	0	11	14	0	17	N/A

*Source: ICF returns; * estimate ;** service was not operational during this period *** problems with the data collection system developed for the IAS (discussed in para 4.57) meant data was not available.*

Table 4. Compliance with the national standards

Standard	Cardiff and Vale	Cwm Taf	Gwent	Powys	North Wales
There is a single point of referral (including self-referral) to the Integrated Autism Service	Yes	Yes	Yes	Yes	Yes
The service has supported adults to access and maintain contact with housing, educational and employment services	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided diagnostic assessment of adults with or without a learning disability or with a mild learning disability who do not have a known moderate to severe mental health difficulty	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided liaison, support and consultation in relation to the diagnostic assessment of adults with a known moderate to severe mental health difficulty or adults with a moderate to severe learning difficulty	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided social learning programmes focused on improving social interaction	Yes	Yes	No– but being developed	No – but being developed	Yes
The Integrated Autism Service has provided structured and predictable training programmes based on behavioural principles focused on improving daily living skills for autistic adults	Yes	Yes	No – but being developed	No – but being developed	No
The Integrated Autism Service has provided structured leisure activity programmes to reduce social isolation for autistic adults	Yes	Yes	No	Yes	Yes
The Integrated Autism Service has provided anger management interventions, adjusted to the needs of autistic adults.	Yes	Yes	No	Yes	No

Standard	Cardiff and Vale	Cwm Taf	Gwent	Powys	North Wales
The Integrated Autism Service has provided psychosocial interventions for challenging behaviour based on behavioural principles and informed by a functional analysis of behaviour for autistic adults	Yes	Yes	No	No	No
The Integrated Autism Service has provided support in conjunction with MH / LD teams	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided advice to those who support autistic children to help the child to develop coping strategies, to access community services and to develop skills	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided support and advice in relation to sleep difficulties to family members of children with autism	Yes	Yes	No	No – but provided by children's services	Yes
The Integrated Autism Service has worked with family members/carers of autistic children to: • undertake functional assessments of behaviour • develop plans of care that address the triggers • educate family members as to how to respond to challenging behaviours	No	Yes	Yes	No	No
The Integrated Autism Service has supported transitions by developing an up to date profile of needs for autistic children based on information gathered from a range of individuals	No	No	Yes	No	No
The Integrated Autism Service has provided support in conjunction with CAMHS / LD teams	Yes	Yes	Yes	Yes	No

Standard	Cardiff and Vale	Cwm Taf	Gwent	Powys	North Wales
The Integrated Autism Service has provided information and advice to family members, families, partners and carers	Yes	Yes	Yes	Yes	Yes
The Integrated Autism Service has provided training to family members, families, partners and carers	Yes	Yes	Yes	No	No
The Integrated Autism Service has provided parent/carer support groups	Yes	Yes	No – but this is being developed	Yes	Yes

Source: adapted from data provided in ICF Returns by each IAS

5. The interface of the IAS with other services

Introduction

5.1. Autistic adults and family members and carers need access to a wide range of services including health, housing, employment and social services and effective joint working is needed to meet the needs of autistic people (SCIE, 2017). As we outline in this section, the interface between the IAS and mental health, learning disability and children's services, education, housing and employment services and the voluntary sector is critical to:

- fill the gap between mental health and learning difficulties services, without duplicating or replacing existing provision;
- ensure that people's needs can be met, as the IASs are not resourced nor intended to meet all needs; for example, the IAS cannot provide social housing, although it may be able to work with housing services to facilitate access to appropriate housing;
- set boundaries to manage demand and ensure that the IAS does not become overwhelmed by demand, or as one interviewee forcefully put it, a "dumping ground" for autistic adults that services are unable or unwilling to support; and
- ensure that pathways to the IAS are well understood, so that those who need the service can access it swiftly and smoothly, and those whom the IAS cannot assess or support are not referred inappropriately and bounced back to other services.

5.2. In response, as we outline in this section (drawing primarily upon interviews with staff in the IAS and other services), all seven IASs have focused upon networking[55] and engaging with others services to

[55] Networking was seen as important to identify and map partners, raise awareness and understanding of the IAS and support future work. As one interviewee observed:" face to face contact helps – very easy to ignore an email, to answer the phone – so you've got to work with the reason."

support referrals, joint working, advice, consultancy, training and signposting (discussed in section 4). Scoping or mapping, and then engaging with services, has been time consuming and is ongoing in all seven regions.

Mental health services

5.3. There is evidence that autism is associated with higher levels of mental ill-health (NICE, 2012). Interviewees for this study often linked autism with anxiety, depression and social isolation and, as we outline in section 6, many of those interviewed for this study currently had, or had had poor mental health in the past.

5.4. Mental health (MH) services have a key role in identifying people who may have autism, undertaking assessment and diagnosis and providing support and interventions. However, interviews with professionals, service users (discussed in section 6) and responses to the online survey (discussed in section 7) all highlighted adults' and families' mixed, and often negative experiences of mental health services. For example in a focus group, parents and carers reported that mental health services**,** like Community Mental Health Teams (CMHTs), were very difficult to access, even when referred to them by social services or GPs; for example, as one described, following a referral they were told by the CMHT: "we can't deal with him, he's got autism". The problem, as another person put it, was: "we know he's got autism, we need help with his depression and anxiety!".

5.5. In a similar vein, one of the adults interviewed for the study described how they were suffering from depression, and referred to a secondary mental health service; as they put it:

> "I ended up getting told I had autism. There was not much advice and support at the time; they told me to get counselling from a charity, but I didn't get much support. I had some, but it was not very

helpful. I thought I didn't have it [autism]; I disregarded the diagnosis then [at that time]. They said I was depressed which I was really…I ended up going to hospital following a psychotic episode."

5.6. It was only after being admitted to hospital that, as the interviewee said: "I'm getting help for everything now". Her medication was changed and she was introduced to the IAS. She described how she was now attending a post -diagnostic group, was exploring volunteering opportunities and was: "being seen by the mental health team quite often."

5.7. There are small specialist diagnostic services in mental health in Cardiff and Vale, Gwent and West Wales, which have been aligned and, to differing degrees, integrated into the IAS[56], and there are also individuals with an interest and expertise in autism across mental health services. As outlined in section 3, the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults made important investments in workforce development, but the impact was patchy (Holtom and Lloyd-Jones, 2016). There were also concerns that progress upskilling staff in assessment and diagnosis (through the Network) had stalled and in some cases deteriorated, as people who were trained moved on, or had not used and maintained their assessment and diagnostic skills. Consequently, building confidence and capacity in mental health services was described as a huge agenda and, for some interviewees, too big an agenda for the IAS alone to take on.

5.8. The gaps in workforce skills led some to question the robustness of diagnosis in mental health services in some areas like West Wales and Cwm Taf. As one interviewee put it: "some people get the IAS and the

[56] For example, in Cardiff, a specialist nurse in the IAS is funded by the MH service and the small specialist services in Gwent and West wales are aligned, or being aligned with the IAS. In Gwent there was some frustration that the national IAS staffing model precludes psychiatrists from the team, although they work closely with the IAS.

rest get the best the health board can manage." This was not a uniform picture though and for example, Cardiff and Vale IAS has worked closely with mental health services to try to ensure there is a consistent pathway and process across the IAS and mental health services.

5.9. There were also concerns that mainstream mental health services (as distinct from the specialist services with expertise in autism in, for example, Cardiff, Gwent and West Wales) were often ill-equipped to meet the needs of autistic adults. Some staff in these services were reported to lack the confidence and skills required, and the interventions offered were felt to be too medical (e.g. focused upon medication and recovery) and sometimes poorly suited to the needs of autistic people, a finding supported by earlier research (Jackson et al., 2011; WG, 2010). Consequently in, for example ,North Wales, instances were given of adults who were discharged from mental health teams, despite ongoing difficulties such as anxiety, morbid thoughts and self-harming, because these were attributed to their autism (Burns, n.d). Similarly, other areas highlighted the difficulties of "teasing out" the extent to which mental health difficulties were primarily attributable to autism.

5.10. The initial focus of engagement by IASs in most areas has been upon secondary mental health services, such as CMHTs. This reflected the crossover between autism and mental ill-health and the consequent blurring of boundaries of responsibility between the IAS and mental health services. This was reinforced by the widespread concern that secondary mental health services, struggling to cope with demand and sometimes lacking the confidence and/or skill in undertaking assessments and supporting autistic people, would refer people with severe mental health problems to the IAS[57]. As one interviewee put it: "we want clarity and assurance from mental health teams – for them to

[57] The national guidance is clear that the IAS does not work directly with adults that have a: "moderate to severe learning difficulty or known moderate to severe mental health difficulty."

take more responsibility for assessments, but they're overloaded"; similarly, as another put it: [mental health services have] "got their waiting lists…they're 'drowning' too. It's not that they don't want to do it, [but] they think we [the IAS] can solve everything; 'it's over to you'; they want to hand [people] over."

5.11. In West Wales, it was also acknowledged that it was important that the IAS did not overwhelm already stretched mental health services by referring people whom it would be more appropriate for the IAS to support.

5.12. Engagement to clarify the respective roles and responsibilities of the IAS and secondary mental health services and support, including training and joint work (illustrated by the case study below), were both seen as vital in managing the interface between the two services. In Cardiff and Vale, the ability to offer Aspects training[58] was frequently cited as being very helpful. Engagement was seen as a long term, ongoing project which demanded skill and patience to manage a potentially challenging relationship. The model in West Wales in which the service manager oversees both the IAS and CMHT appeared to be a promising one in helping manage the interface between services.

[58] Adults Autism Psychology Limited were commissioned by the national team to deliver a mental health and social care training package to raise awareness and provide information on how services could adapt their practice.

Jack

Jack (not his real name) was the subject of joint working, with the main aims of increasing independence and to break the cycle of returns to the crisis team and admittance to the ward.

Mental health services continued to support Jack's mental health needs whilst the support worker's role was to increase the confidence of the young person in accessing public transport to attend the social group without travel assistance. This was an important step on the road to independence for Jack. He went from quiet and reserved, unsure, with head slightly bowed at all times to visibly walking taller. Not quite strutting yet, but definitely far more sure of himself and rightly proud of the achievement. Jack is now looking forward to college in September and being able to attend the Social and Leisure Group as and when he feels like it. without having to rely on others to get there.

The service reports that this was achieved by the professionals involved staying in contact with each other, but not stepping on each other's toes. Having faith between services is as important as having faith between practitioners and clients.

Adapted from the National Autism Team Case Studies Library

5.13. In Cardiff and Vale, the IAS has also worked closely with primary mental health services, providing training and also joint work to support autistic adults who need the therapeutic interventions offered by primary mental health services. Across all areas, links to other mental health specific services such as personality disorder or forensic services were generally less developed, but were seen as important areas for the future.

Learning disability services

5.14. There has been relatively little engagement by IASs with learning disability services, compared to mental health services. Training and joint working between the IASs and the learning disability service, for adults who already have a diagnosis, has been delivered by Cardiff and Vale, but does not feature strongly in other areas. This reflects learning disability services' traditionally having greater expertise and experience in working with autistic people. It was also observed that, in contrast to mental health services, there is much less of a grey area about where responsibility lies, and pathways are therefore much clearer.

Children's services

5.15. Given the IASs' remit to support family members and carers and also young adults making the transition from children's to adults' services, the interface between Children's Neurodevelopmental (ND) services and IASs is important. Children's ND services (see boxed text) were initially developed in parallel to the IAS and early opportunities to align and integrate the services were felt to be missed. Moving forward, there has been a desire to align the two services and, for example, in Powys, Cardiff and Vale and Gwent there are close links between IAS and ND services and in West Wales, one of their staff also works on the ND team, and there are hope to co-locate the two services, helping strengthen links. However, the scope for ND services and IASs to work together has been constrained by the (limited) capacity of ND services in each area and the differences in ethos and approach between ND services and the IAS[59]. Cardiff and Vale and Gwent IAS have worked jointly with their ND and education services to deliver training and workshops. In contrast, in Cwm Taf, there has been little engagement,

[59] The ND service was intended to enable a shift from a diagnostic label driven assessment toward more holistic assessments of an individual's strengths and needs. In contrast, while the IAS's assessment is intended to consider strengths and needs, establishing if a diagnosis of autism is warranted is a key purpose of the IAS assessment process.

and in Western Bay the pressure upon ND services has narrowed their focus to assessment and diagnosis, and delays establishing the IAS mean there has been no joint work.

The Together for Children and Young People Programme

The Together for Children and Young People Programme (T4CYP) was launched in February 2015 to reshape and refocus emotional and mental health services for children and young people. One of the programme's priorities was improving neuro-developmental services for young people and the work stream to support this included plans for developing care pathways for autistic children and young (NHS, 2015).

The ND work stream was intended to systemise good practice across Wales, increasing consistency [60]and the sustainability of services through new national standards and increased funding (£2m for ND services). This was intended to: "reduce the time from referral to diagnostic assessment"; ensure there is a "child-centred assessment" and: "timely and multi-disciplinary discussion of those involved in the assessment"; "improved communication and feedback of the outcome with follow up with the family and, where appropriate, the child to support delivery of the action plan" (PHW, n.d.).

5.16. The IAS does not work directly with children, and where services have engaged with education and other children's services, this has generally been around the provision of support for parents and carers; for example:

[60] An All Wales high level neurodevelopmental assessment pathway was developed to provide a consistent approach to assessment, diagnosis and feedback to children and families across Wales.

- Gwent is working in partnership with ND and the specialist Child and Adolescent Mental Health Service (CAMHS), portage and the LA education service, by pooling resources to fund and deliver Early Bird, Early Bird Plus and Cygnet workshops to give family members and carers insight into the condition, although this has been complicated by differing LA arrangements[61] ;
- Cardiff and Vale is working with the education outreach service and ND service to deliver Incredible Years, Teen Years and Early Bird Plus. They also work with the CAMHS team and signpost parents and carers to workshops run by the ND service on, for example, anxiety and sensory issues and support Barnardo's who deliver Cygnet courses in Cardiff;
- Powys has used existing provision for parents and carers provided by children services; and
- Cwm Taf was developing a Positive Behaviour Support (PBS) course for parents and carers of children with autism.

Social services

5.17. Social care has a key role to play in identifying people who may have autism and in assessing needs and supporting autistic adults. However, access to social care can be difficult for autistic people. As Lisa's experiences illustrate, they can struggle with the bureaucracy and systems, such as telephone contact centres; assessments do not always identify their needs; and they may need different types of support to that usually offered by social services. This means that many struggle to access support until their needs escalate to crisis point (SCIE, 2017).

[61] For example, rather than contributing to regional service provision across Gwent, Blaenau Gwent LA commissioned Barnardo's and Families First to deliver Cygnet and Early Bird in their area.

Lisa

Lisa (not her real name) is an adult with autism with three children, one diagnosed with autism, one awaiting assessment and one away at university. Lisa has no close family members nearby and has been unable to access support for herself and her children.

Lisa finds it difficult to communicate over the phone and often experiences anxiety interacting with services as she feels that: “I am rarely fully understood.” She found it impossible to access a social worker, and her social services assessment over the telephone had concluded with a “no services” outcome and she consequently was denied access to direct payments.

Lisa asked the IAS by email if they could do anything to support her and her family’s needs. Lisa struggled with the ten-page referral form sent by the IAS, which took several days to complete and which she felt did not allow her to describe her true situation. She reported that she was subsequently sent an email explaining that the IAS wasn’t a crisis intervention team and explained what IAS could and couldn’t provide. Lisa reports that it was only after an intervention by her local MP that the IAS re-engaged. Her subsequent engagement with the IAS was fraught, with multiple misunderstandings, inaccurate judgments about her behaviour, difficulties meeting (she struggles in noisy environments and has poor physical health) and finding support and referrals to services that Lisa felt were appropriate and met her needs.

5.18. Research in England has identified “islands of accessibility” created by the commitment and skill of individuals, often working against, rather than with, institutional systems. Despite the Social Services and Well-being Act (see boxed text), earlier research (in Wales) (Holtom and Lloyd-Jones, n.d.) and research for this study suggests a similar picture in Wales. For example, many of the written comments in the online

questionnaire praised individuals, rather than a particular service; and in West Wales, access is reported to be generally straightforward in Ceredigion, where there is an adult autism service led by a social worker[62], but in Pembrokeshire and Carmarthenshire, access is much more dependent upon services' relationships with key individuals. Similarly, in some part of North Wales, vulnerable adult teams will support autistic people, but in other parts of North Wales they generally will not. As a consequence of these difficulties, as one adult with autism described it:

> I have only had a telephone assessment from the First Contact team, which was inadequate, did not provide reasonable adjustments for my communication difficulties, and did not provide opportunity for me to obtain advocacy support or family input. When my advocate called social services to enquire about the assessment on my behalf, the person who had conducted the call informed her that she "doesn't know anything about Autism any way ".

5.19. Despite the IAS's status as an integrated health and social care service, led in two areas (Gwent and North Wales) by social workers, engagement with social services has been more limited than engagement with health services. Although training of social care staff has been delivered in Cardiff and Vale, Gwent and Powys, Gwent and Cardiff and Vale's work with mental health services (discussed above) has been prioritised. There have also been difficulties in engaging social care services in larger regions, like Gwent and North Wales, given the number of different LAs, all of whom have different approaches to social care.

[62] In Ceredigion, if people need care and support, this is generally offered by the Ceredigion Autism Spectrum Team (CAST) via spot contract or direct payments, with monitoring and review by a social worker from the team. In more complex cases, this could involve developing a model of support. If an adult was not eligible, they might perhaps play a mentoring role and meet once a month.

5.20. Moreover, despite the Social Services and Well-being Act (see boxed text) Cardiff and Vale, Gwent and North Wales IAS report struggling to have referrals to social care services accepted; for example, one interviewee described the difficulties identifying which service they should refer to and the: “fight to have referrals accepted” by services. Moreover, even where referrals for assessment were accepted, it was felt that adults’ needs were not always recognised. This could be because those undertaking the assessment lacked the skill or confidence needed; because needs were missed when adults appeared to be high functioning and/or struggled to articulate or explain their difficulties to assessors; and/or their eligibility thresholds were set too high to meet needs.

The Social Services and Well-being Act 2014

As the refreshed ASD SAP outlines, the Social Services and Well-being (Wales) Act 2014 is intended to transform the way the needs of all people with care and support needs in Wales are met. It aims to put people at the centre of decisions about their care and support and give them the power to define their own outcomes. The act includes requirements for local authorities to:

- promote preventive services and ensure that there is easy access to information and advice about all of the services available in an area;
- undertake assessments if someone needs care and support, or a carer needs support, and to do the assessments in the best way to meet an individual’s needs; and
- meet the needs of people who meet the eligibility criteria.

Adapted from WG (2016a) and WG (2015b)

5.21. There was also a lack of clarity about how the IAS fitted into existing social services pathways. Interviewees were not always clear if people should go to the IAS first for information and advice and then be signposted to social services, or if they should approach social services themselves via a "single point of entry" (often a contact centre).

5.22. Given these difficulties, some autistic adults accessing the IAS still struggle to access the social care they feel is necessary to meets their needs; for example, in Cardiff and Vale, Gwent, Powys, and North Wales, there are reported to be a small number of people who do not have a learning disability, but who need longer term, ongoing support that the IAS is not equipped to provide. It was reported that the IAS's model of short-term outcome focused support was not always sufficient to help people who might have grown dependent upon the support of others (most notably family members and carers) and/or who struggled to learn the skills needed to live independently. In Cardiff and Vale, Gwent and Powys, the on-going support needs that were identified were often quite modest; help with day to day tasks like paying bills and filling out forms, dealing with authorities, self- care or making decisions, but they were felt to have the potential to make the difference between being able to live independently and the risk of eviction and homelessness (SCIE, 2017).

5.23. In these areas and also in West Wales, as Richard's story illustrates, examples of people who were high functioning, but who had specific problems, were highlighted and it was reported that, given their intelligence, their needs were often missed in social care assessments. In contrast, the unmet support needs in North Wales appeared to be more complex[63].

[63] The level and complexity of presenting needs across IAS was not systematically measured, so this was an impressionistic assessment.

Richard

Richard (not his real name) was diagnosed as a child with Asperger's syndrome in the late 1980s and more recently was diagnosed with anxiety disorder. Richard has a high IQ and went to university, but struggled to cope with social and academic demands; for example, he described how he found living in halls of residence difficult: "it's difficult to cope with other people being around I wanted a place where I could shut my door on the world."

Richard described how he struggled to balance his involvement in a student society and his course work and: "ended up with five to six, maybe eight pieces of coursework". As he explained: " I was only given one of one to one dyslexia support a week; I was issued one piece of coursework, then another, then another" all of which were set towards the beginning of the same month, with a completion date by the end of the same month.

Richard described how he was referred to a counsellor and: "told to prioritise my coursework…it [was] just 'focus, why don't you just work on this? Why don't you just prioritise? You'll get it done'". Richard said he felt blamed for his difficulties and that the model of support the university and support services was working under was "the biopsychosocial model of disability" (in which disability is seen as caused by a combination of factors at the physical, emotional and environmental level), "rather than the more appropriate social model" (in which disability is seen as arising from a lack of societal organisation and a lack of awareness, understanding and adjustment). As a consequence, as Richard put it: "you have to get to a crisis before anything happens" - before any support is given and soon after, as he put it: "I blew a gasket; [with a] panic wave…one panic attack after another". After his breakdown, Richard described with sadness how he was "let-go from my university course because they basically said I was not meeting their expectations and that

they couldn't support me properly."

Richard said the crisis he experienced at university was: "a big wake -up call: after all that success I came to an impasse…then I realised certain things that others expected of me, as this educated individual…lots is due to society –…all their [other's] expectations, when you do something, they don't expect you to do, like not being able to drive…people don't understand how it can be so difficult? [they think/feel] why not just try? but it's just me, being my autistic self; this is who I am."

5.24. Although IASs reported that they could offer consultation, training and joint assessments to social care staff, there was reported to be "no quick fix" to this challenge, given the pressure social care services faced as a result of rising demand and expectations alongside cuts or freezes in their budgets. One interviewee expressed the hope that, by "shining a light" on this group it would force services to develop clear care pathways. Others felt that integrating social workers into the team, following the example of the Sheffield Autism Service, might be necessary. In North Wales, the service leader, who is a social worker, has begun undertaking complex assessments of need for adults who do not fit into existing services and is exploring the scope for the IAS to take on case management of vulnerable autistic adults who do not fit existing social work criteria for case management.

Sian

Sian (not her real name) is an adult with autism. She is a single parent living in social housing. Her teenage old daughter has a diagnosis of autism and her preschool aged daughter has not yet been assessed, but will be in the future.

Sian was assessed by the IAS at home with an advocate present. The assessment identified that Sian's autism impacts on communication, understanding the world around the person, sensory overload, poor

organisation and inability to cope on a daily basis. She also has a range of other medical physical and mental difficulties including depression and anxiety. Sian is in constant pain and never feels well.

The assessment identified a range of needs, and services that could help her build her independence, including help from an IAS support worker to assist with self-organisation and motivation to clear and clean the home, setting up time tables and a managing phone app, the use of telecare and also referrals for an Occupational Therapy Assessment regarding the suitability of her home, support from Home-start with parenting and personal organisation and advocacy support from CAB with financial issues. Sian reported she had tried many of these before and they hadn't worked for long-term.

Sian had spent months preparing a document detailing her needs in preparation for the assessment, but felt that little of this information was transferred over. She disagrees with the analysis of her needs and with the solutions identified and has sent her response to the IAS Worker. She has not yet had a reply. Sian identifies her needs clearly as needing new, more suitable accommodation that meet the needs of the whole family and also direct payments to cover the cost of a personal assistant to support with every day tasks, to plan her life and motivate her to be able to live a life of choice. The IAS hope to continue working with Sian to develop a plan that can meet her needs, but given the fundamental different solutions, without redress to mediation or arbitration, it is difficult to see a way forward.

The voluntary sector

5.25. IASs have generally been keen to work with the voluntary sector, valuing the complementary support and social provision it offers. However, IASs' scope to do so has been constrained by the strength (or weakness) of local voluntary sector organisations in their region and

the nature of the IAS model, which has limited the scope for IASs to commission services from the voluntary sector; for example:

- in Cardiff and Vale, a post- diagnostic handbook was developed with ASSC, they support Barnardo's and have begun some joint work with adults supported by NAS;
- In Gwent the IAS has worked with voluntary sector organisations able to provide space and has, for example, worked with the Gwent Wildlife Trust to establish an autism aware local geo-caching group;
- Powys Association of Voluntary Organisations (PAVO) has been very supportive in Powys and the IAS has worked with and delivered training to voluntary sector organisations, including Action for Children and Powys People Direct; and
- In Cwm Taf, scoping work to develop an information booklet on local opportunities and support signposting has been completed, but links were still inchoate.

5.26. Cuts in funding for voluntary sector organisations like ASSC, which runs 21 High Street, were a cause for concern and described by an interviewee as a "huge loss". It meant the loss of expertise in areas like advice on benefits, and it was felt in Cardiff and Vale to have increased demands upon the IAS.

5.27. As we outline in section 6, the complexity and inaccessibility of the benefits system was highlighted by a number of interviewees. The processes for applying for benefits were described by one interviewee as "horrendous" for autistic people, and these problems increased the risks of eviction, reliance upon food banks and mental health crises. For example when parents and carers in a focus group discussed Personal Independence Payments (PIP), they told us: "I heard it's mortifying – you can say the wrong thing [and lose your benefits], it's very scary". Others described: "having to go through it all again", to have their child's needs assessed again, as they had often been

assessed in the past by education and social services; as one person put it: “it’s like reliving it all again, it’s as if he’ll get better”. Equally, some shared more positive experiences of the assessments.

5.28. Similar concerns about the benefits system and processes were identified by research by the Social Care Institute for Excellence (SCIE), who identify that:

> “people with autism[64] can be anxious about applying for, and perhaps being refused, benefits. The forms involved can be forbiddingly complicated, and the office spaces that house benefits staff can be bright and noisy” (SCIE, 2017).

5.29. Support from organisations like ASSC, through 21 High Street in Cardiff, was therefore seen as very important, as other advice and support services (like the CAB) were not felt to have the autism awareness and skills of ASSC.

Other services

5.30. Engagement with other services, such as education, employment, leisure and housing has generally focused upon advice and training; for example, Cardiff and Vale have built upon their existing links to develop training for Job Centre Plus staff and Powys has worked with the Powys disability sports advisor to deliver the Welsh Government’s Autism Leisure Programme to 15 Powys leisure centres. Over time, IASs’ engagement with other services may develop as, for example, Powys IAS is part of a project intended to influence a local housing development in the Llandrindod Wells area, providing information on housing needs of autism individuals (WLGA, n.d).

[64] The term “people with autism” is drawn from a direct quote and, as such remains unchanged in this report.

Discussion

5.31. Positive relationships with key services are being built, and engagement is felt to have improved access to services and helped manage demand. However, it is time consuming, often requires a mix of deference, patience and skill on the part of IASs to manage potentially difficult relationships. It is very much a "work in progress" and the first three IASs to get established (Cardiff and Vale, Gwent and Powys) are furthest ahead. IASs' efforts have also been constrained by the pressure almost all other services faced, which, as one interviewee put it, created "blockages" and limited their scope to work with the IAS.

5.32. More broadly, getting the interface right between services such as health, education and social care was seen as critical in meeting needs. As one interviewee observed: "if you get this right, you may never need to see the IAS" (as other services would meet needs). Examples of joint working, training, advice and consultation that were helping other services meet need, were important and valuable impacts of the IAS. Yet these could be invisible to service users and the impact might therefore be difficult to evidence.

5.33. Equally, it was also observed that the IASs are a small, albeit specialist, service and could not be expected to take both a strategic and operational role. Developing the role of RPBs and other strategic bodies like Public Service Boards (PSBs) and integrating them with the local infrastructure of ASD leads and groups, was therefore seen as crucial in promoting effective joint working across services. This was seen as challenging, as autism is only a small part of a very large agenda for RPBs and PSBs and, although autism sub groups have been established by RPBs, these typically focus only upon the IAS. The National Autism Team encouragement to identify autism champions in RPBs was therefore welcome.

6. The experiences of individuals and families accessing the IAS

Introduction

6.1. In this section we discuss the experiences of service users, drawing primarily upon interviews with service users but also, where relevant, focus group discussions with autistic adults, family members and carers, and responses to the online questionnaires.

A specialist service

6.2. The thing that many autistic adults and family members and carers interviewed for this study most valued was that the IAS is an autism specific service. This meant, as they described it, that they did not have to explain themselves. Most talked about feeling understood and comfortable with IAS staff. As one interviewee said: “I can tell them anything, and coming from me that is a really big thing”; another described how the first time he talked with an IAS staff member he said: “where have you been all my life?” Similarly, as one person commented: “the IAS staff is all helpful and friendly. This manner makes the IAS service very approachable. I think it is great having an autistic specific service in North Wales.”

6.3. Many interviewees talked about the relief of finding the IAS, after a lifetime of hiding their concerns and not talking about it, and one parent of an adult diagnosed with autism as a young child said:

> “the whole attitude is very understanding- almost a celebration of people with autism, with a focus on empowerment. We have never experienced this before and it really helps. Having been in so many ineffective, inappropriate services, nothing has come anywhere close to this.”

6.4. Some talked about the way the service filled a gap – as one put it "it fills the scandalous gap in services for autistic adults" and others described how "I've not had help like this ever" and the "IAS is the only help I've had". People using the IAS generally trusted the staff and their professionalism: "they know what they are doing" and another commented: "the support workers and the psychologist are extremely knowledgeable about autism – they are very professional but very in tune with people with autism[65]."

6.5. However, in a few cases (in different part of Wales), autistic adults complained that:

- the buildings used for meeting were not autism friendly and there was too much reliance upon communication by telephone;
- staff did not always understand autism or their needs;
- that staff saw the responsibility for overcoming difficulties resting with the individual, rather than the service; for example, autistic adults complained that they had only been signposted to support services or offered tools and approaches that they could use themselves;
- there was a lack of understanding of women with autism; or
- that they could not access the service, because they did not meet the criteria, typically as they were being supported by another service, or in one case, because their diagnosis was not initially accepted by the IAS[66].

6.6. Even amongst those who praised the service, there was criticism, but this was usually focused on wanting more support (rather than criticism of the support they had). Interviewees sometimes wanted more one to one mentoring and advocacy support and access to key-worker type

[65] The term "people with autism" is drawn from a direct quote and, as such remains unchanged in this report.
[66] He explained that he did not have a letter saying he has a diagnosis as he was diagnosed before the autistic criteria were consolidated. Eventually his GP wrote a letter confirming that he has Asperger's syndrome and he was accepted by the IAS.

support that would mean they could be accompanied to the activities they are referred to, at least in the beginning. As outlined in section 5, this was sometimes fuelled by frustration that their hopes for the new service could not be met; for example, one parent described how: "the IAS changes its goal posts too often about the services it provides. Saying it works with all ages, then it says not children." Another said: "IAS was delayed endlessly – was promised and promised" but never materialised.

Assessment and diagnosis

6.7. Not all of the interviewees had received their diagnosis via the IAS. There were a variety of routes that people had taken to, and from, diagnosis. Some were diagnosed in childhood but most of those interviewed for this study were diagnosed as adults. Five had paid privately for a diagnosis and others talked about being diagnosed by mental health services.

6.8. The trigger for seeking a diagnosis amongst adults was, in many cases, a period of crisis leading to acute anxiety or, as many people described it, a "meltdown"[67]. This usually led to contact with mental health services, who then suggested that they seek an assessment for autism. However, this was not described as an easy process and could take a long time. One interviewee was angry that they had been with mental health services for 12 years before someone suggested that they ought to be assessed for autism. A parent described their son's experience of mental health provision as having done great harm. He had been diagnosed with autism as a child and she felt there had been a poor response to his needs, talking about the IAS as "a breath of fresh air" because of its understanding.

[67] As one professional put it, many of the adults he saw had been: "in emotional distress all their lives, but had hidden in plain sight, feeling, 'isn't this how it is?'". They described how many of the adults they worked with had coped for years, often masking their difficulties, until eventually, exhausted, they could no longer cope.

6.9. Referrals to the IAS from mental health services were common amongst interviewees and one IAS, for example, said that most of their referrals came from primary mental health service teams. For this group, assessment often came at a difficult period in their life, when they were unwell and their anxiety levels were high and a lot talked about feeling very stressed about the process before it started. However, all were happy with the assessment process and those people who had been diagnosed by the IAS talked very positively about it.

6.10. People generally talked about the relief of finding a service that was shaped around their needs, including about how lighting was kept low, the need for breaks was recognised, background noise levels were controlled and relatives were able to come in for parts of the process.

6.11. Another group of interviewees sought diagnosis because people around them suggested that they should. Two interviewees said that they were told by a Job Centre Plus disability adviser that they should seek an assessment for autism and they were told about the IAS by the Job Centre. Three interviewees were attending services as the parent of a child with autism and it was suggested that they also seek an assessment. Others talked about partners or family members or work colleagues encouraging them to ask for an assessment and a number of interviewees talked about how they had sought a diagnosis after another family member was diagnosed and friends or relatives spotted similarities.

6.12. These people were not being treated by mental health services before being diagnosed, although all described having been very anxious and really struggling. They were, as a group, less likely to talk about the diagnosis as a relief, although they did all say that it explained a lot of problems they were having, and some of them found accepting the diagnosis a challenge.

The impact of a diagnosis

6.13. All interviewees said it was important to have a diagnosis, but there was a variation in how they felt about receiving it. Some described it as a relief and, as Ashley's story illustrates, nearly all said that it helped to explain a lot about their lives. However, for some, the diagnosis was traumatic and they valued the support that the IAS could provide in helping them understand and accept it.

Ashley

Ashley (not her real name) was diagnosed as a young adult. She described consciously controlling her mannerisms and supressing her personality before she got the diagnosis and she thought everyone did that. It was only on diagnosis that she realised everyone does not do that. She also reported that the pain she experiences from a medical condition was easier after diagnosis, as she wasn't controlling her body so much.

6.14. An interviewee who had struggled with mental health problems all their adult life said that the diagnosis was: "a shock, then a relief, and then I got really angry for a while – that it had taken so long."

6.15. Another described the value of having time to adjust to a new self - identity:

"I had been on the waiting list for two years so by the time I had the diagnosis it was not a shock, but it took a long time to sink in. Being on the waiting list helped us to adjust. Without the diagnosis I would not be with my partner now – I was coping in work but terrible at home and I just couldn't understand why."

6.16. This interviewee was glad that by the time the diagnosis came the IAS was set up, because of the post-diagnosis support, saying that to have the diagnosis but no follow up would have been terrible. She described being given a reading list, and books from the IAS library and meeting with a specialist psychologist over months to talk about her anxieties: "how would you get through this madness without the IAS? It is like a bomb has gone off, and you are wading through a minefield."

6.17. There was no pattern in how people responded to the diagnosis; for example, some talked about finding it helpful being able to tell other people you are autistic and others told no-one, finding the label problematic and wanting to be seen as normal. Some talked about doing a great deal of research, using the internet, to learn about autism; others avoided information sites on autism as they did not want to be categorised as autistic. This is illustrative of the width of the spectrum and the significant differences between the people the IAS works with. However, there were usually sufficient commonalities for people to appreciate meeting others, even though people attending groups sometimes commented on how they struggled to understand other members' behaviours or problems.

Changing needs

6.18. People talked about how the impact of their autism had changed at different points in their life. People often described having coped with life, albeit realising with hindsight that they had always struggled, until hitting a crisis. This might be triggered by the death of a relative, loss of a job or the end of school or university, the breakup of a relationship and/or a combination of stresses coming together. Interviewees had sometimes sustained employment for decades, had long term relationships, completed university degree courses and functioned sufficiently to get by in society but now their lives were very different. These crisis points had a major impact on confidence and self -esteem,

so that some interviewees did not expect to be able to regain the life they had once had.

6.19. One interviewee said: “anxiety and frustration builds up with me and small things can make me lose control. It got a lot worse when I was in my forties, a lot worse.” Another was grateful about becoming a parent in his forties, as he said he would have been unable to care for a child before that age. There were interviewees who had found school extremely difficult and were relieved when they could leave, and others who said that they coped well in school but lost some of those coping skills when they had to leave:

> My main problems are maintaining employment, dealing with other people and coping with changes. As I’ve got older and had to deal with adult responsibility it got too difficult to maintain the façade and the stress led to several meltdowns.

6.20. For some people who did not cope at all well in school, there was a different pattern. For them, adult life has sometimes been better, because they are more in control of what they do. As one put it: “I am absolutely fine as long as I am only doing what I want to do.” This led to a concern amongst some interviewees about employment because it meant having to do what others tell you to do and being out of control of the environment.

Family support

6.21. It was clear that, for some people, partners and family were absolutely crucial in enabling them to function. Around half the interviewees lived with family members, five were married or lived with partners and the rest lived alone. Where people were living with families or partners, it was clear that living with autism is a whole family experience and there was appreciation that this was recognised by the IAS.

6.22. Those that lived with others often (though not always) received a great deal of practical support ranging from help with basic daily tasks such as getting dressed, to financial help and money management, and support in their employment. Family members frequently described households structured around meeting their adult son's or daughter's needs and concerns about the future when they would no longer be able to provide support. Their IAS priority was most frequently around promoting independent living skills and it was clear that this was something they found very difficult to do on their own.

6.23. The support of the IAS for family members was seen as important, both by family members and by interviewees with autism. Family members described how their relationship to adult services changed, but often their role at home did not: "when your child reaches 18 you become a carer, not a parent. I found that really difficult. It creates real problems around sharing information which is as hard for him as it is for us."

6.24. The way that the IAS recognises the role of family members and partners was described as valuable:

> The parent workshop was excellent – very well presented. Being with family members in the same situation made me feel rejuvenated and refreshed. There were rumblings about forming a support group for family members and I have never come across this before. There have to be boundaries when they are adults but this is a really good way to re-engage family members.

6.25. One interviewee who has a number of family members with autism described going to the IAS for the first time: "walking away from the IAS, as a carer, I felt like a great weight had been lifted off me. They provide support for them and for me too."

6.26. Around half the family members interviewed were single mothers and their children. Most described a deterioration in their son or daughter after completing education, even if school years were difficult. Those family members who still had their child living with them often described a household structured around meeting that person's needs. This was done both to alleviate real distress in their child and also, often, from a fear of consequences if they tried to push the adult child. Only two spoke about experiences of violence, but others spoke about experiencing "meltdowns", anger and shouting. One, struggling with her son's aggression talked about how the IAS was building her confidence to be able to manage situations and how important this was for her.

Support

6.27. Interviewees became more positive about the IAS as the evaluation progressed, reflecting how the services have developed in the last year. In Cardiff, where there had been a pre-existing, albeit limited, adult autism service, the picture emerged of a fairly seamless process from existing services to the new IAS. Interviewees talked about the support they had from the IAS two years ago, before it was actually set up, because they did not differentiate between the old and new services. Some of the staff are the same and a community group has continued, with participants not really noticing the introduction of the IAS.

6.28. In Gwent and Cwm Taf, the IAS and the support being offered was completely new and, inevitably, this has taken longer to get established. Some people interviewed last August, for example, said that although they had met with the IAS, no support had been offered, but by the late Autumn interviewees were identifying more support.

6.29. In North Wales, where the IAS is still establishing itself, there were very mixed experiences. Some talked very positively about the IAS. As one interviewee put it: "a very promising start and a lovely bunch of people

who are keen to learn and do what they can." However, others, who all had negative experiences of services in the past, described real frustration with the IAS, recounting misunderstandings, difficulties both accessing the service and having assessments completed, with offers of support they did not feel understood or met their needs; for example, as another interviewee put it:

> "if the IAS is there to signpost then it's a waste of time, no-one listens and families have already done the round of agencies. Telling your story again and again is re-traumatising. What is the point? They [the IAS] should challenge, give information, advocate for rights and always begin with 'What Matters?"[68]

6.30. It is important to note that negative experiences were reported in several other areas, and sampling of service users was uneven, so this should not be interpreted of evidence of a particular failure of the IAS in any one region.

The types of support offered

6.31. Most people interviewed had attended at least one course and these were described as helpful.

> It helped a lot to meet others who also had a late diagnosis, I saw a lot of similarities between others on the high functioning end of the spectrum and myself, which helped to assuage any doubts about my own diagnosis. I also found out about other services that I wasn't aware of such as employment services which I haven't used yet but it's good to know that they're there when I'm ready to do so.

[68] The Social Service and Well-being Act aims to transform services and help individuals achieve their well-being outcomes by asking: "what matters to you?"

6.32. People talked about how one to one support helped them tackle a specific barrier, for example, travel training so they can get to college or work, introducing people to social activities, tackling eating problems, helping with family or social relationships and helping build self-esteem.

I was nervous about the IAS. I didn't know if I would like it but when I met with (worker) I saw how he could help. I got comfortable talking to him and when I met him again I was happy to talk to him and I felt that I would stay with him. I got more comfortable talking to him. He has made a plan for me to eat more and to eat more healthily: he gave me the plan and it works, I am eating better. He has helped me to understand my condition more – he explained that there are five kinds of Asperger's and that my eating problems are because I am type 5. Understanding my condition helps. He will help me in other ways but the main first thing is eating.

6.33. One mother of an adult with autism described how he had had a breakdown but had had no mental health support, but that the support from the IAS had made a significant difference: "the combination of support and organised activities have helped his mental health and he doesn't really need mental health support now."

6.34. Interviewees talked about how the IAS has helped to lever in support from others; for example, one interviewee said that the best thing the IAS had done was to put her in touch with a housing support worker employed by her social landlord.

Social Inclusion and exclusion

6.35. A common challenge for interviewees was around managing contact with officials and public bodies. One talked about not having any heating because they did not want to contact their landlord to say it had broken down, and others were not claiming a benefit they were entitled

to, because filling in a form and talking to officials was too difficult. Visiting a Job Centre was described as extremely stressful, having to talk to a stranger in a public, noisy room where so much else is going on. Interviewees described how stress levels increase in these situations and can result in their getting angry and being told to leave. As a consequence, many interviewees said that they get extremely stressed before a visit, meeting or interview, and find it helpful to write down and rehearse what they will say. A couple of interviewees talked about how they write about their thoughts before seeing the IAS psychologist and then just give them their notes as it is, for them, a much more effective way of sharing how they feel. Equally, in Cardiff and Vale there were positive experiences of support and also adjustments made by the Job Centre, possibly linked to the IAS and adults' autism services' awareness -raising work with the Job Centre.

6.36. The medical assessment process for claiming a PIP was described as very difficult by a number of interviewees. The stress of having to prove your needs, especially if you do not always see those needs yourself and/or you don't understand why someone would disbelieve you, makes it very hard. So people do not apply, to avoid going through the trauma involved.

6.37. Nearly all family member interviewees raised issues about self-care and hygiene, and interviewees with autism talked about how they were getting support from the IAS with washing, cooking, eating and looking after your environment (house, flat, room). Sleep is also a key issue for interviewees. Nearly all talked about being up at night and said that mornings were really difficult for them because that was when they slept. Some commented that IAS activities and meetings were nearly always in the morning, which made it difficult for them to attend. Similarly, one interviewee talked about the lack of any opportunity to access IAS activities or support at the weekends or evenings. In order to see a support worker, he had to go in his lunchbreak from work and that meant everything was too much of a rush

6.38. The interviews illustrated the big variation in functionality amongst people accessing the IAS. One interviewee, for example, was in their last year at university and also had a part-time job. This person valued the IAS as a way to better understand autism (having attended a course) and to offload in a support group. The role of the IAS for people like this could be to help them avoid the crisis points that others have faced. This person was facing final exams and decisions about the next career stage and having a resource to support them through these critical points could make a significant difference.

6.39. Others accessing the IAS described themselves as unable to function at all well in mainstream society. The combination of autism and mental health problems meant that some rarely leave their homes. One described his ambition as being to get to a point where he could meet his family for a meal in a restaurant, something he could not manage now. Even those who say that they are coping now, say that functioning is not enough, because it is so hard to keep getting it right that eventually something will give way.

6.40. However, all of those who accept that they have autism said that they have common traits with other autistic people and even the high functioning ones valued being with “people who get me” and the help they get from the IAS in interpreting the world.

6.41. Seven interviewees were in work and another seven talked about wanting to get into employment or back into employment. Employment (for some) provided a valuable structure to daily life and helped in maintaining communication skills. Some talked about finding it difficult to keep jobs and the importance of finding suitable work.

6.42. Those who did not expect to work again talked about not working as a way of keeping well. They saw employment as a stimulus to anxiety and stress, and a strategy to keep ill health away was to avoid such

situations. Some family members also talked about how their adult children did not plan ahead or think about the future, so did not have the incentive to do things that would create changes, although others said that their child did worry about what would happen in the future.

6.43. A number of those interviewed described how they had struggled to access, or chosen not to take up, support in the past; for example, as one adult put it: “I have a difficulty asking or help – I’d like help, but I don’t like to ask. I’ve always been like that, I don’t know why”. Another described how, although they had been diagnosed, they lacked the confidence to approach people to ask for support at university, and as a third put it: “I didn’t get much support, I ended up leaving [university] because I didn’t seek any support”. The proactive offer of support from the IAS was therefore very much valued.

Information

6.44. As noted above, the amount and type of information that interviewees wanted varied significantly, from those who undertook significant research to try to understand their condition, to others who had done no independent investigation and had not read the leaflets they had been given.

6.45. One interviewee described the information initially given as being “rather a medical model” but said that the A4 booklet given out was better, as it did not use medical language. It was also suggested that the IAS could provide more information on social media links, to direct people towards helpful ones.

6.46. Most interviewees had heard of the ASDinfoWales website and especially, the Orange Wallet Scheme. However, relatively few had visited the site or used it often. Interviewees were more likely to know about the Orange Wallet Scheme, for example, from professionals who used the site. At least one interviewee had not been able to download the app linked to the site as it does not conform to an IOS update, and found that frustrating.

7. Progress made in delivering the priorities for action set out in the refreshed ASD SAP

7.1. The previous sections discuss assessment and diagnosis for adults and access to support for adults and family members and carers (through the IAS). In this section we consider progress in relation to four other priority areas in the refreshed action plan:

- assessment and diagnosis for children;
- education;
- employment; and
- access to health and social care.

Assessment and diagnosis for children

7.2. The refreshed ASD SAP identifies that:

> "timely access to assessment services is vital for families so that each child's needs are understood and appropriate services are put in place to support them to lead fulfilling lives. An early diagnosis will also enable family members to understand their child's needs and to seek appropriate support in their caring role."

The value and impact of diagnosis

7.3. Interviews with IAS service users (discussed in section 6), responses to the consultation (WLGA, 2015) and many of the written responses to the online survey all confirm the continuing value of diagnosis for families. Diagnosis is felt to improve access to support, particularly around education, access to services, such as children's disability services, voluntary sector provision, including support groups; and to provide understanding; for example, written comments in the survey

included: “a diagnosis meant I could understand my child and find strategies to help him cope better”; and

> it gave me something concrete which I could give / take to education which they had to take seriously. Up to that point my child's difficulties and my concerns had not been acknowledged, listened to and just shrugged off as her and I just being ' difficult'. My child's needs didn't change with her diagnosis but in my experience her 'needs' were not enough to get support, despite insistence from professionals and policy makers that support is based on need, not on diagnosis.

7.4. Many also stressed the way a diagnosis helped others understand; for example, when asked what was good about the assessment and diagnostic process responses [69] included:

> I could have a reason for why he was different. Was able to google it to try and understand him.

> Being believed after 9 years of being told he was just quirky.

> Confirming my suspicions (from about three years of age) made me feel that I wasn't a paranoid bad mother and that I wasn't mad or exaggerating it gave me more understanding and confidence as a mother. I relaxed more and so has my son.

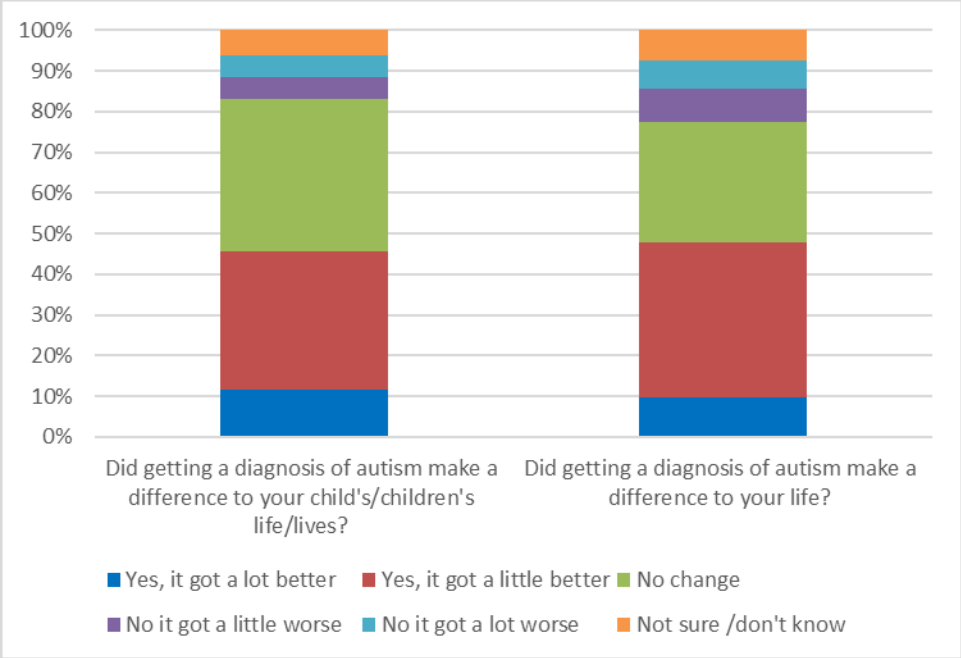
> It was a relief to know what was wrong as our son’s behaviour. It had been put down to bad parenting by the school. we had to fight for nearly two years to get to this point, school didn’t want to believe there was a problem as my child masks in school then has aggressive meltdowns at home.

[69] Some typographical errors in the written comments have been corrected.

People became more understanding and accepting of him. People changed their reactions to his behaviours and offered more compassion and patience. School adopted a different approach to working with him which was beneficial to his well- being.

7.5. However, as graph 2 illustrates, a diagnosis, of itself, does not necessarily improve or change people's lives - with less than half of those surveyed reporting that it improved their or their children's lives- and, in a small number of cases, may be felt to have a negative impact. As the WLGA's national consultation identified: "for some parents / carers being told their child had autism was devastating news" (WLGA, 2015, p. 9). Similarly, as one parent and carer commented on the online questionnaire: "she felt she wasn't broken, now [she] gets upset at not being normal - her words not mine". Others commented that: "it was very hard on all the family. There was no service to explain to us about autism. My son found it very difficult to understand his condition. The only positive was we were able to explain to others why he is the way he is"; and that: "I can't think of any positive thing about my son being Diagnosed with Autism. There are no services in my local area that can help me or my son, I've looked."

Graph 2. Family members' responses to the question "did getting a diagnosis make a difference your or your child's life?"



Source: People and Work family members and carers survey (n=147-146)

Children's assessment and diagnosis services

7.6. Many family members in Wales have struggled in the past to access a timely assessment, as increases in awareness and referrals left services in many areas unable to cope with demand (Holtom and Lloyd-Jones, 2016). Whilst some parents who completed the online questionnaire described being "lucky" and having a swift diagnosis, others described waiting years for diagnosis and/or battles to have request for assessment accepted by GPs of CAHMs; for example, as one put it:

> it took ages / years to even get her on the waiting list with CAMHS [for an assessment]. Three referrals where rejected from professionals. One from her 'children with disabilities' social worker, one from the senior social worker, one from her GP. Finally the referral from the Educational Psychologist was accepted.

Post diagnostic support

7.7. Many parents and carers who contributed to this study described their frustration and anger at the lack of post-diagnostic support. As one parent or carer put it: "we were given a diagnosis and then it was good bye. We are still desperate for help and advice but have none." Consequently, as another summed it up, the experience "was hell". Similarly, consultation to support the Interim ASD Delivery Plan (WLGA, 2015) highlighted the difficulties family members and carers reported in relation to access to assessment and diagnostic services[70]; long waiting times and a lack of post-diagnostic support, illustrated by Jen's and Rhys's experiences.

Jen and Rhys

Jen (not her real name) explained that Rhys's (not his real name) assessment for autism was good: "all open and closed in a day…it didn't take long to get a diagnosis. A lot of people wait a long time, but mine happened almost overnight [it was] only a couple of months [but after diagnosis] I got nothing from the paediatrician …I just got a book with a list of contacts…lots of different groups…you just get a booklet and off you pop. What am I supposed to do?"

The Together for Children and Young People programme

7.8. In response to the problems with assessment and diagnosis, the refreshed ASD SAP outlines how improvements are to be made, by the T4CYP programme and by children's ND services working with the IAS: "to ensure additional support is available" for family members and

[70] Including: "referrals bouncing between CAMHS and paediatrics" and: "a clear lack of understanding about the requirements for referral" (WLGA, 2015, p.6).

carers. As outlined in section 5, a national pathway and children's ND services have been established in each region. This is reported to have improved clarity and understanding of referral processes, although not uniformly, and also access to assessment and diagnosis across Wales. However, ND services across Wales have struggled to cope with demand, and long waiting lists have developed. There are also differences in the referral pathways with, for example, referrals in Western Bay only accepted via schools, whereas in West Wales they come via paediatricians. This can cause concern that waiting times may be extended by delays having a referral made to the ND service.

7.9. Like each IAS, children's ND services have reviewed their processes and sought to maximise efficiency without compromising the robustness of assessments. As the case study below illustrates, they are also exploring different ways to provide post-diagnostic support. However, they have found that the number of referrals continues to exceed their capacity to assess, and consequently their capacity to provide post-diagnostic support has been severely curtailed. We discuss this in detail in a forthcoming report. PHW has also identified a number of gaps in service provision, including: "a lack of direct clinical intervention for young people, particularly between the ages of 12-15 years without a formal diagnosis of ASD…" and: "no formal pathways between neuro-developmental, IAS and across other services e.g. Child and Adolescent Mental Health Services (CAMHS), mental health and learning disabilities services" (PHW, n.d., pp 4-5).

Virtual support - Newport ASD steering group and tertiary neurodevelopmental team, specialist CAMHS, Aneurin Bevan University Health Board

Virtual Groups for Family Members and Carers were established to deliver post-diagnostic support virtually to family members/carers of children with autism in Gwent in a timely, effective and equitable way. This was intended to address:

- inequitable and patchy post diagnostic support;
- increased demand and limited resources;
- the large geographical area to be covered;
- inappropriate use of services - present as crisis;
- increased re referral rates to CAMHS; and
- parental anxiety and family stress.

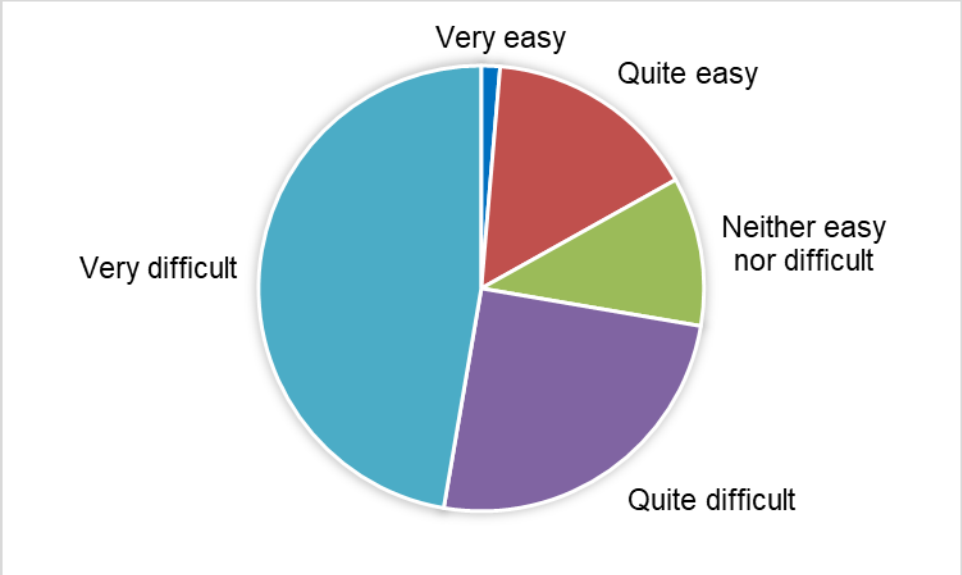
Feedback from families was positive, highlighting the value of the "really useful information" provided. As one commented: "strategies given to cope with meltdowns very good and helpful. More of these groups please."

Adapted from the National Autism Team Case Studies Library

7.10. As Graph 3 illustrates, responses to the online survey from parents and carers indicate the difficulties parents and carers have experienced accessing assessments and diagnosis, with almost three quarters (n=107) reporting it was either quite difficult or very difficult. This may reflect both experiences of assessment and diagnosis before the T4CYP programme's investment and the way in which long waiting lists have offset recent improvement in the referral pathways. Interviews and focus groups with parents and carers painted a similarly mixed picture, with those who had more recent experience of assessment and diagnosis generally reporting a better experience. It was striking that many of those who had had a positive experience described

themselves as “lucky”. As we discuss below, this may reflect the way that the sharing of negative experiences through social groups and online forums colours people’s expectations of services.

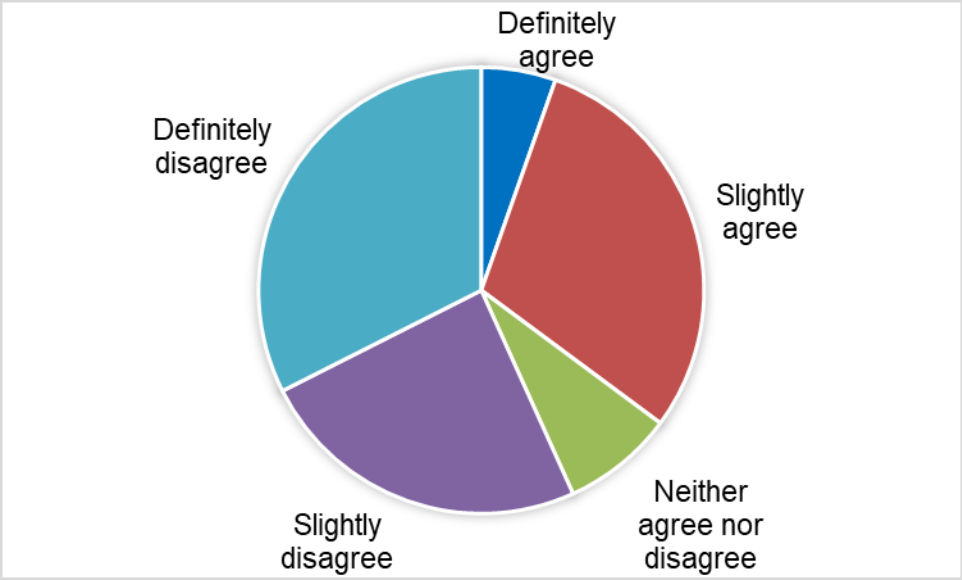
Graph 3: Parents and carers’ responses to the question “how easy was it to see someone who could assess if your child/children had autism or not?”



Source: People and Work survey of parents and carers n=148

7.11. As graph 4 illustrates, responses from professionals were a little more positive, with just over half (n=21) of those making a judgment, reporting it was difficult to access children’s assessment and diagnosis.

Graph 4: Professionals' response to the statement "children in my area have access to timely referral, assessment and post diagnostic services, which meets their needs."



Source: People and Work survey of professionals n=37

7.12. As outlined in section 5, whilst the IAS can work with parents and carers it cannot work directly with children. There has therefore been a reliance upon education services to provide support to children following diagnosis but, as we outline below, there are continuing weaknesses in education provision for children with autism. There are also concerns that this means there is little support for parents in the home, and that children who are not in schools, such as those who are home educated, are left unsupported.

7.13. Responses to the online survey from parents and carers also indicate containing gaps and weakness in post diagnostic support, with almost half (n=61) reporting they had no support after diagnosis. There was little difference in responses for those diagnosed within the last two years and those diagnosed more than two years ago.

Education

7.14. Consultation to support the Interim ASD Delivery Plan (WLGA, 2015) identified concerns about: "the level of knowledge and skills amongst school staff" and also that: "parents / carers also described difficulties in working cooperatively with school teachers" (ibid., p.11)[71]. Similarly, many parents and carers who contributed to this study described their "battles" to access what they consider appropriate support from schools and specialist SEN services; for example as one parent put it, the local authority:

> ...initially refused to assess my son for additional support/statement despite him being diagnosed and the school and us parents having concerns. Following assessment they still have not provided a statement despite the paediatrician, occupational therapist, school and educational psychologist stating he needs additional support. We will now have to start the process again. We were advised to wait another year to show that the school action plus is not meeting his needs. The ongoing fight, meetings, appointments, communicating with agencies has resulted in me having to take a career break.

7.15. The difficulties where a child copes in schools, sometimes described as "masking", but struggles at home (as in Jen and Rhys' case, discussed below), often "melting down", featured in interviews with parents and carers and some professionals (and also some adults described coping in work but having "meltdowns" at home). It fuelled parents' and carers' frustration with schools and other services because they felt that they were not believed, and this accentuated the anxiety and stress many

[71] Similarly, the refreshed strategy identifies that: "families have told us the current system is inefficient, bureaucratic and costly and is not child-centred or user-friendly. Needs are sometimes identified late and interventions are not planned or implemented in a timely or effective way. Families say they feel they have to battle at each stage of the process to get the right support for their child and that they do not know where to turn to for advice and information."

experienced. As Jen's story below illustrates, many felt there was no support for autistic parents as they fought for services for their children.

Jen and Rhys

Jen (not her real name) described how from an early age, Rhys (not his real name) her son, always had "his quirks" and by the age of three, as his behaviour became more challenging, he was referred to a paediatrician for an assessment and was later diagnosed with autism at the age of four and half. We pick up their experiences of this in section 7.

Rhys has a Statement of SEN and attends a mainstream school. Jen started the interview by describing her difficulties with Rhys's current school. As Jen put it: "they just don't listen – no acknowledgement…I feel I'm made out to be a liar…my child doesn't have the same symptoms as other children – he is verbal, he can read and write, he's on chapter books…he's very intelligent, he's registered as a MAT child", but his school reports don't mention autism or ASD. As Jen described it "he copes" at school, but at home, he's a completely different child: "it's [home's] his safety net. I feel I'm justifying myself to the school constantly". As Jen put it: "my son, if he doesn't tick their boxes, he doesn't get any support [it's as if it's] not seen, it's not there" and: "the constant questioning if there is a problem, means you start to talk yourself into believing, is this the case? But he's got a diagnosis, so I know it is."

Jen described: "when I'm complaining, they make me want to justify myself all the time, but if I feel something is not right, I'll scream until all the cows come home". Later Jen explained that: "I don't want to be the mum who shouts the loudest" and she: "wants to work with the school, I want to communicate with the school, I don't want to work against the school, but they seem against me all the time. I've been told if I'm not happy, look at other schools. It's like fighting the inevitable all the time, but I know I'm fighting for the right reason."

7.16. The difficulties, such as anxiety and bullying that children and young autistic people experienced in schools were frequently raised. It was observed that while school might offer some structure, they also often presented challenging sensory environments, and the other children and young people in the school were rarely predictable. A number of contributors described how their children were either excluded from school, encouraged to change schools, or home educated, because the school could not cope with their needs, and in particular, their behaviour, or because their children were so badly bullied; for example, as one family member put it:

> Was refused mental health services when he was suicidal, they said it would be inappropriate. No support to help with severe anxiety and depression at school, we eventually had to deregister and now home educate him.

7.17. Similarly, as another parent put it:

> due to the way we were treated when having difficulties in school, transitioning to comprehensive, my daughter built up a complete distrust of all services; I had no choice but to take her out of school aged 12. She is now 16 and about to start college (part time) in adult education. She has a support worker with Inspire to achieve who has helped with this. Because she has no qualifications my daughter was unable to do the course she wanted to do. Realistically, I feel she may not have coped anyway. I feel there is a complete lack of understanding in schools and colleges, and lack of appropriate provision

Assessing ALN provision in schools

7.18. ALN provision is judged by Estyn to be generally good or improved in schools[72] and some parents and carers were very positive about the educational provision made for their children. However, as Christine's story illustrates, complaints about education were common, including:

- concerns about late recognition and diagnosis of autism;
- difficulties accessing what parents or carers feel is adequate additional support in schools, and in particular, difficulties getting a statement of SEN;
- the reported reluctance of some schools to accept children with SEN and, conversely, reported pressure from LAs for placements in mainstream schools, that parents or carers do not feel is appropriate; and
- the lack of post-16 provision for learners with autism in mainstream schools, limiting learners' options at 16.

Christine

Christine (not her real name) flourished at nursery school, but was bullied at primary school and at around the age of eight at primary school began to suffer from depression. Her family moved her to a secondary school in a new area in the hope that this would help, but she continued to struggle. Suffering suicidal thoughts, Christine was referred to CAHMS. There was an 8 month waiting list at the time and her family paid for a private assessment. Christine was diagnosed with several things including PTSD, depressive episodes, dissociative disorder and hallucinations (her diagnosis of autism came later).

Christine continued to be bullied and began attending school only

[72] "Between 2015 and 2018, care, support and guidance have been good or better in over nine-in-ten primary schools, seven-in-ten special schools and secondary schools, and a third of PRUs."

sporadically. The family's relationship with the school broke down. Christine tried to return to school, but dropped out again due to bullying. Home education was offered, but initially only five hours a week. This was only slowly increased to 25 hours a week, and the family reported difficulties with the tutors offered. Eventually, Christine secured four GCSEs in English language, maths, numeracy and physics. At age 16, Christine began to suspect she was autistic and was eventually diagnosed when she was 18. When interviewed, Christine was attending college, studying for three A levels, but felt unsupported by either the college or the LEA, and without an educational plan making reasonable adjustments for her needs, she worries she has been "set up to fail". Christine's anxiety is increasing and she fears her opportunities are slipping away from her.

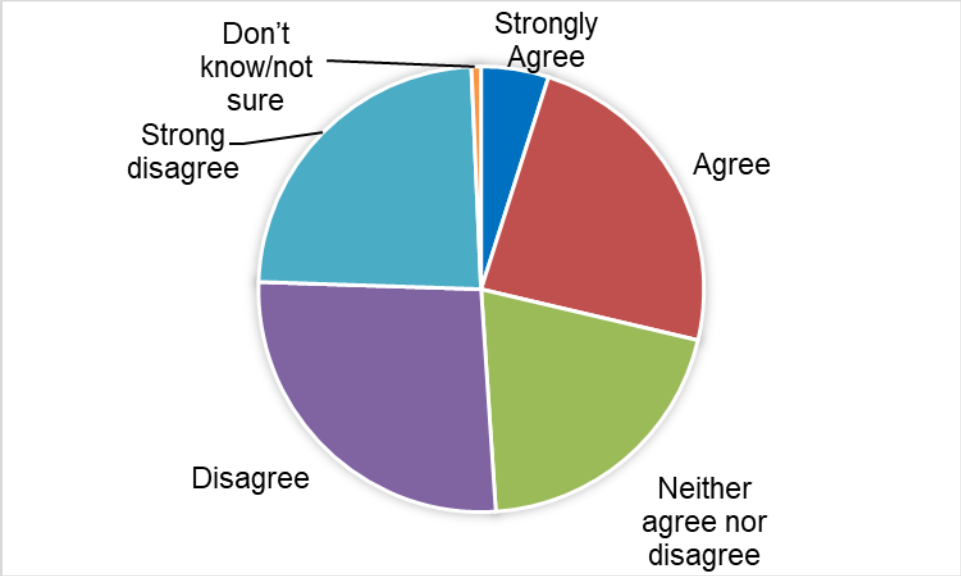
7.19. Overall, the issues raised in interviews and focus groups with parents and carers for this study were broadly consistent with evidence from family members and carers to the Health and Social Care Committee (N/AFW, 2018), highlighting greater satisfaction with specialist provision in schools, but also difficulties in accessing specialist provision and support.

7.20. It is difficult to assess how widespread or representative these difficulties are. As noted, ALN provision in schools is judged by Estyn to be generally good or better than previously. Negative experiences may therefore reflect unmet expectations, which schools may challenge as misplaced; for example, many parents and carers consider one to one support in the classroom as the "gold standard", but educationalists often question this, as it can mean learners are educated by less highly qualified support staff, rather than teachers (see Blatchford et al., 2009). Equally, negative experiences may reflect weaknesses in provision; for example, knowledge and understanding of autism across schools is variable, teachers do not always differentiate effectively (WG, 2014; Estyn, 2018) and support services like educational

psychology are stretched (N/AfW, 2018; Bowen and Holtom, 2015); points echoed by a number of professionals interviewed for this study.

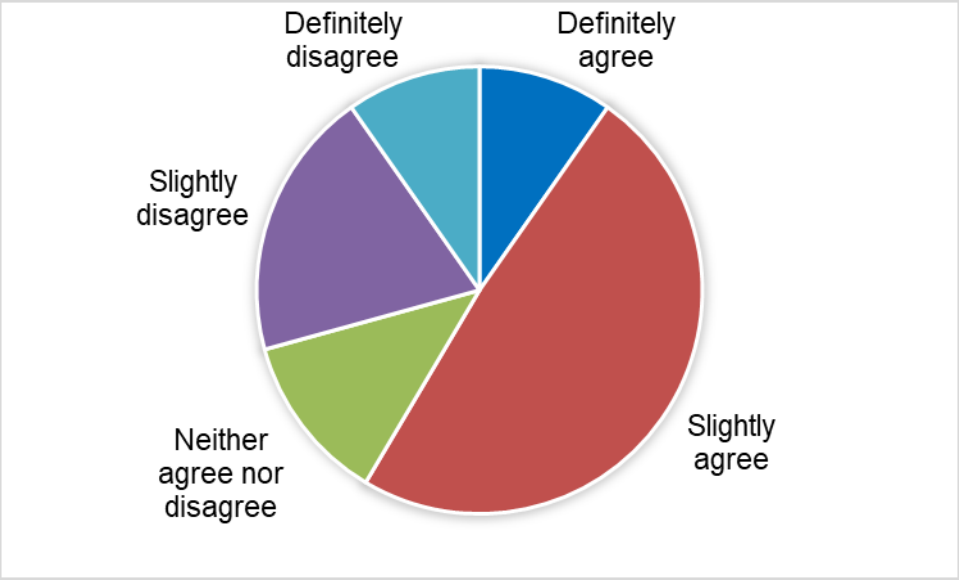
7.21. Even if it is not possible to quantify the proportion of parents and carers with negative experiences, there is solid evidence that, for some parents and carers the education system falls well short of their expectations. As a consequence, as graphs 5 and 6 illustrate and the online survey of parents and carers and, to a lesser degree, professionals, indicates, confidence in education can be low, with less than half of all parents and carers surveyed (n=72) expressing confidence that their child could access the advice and support needed to meet their needs in school.

Graph 5. Parents' and carers' responses to the statement: "I am confident that I or my child/children can access advice and support services that meet his or her needs in education (e.g. in school)."



Source: People and Work survey of parents and carers with children with autism n=143

Graph 6. Professionals responses to the statement "in my area, children with autism can access education services that meet their needs."



Source: People and Work survey of professionals n=41

The role of the IAS

7.22. As outlined in section 5, concerns about education were frequently raised during engagement events organised by the IAS, and there was frustration that the IAS does not have a remit to work directly with children. Nevertheless, there were examples, as the case study below illustrates, of how the IAS could support parents and carers struggling to engage with schools.

Case Study from Cardiff and Vale IAS

A parent of a child in secondary school contacted the service seeking support and advice. The child was struggling in her educational setting. The parent needed support with that and specifically in respect of a meeting scheduled with the board of governors of the school. Information, advice and assistance was provided to support the parent in engaging positively with the board of governors. Information was

also supplied on a range of support groups and activities that may be suitable for the family and/or the young person.

Adapted from the National Autism Team Case Studies Library

The ALN transformation programme

7.23. In response to the difficulties families experience, the Welsh Government has committed itself to introduce a new system to support children and young people with additional learning needs (ALN) from 0 to 25.

The ALN transformation programme

The Additional Learning Needs and Education Tribunal (ALNET) Act is a central part of the ALN transformation programme. The Act replaces the existing legislation around SEN and the assessment of children and young people with learning difficulties and/or disabilities (LDD) in post-16 education and training, and aims:

- to provide a unified legislative framework to support children and young people aged 0-25 with ALN in schools and colleges;
- to promote an integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions; and
- to have a fair and transparent system for providing information and advice for resolving concerns and appeal.

The Act is being phased in and will not be fully rolled out until 2023.
Other key elements of the ALN transformation programme include:

- workforce development, including the roll out of person-centred approaches, the development of the Additional Learning Needs

Coordinator (ALNCO) role, and additional investment in specialist SEN services, such as educational psychologists;

- awareness raising to ensure that staff better understand the evidence base for interventions, including a Rapid Evidence Assessment (REA) of educational interventions to support learners with autism and the Learning with Autism Programme; and
- additional support for transformation, including grants, guides and the work of ALN transformation leads.

Adapted from Estyn (2018) and WG (2018)

7.24. One of the key premises of the ALN transformation programme (see boxed text) is that the existing system is too adversarial, insufficiently child-centered and fails to ensure that all needs are identified early and that all learners with ALN can achieve their full potential (WG, 2018b). The ALN Transformation Programme is a key part of the refreshed ASD SAP, but it is too early to judge its impact, although the early indications are encouraging. Estyn reports that the emerging impact of Person Centred Planning (PCP), which is expected to play a key role in improving schools' and colleges' understanding of learners' needs, and also in improving relationships with family members and carers, has been encouraging (Estyn, 2018). This is in line with evidence from the ALN pilots (Holtom and Lloyd-Jones, 2014) and contributes to the Welsh Government's confidence that the ALN Transformation Programme will improve experiences and outcomes for learners with autism and also their parents and carers. However, there is also recognition that the programme is: "not a silver bullet". The cultural change required will take time and in many ways, the ALNET Act reinforces changes in culture and practice, adding greater emphasis to, and extending, legal rights of redress, rather than marking a radical change of direction.

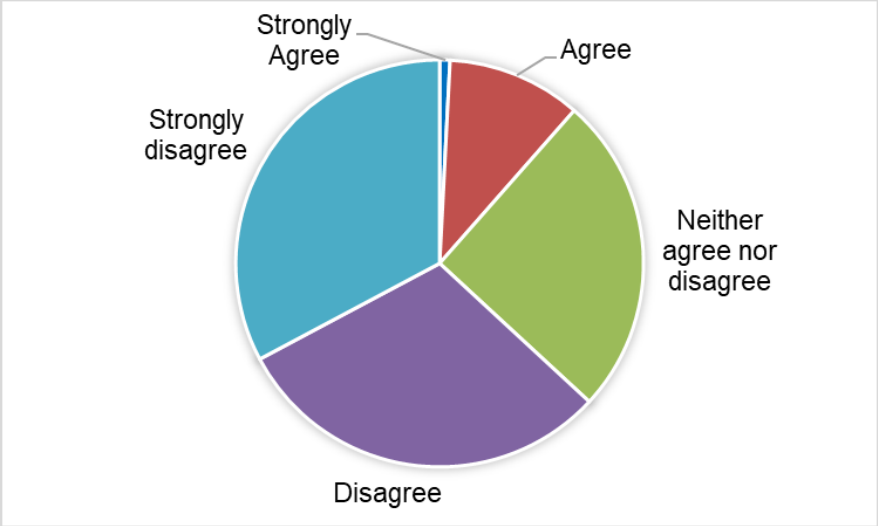
Education and post-education outcomes

7.25. Currently, only 32 percent of pupils with autism achieved the level 2 inclusive standard in education, compared to 55 percent of all learners (Welsh Government, 2017). However, given the range and complexity of needs associated with autism[73], it is difficult to interpret the performance of pupils with autism (Estyn, 2018).

7.26. The transition from school to college, and college or university to employment, is often difficult for young autistic people (Holtom and Lloyd-Jones, 2016) and concerns about this were frequently expressed in focus groups with parents and carers and in interviews with adults. This was also reflected in responses to the online survey. As graph 7 illustrates, only around 10 per cent of those surveyed (n=14) were confident that their child would make a successful transition from school. As one put it the whole process was “hazy” and very worrying. Another described how the “Transition to college was a total fail, with no transport and no support, which was organised by a transition officer. The family was left to rearrange everything into the second week of college. Thankfully now all is well”.

[73] This includes pupils with complex learning needs in highly specialised settings as well as those with ASD who may be educated in mainstream schools.

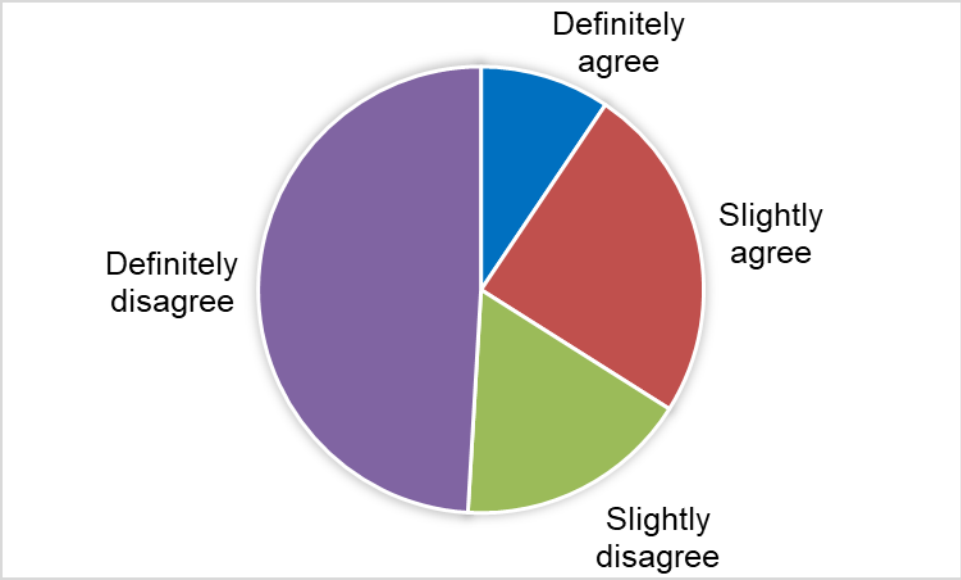
Graph 7. Parents and carers' responses to the statement "I am confident that my child/children will make a successful transition from school to, for example, college or employment."



Source: People and Work survey of parents and carers n=122

7.27. The consultation to support the Interim ASD Delivery Plan (WLGA 2015) found only limited evidence of unmet needs in further education and training. However, interviews with adults for this study identified several who had dropped out of university or college, or struggled when leaving university, and examples were given of the IASs' helping adults sustain their participation in education and training. The online survey of adults also suggests potentially unmet needs. As graph 8 illustrates, only around a third of adults surveyed, who made a judgment (n=18), expressed confidence that they could access advice and services to help meet their needs in education or training.

Graph 8. Responses from autistic adults to the statement: "I can access advice and services to help meet my needs in education or training."



Source: People and Work autistic adults survey n=53

Employment

7.28. As outlined above, the transition from education to employment can be challenging for young people and autistic adults. Consultation to support the Interim ASD Delivery Plan (WLGA, 2015) identified that a: "lack of support for employment was frequently reported as an unmet need for adults" and employment rates for autistic people have historically been much lower than for the general population (WG, 2014).

7.29. In response, the refreshed ASD SAP outlines that a new All Age Employability Programme (see boxed text) is being developed. Training, including the Working with Autism programme, will be disseminated and the Engage to Change programme has been funded[74].

[74] Engage to Change is a Wales wide project. It aims to help 1000 young people aged 16-25 with autism and/or learning disability gain experience in the workplace and: "develop transferable skills through a person-centred approach." It will work with 800 employers and

Employability Programme

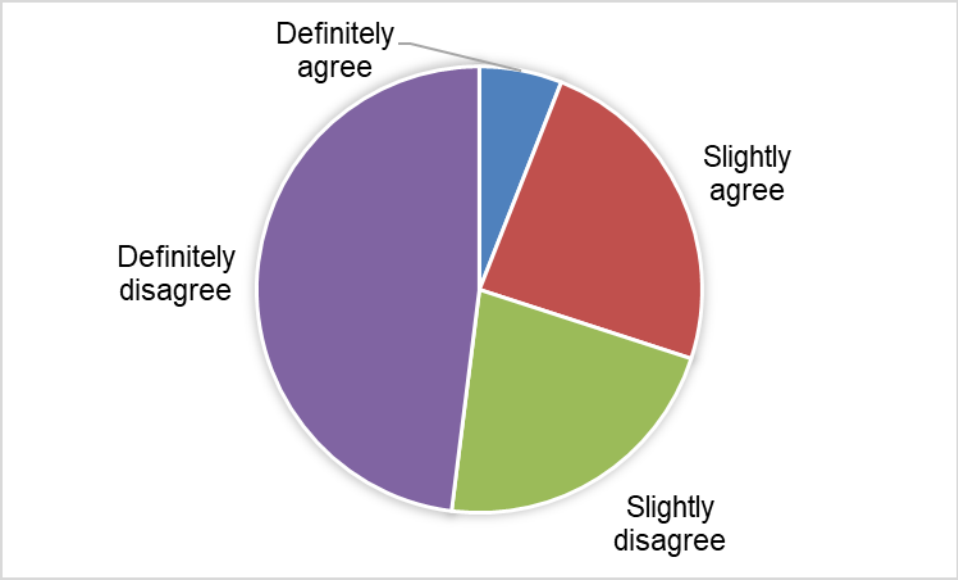
The new employability programme will:

- offer person-centred support, with the Employment Advice Gateway offering a single point of access, assessment of needs and brokering access to a range of services, including Communities for Work (CfW); Parents and Childcare Employment (PACE) and Jobs Growth Wales;
- work with and influence employers;
- address current and future projected skill needs and gaps; and
- the future of work in Wales (WG, 2018c).

7.30. Overall, there has only been limited progress in this area and it is too early to judge what the impact of the Employability Programme and Engage to Change programmes will be. There is anecdotal evidence that, where training for employment support services has been delivered (e.g. in Cardiff and Vale), it has been well received. However, as outlined in section 5, the scale and scope of training with employment services has been limited and IAS staff were not expected to have expertise in relation to employment support. This assessment is supported by responses from adults and professionals. As graph 9 illustrates, only 30 per cent (n=15) adults surveyed, who made a judgment, were confident that they could access advice and services to help meet their needs from employment services. As graph 10 illustrates, responses from professionals were similar.

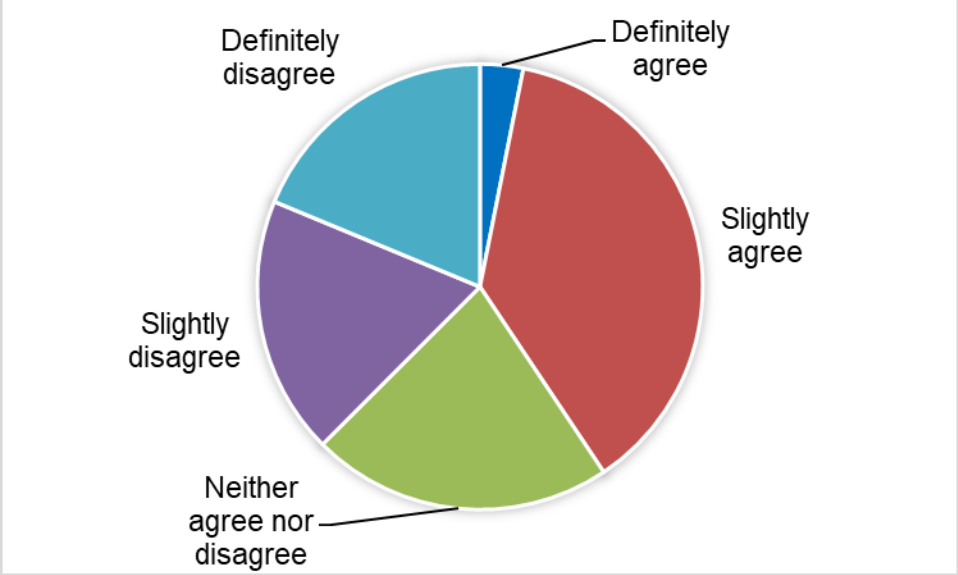
offers one to one job coaching and specialist employment support to both the young person and the employer.

Graph 9. Responses from autistic adults to the statement "I can access advice and services to help meet my needs from employment services."



Source: People and Work Adult with autism survey n=50

Graph 10. Professionals' responses to the statement: "in my area, autistic adults can access services that meet their needs in education or training."



Source: People and Work Survey of professionals n=32

7.31. It is important to note that although as outlined in chapter 6 some adults interviewed for this study wanted to work, this was not a uniformly shared aspiration. Some did not feel ready or well enough to work. In North Wales there were also suspicions amongst some adults that the IAS had a hidden agenda of getting people back into work because IAS staff were reported to be keen to suggest work and volunteering as options and used JCP offices as venues. This raised concerns that people might lose their disability related benefits.

Access to health and social care

7.32. As outlined in section 5, access to and support from mental health services, identified as difficult by the 2015 consultation (WLGA, 2015) remains problematic, given the heavy demand for services, high thresholds for eligibility, and concerns that therapeutic interventions (as distinct from medication) for autistic people are under-developed. Many written comments from parents and carers in the online survey focused upon problems accessing CAMHS; a problem other reviews have identified given the pressures CAMHS face (NAfW, 2014). For example, as one family member reported:

> I asked for CAHMS support for my son's anxiety via GP referral and was told he wasn't suffering enough. As anxiety, self harm and depression are known to be experienced by autistic children I would've thought there would be support, not rejection until a crisis situation.

7.33. Another reported: “there is nothing. Camhs [sic] say our daughter needs counselling but there is none available for her.”.

7.34. A small number of adults made written comments about adult mental health services; for example, as one put it: “mental help is terrible in this country from child to adult” and as another put it:

> I have honestly found the CMHT very judgemental, unfriendly/unhelpful and very poor service e.g. accessing services. Waiting times for psychological therapies are far too long. People are dying waiting for this service… I feel really let down by the mental health provision …[The] psychology liaison team at Ysbyty Glan Clwyd wer amazing when I needed them though. I can't thank them enough.

7.35. As section 4 outlines, there are also reported to be problems in accessing social care services. These include the greater time and expertise needed to assess autistic people, and pressures upon services, which have led to high thresholds and which may encourage "defensive decision making" during assessments. These problems were reflected in comments made by family members in the online questionnaires; for example as one put it: "social services did not want to know our family and would not help in any way" and as another put it:

> there is no support available for those with autism/carers/families. There …is nothing available for those who work during weekdays. I reached the end of my tether approximately a month ago as I find that my child who was diagnosed 'on the spectrum' is getting worse in terms of her autism. I rang the Social Services as I'd heard from a friend who used to work for them that they may be able to help; take the child for swimming lessons or trips occasionally. This would have been such a benefit to the child …and allow us as parents a little breathing time as we have absolutely no family support. I was told by a member of the social service, without even carrying out an assessment that the child would no way meet the criteria as she would have to have a severe physical disability also; because the funding is so tight the criteria is extremely high. I am extremely disappointed in the whole system.

7.36. Interviews and focus groups with family members and carers and with professionals also highlight problems in accessing health and social care services, such as noisy reception areas and an increasing reliance upon telephone contact, which some autistic people struggle with. The difficulties autistic people can face in hospitals, given the environment (which can be difficult for those with sensory issues), and gaps in staff awareness and skills were also highlighted.

7.37. Family members and carers often struggle with the emotional and practical demands of caring for and supporting someone with autism. It can limit their independence and employment and undermine their mental and physical health, and social care has an important role in assessing their needs. Carers' difficulties can also be compounded by the exhausting "battles" many experience accessing services for those they care for and for themselves (SCIE, 2017). In both Gwent and North Wales, participants talked about the stress of having to fight for services for their children. One likened working with agencies to calling for an ambulance to help your child and then watching it repeatedly driving over/reversing over your child time and time again. It was felt not only were services not helping them and working against them, but also denying them time with their children as it takes time and energy to secure access to services for their children. Some provided extensive documentation of their battles and appeals to the local authority and Ombudsmen, and also in the case of education (discussed above), the Special Educational Need Tribunal for Wales (SENTW). As one interviewee put it in an email (describing experience that pre-date the IAS):

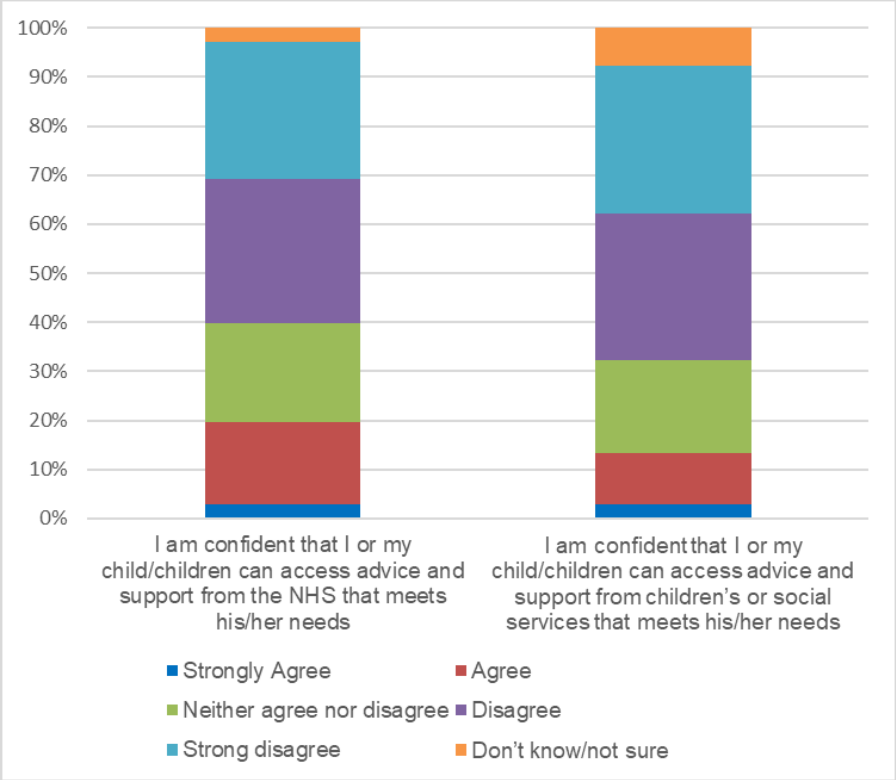
> [I have been] fighting for 16 years to get services from SS [social services] for my son who is unlikely to ever live independently, is in receipt of high-rate PIP [Personal Independence Payment] and has had to have a bespoke education service from the LA. I've been lied to, blamed for my son's difficulties, verbally attacked by SS officials, told autism isn't a disability as s defined under the Equality Act 2010

(wrong, the Act actually mentions autism along with other “mental impairment”), all from SS personnel who are supposed to make life easier and less stressful.

7.38. Responses to the online survey from family members and carers and autistic adults, and also the experiences of people like Lisa (discussed in section 5), indicate that as a consequence of their experiences, many have little confidence in health and social care services; for example:

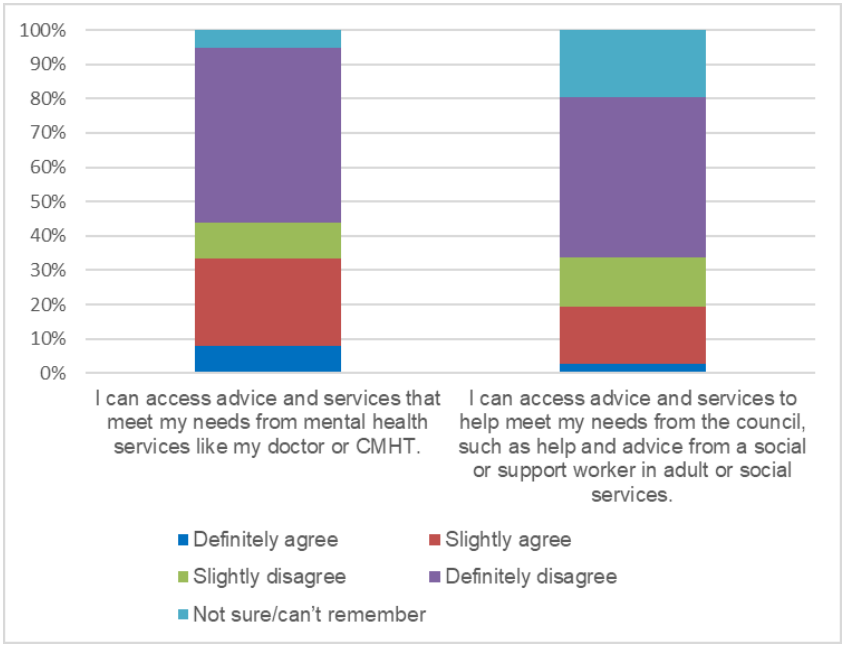
- as graph 11 illustrates, less than a fifth (n=28) of family members and carers surveyed were confident that they could access health or support from the NHS or social care services that met their child’s needs;
- as graph 12 illustrates, while a higher proportion of adults surveyed were confident that they could access health or support from the NHS or social care services that met their needs, still less than a third (n=25) actually said they were confident; and
- as graph 13 illustrates, professionals were somewhat more confident (37 per cent, n=17) than adults or family members and carers, but the proportions who were confident in services were still low.

Graph 11. Family members' and carers' confidence accessing advice and support from NHS and social services.



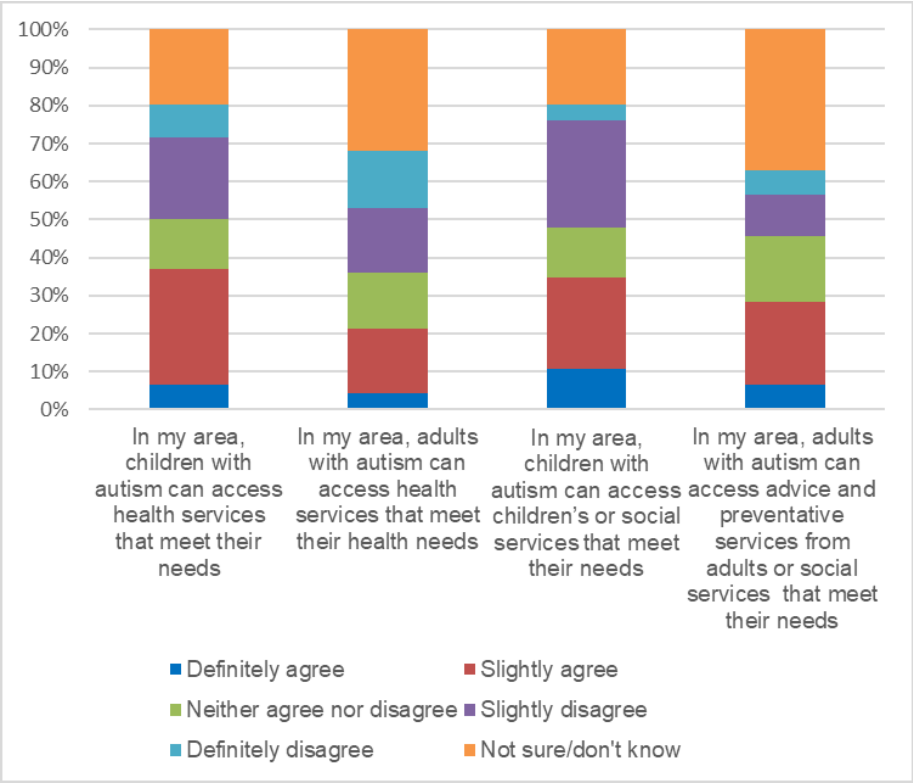
Source: People and Work survey of parents and carers n=143

Graph 12. Adults' with autism confidence accessing advice and services from mental health and social services



Source: People and Work autistic adults survey n=75-77

Graph 13. Professionals' responses to questions about access to health and social services to meet children's and adults' needs



Source: People and Work survey of professionals n=46-47

8. Awareness raising, information and training resources

Introduction

8.1. Raising awareness across services, to make all services better for autistic people, will improve the lives of autistic people and reduce the need for specialist services like the IAS (SCIE, 2017). It should improve access to, and the support provided by, education, health and social care services (discussed in section 7). As Richard's account illustrates, many of the autistic adults who were interviewed reflected upon the difficulties they experienced living in a "neuro-typical"" world.

Richard

Richard (not his real name), whose experiences of university are discussed in section 5, has Asperger's syndrome. As he described it, around the age of 16 he began to feel: "very out of touch, even with my brother and sister". As he put it, he felt: "what am I doing? Why can't I focus upon my innate interests? And why are they boring to others? How do I ask this girl I like, out?" "It was almost like everyone else knew the answers, but for me, why are these things happening?" As he put it, the "workload" of trying to fit into society and its "hidden language and hidden doors" could be a huge strain. Richard also vividly described examples of discrimination and bullying and how, for example, he was singled out by a bus driver: "as If I'm entertaining…as if I'm someone to pick on."

As Richard put it, the education system: "may teach us how to pass tests, but they don't teach us the necessary skills for…day-to-day living" and how to cope and when things go wrong: "how to deal when said society isn't always there to pick up the pieces, which is where IAS should have come in for people like myself."

8.2. It was also observed by interviewees that increased awareness and understanding of autism could mean that autistic people were more willing to disclose that they were autistic, which increased the likelihood of services understanding their needs and making adjustments. As section 7 outlines, providing information can also help autistic people and their family members and carers both better understand, and cope with, the impact of autism.

The ASDInfoWales website

8.3. The National Autism Team has worked with partners across Wales to develop resources to increase awareness of autism and to support children and autistic adults, parents, other family members and carers, professionals and service providers. The team has organised and publicised its resources (see boxed text) on the ASDinfoWales website and, as one interviewee put it, there are: "fabulous resources on the website."

National ASD Resources

The resources available on the ASDSinfoWales web-site include autism awareness and:

- the Can You See Me? campaign that aims to promote understanding and acceptance amongst communities in Wales, to improve access to facilities and reduce the stigma that many autistic people and their family members and carers experience;
- Growing with Autism is aimed at family members of children and younger adolescents, including a wide range of resources to help family members and carers;
- the Learning with Autism programme provides support in different education settings, from early years and through primary and secondary school, and includes an extensive set of materials that

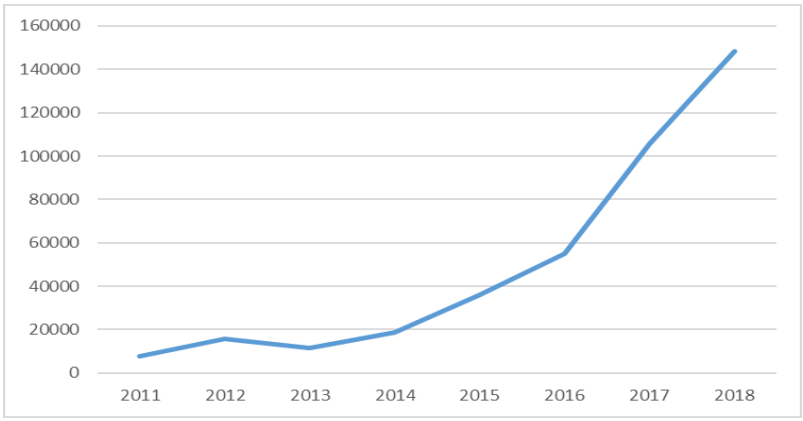
can be used and adapted in classroom settings (all available as resources free of charge);

- Living with Autism provides advice and tips for everyday life to adults who have been diagnosed with an autism spectrum disorder;
- Working with Autism includes a range of resources for those supporting autistic individuals into employment;
- a Sports and Leisure scheme aims to increase knowledge and awareness of the needs of autistic people to support access to sports and leisure activities;
- clinician and practitioner Toolkits, based on NICE guidelines, support professionals in their specialist diagnostic and post-diagnostic interventions.

Adapted from WLGA(n.d. b)

8.4. The resources are promoted by the national team through campaigns, such as Can You See Me?, and work to raise awareness of the resources with bodies such as the Association of Directors of Education Wales (ADEW) and RPBs. They are also promoted by IASs and local ASD leads. As graph 14 illustrates, data on use shows a steady rise from the launch of the website in 2011, and an acceleration in the numbers after 2016, which coincided with a refresh and relaunch of the site. There are also reported to be “spike”’ in use of resources following campaigns by the national team.

Graph 14. The number of ASDinfoWales Website Sessions[75] (2011-2018)

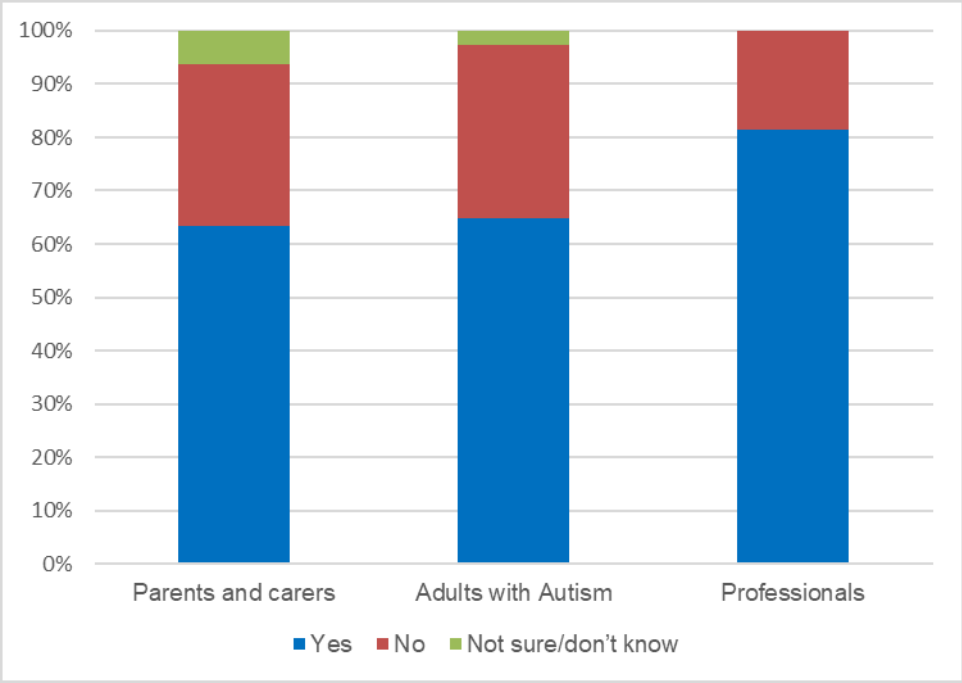


Source: WLGA

8.5. As outlined in section 6, most interviewees for this study had heard of the ASDinfoWales website. However, relatively few had visited the site or used it often. As graph 15 illustrates, responses to the online survey indicate that over 60 percent of parents and carers (n=90) and adults (n=50) surveyed were aware of the ASDinfoWales website. Awareness amongst professionals was higher.

[75] A session is a group of interactions that take place on your website within a given time frame, such as multiple screen or page views (Pers. Comm. Tracy Hinton)

Graph 15. Parents' and carers', autistic adults' and professionals' responses if they "know about the ASD info website?"



Source: People and Work parents and carers (n=142), autistic adults (n=77) and professionals (n=43).

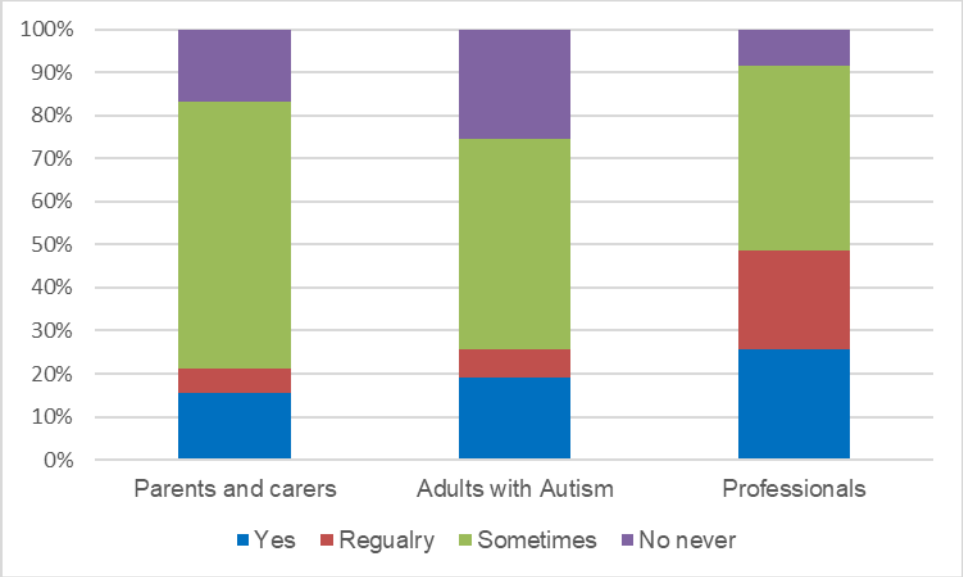
8.6. One of the professionals interviewed for this study observed that the: "reliance on technology [like the ASDinfoWales website] should suit autistic people", but that autistic adults have got to be "motivated to go rooting" around on the website. "Finding the motivation, something to draw people in, finding what interests them" was seen as important. This was supported by some interviewees who described how they like research and "deep dives"; as one put it: "information, that's for me", but only in the areas that interested them. Therefore, one concern of a professional interviewed for the study was that the resources on the

website could be “too focused on what everyone thinks you’ve got problems with.”

8.7. Given the need to engage people’s interest, the sometimes “disorganised” lives that autistic adults have, and the difficulties some have, as one interviewee put it, just signposting to the website “was a dead loss”. Similarly, as one adult put it “With my autism and related learning difficulties I would not have the motivation to use a website such as ASDInfoWales. This is something my parents would have to do”. However, as outlined in section 4, supporting people to use the resources on the website was seen as much more effective. Community support workers were seen as having a key role in, for example, helping get autistic adults “started” and using the resources.

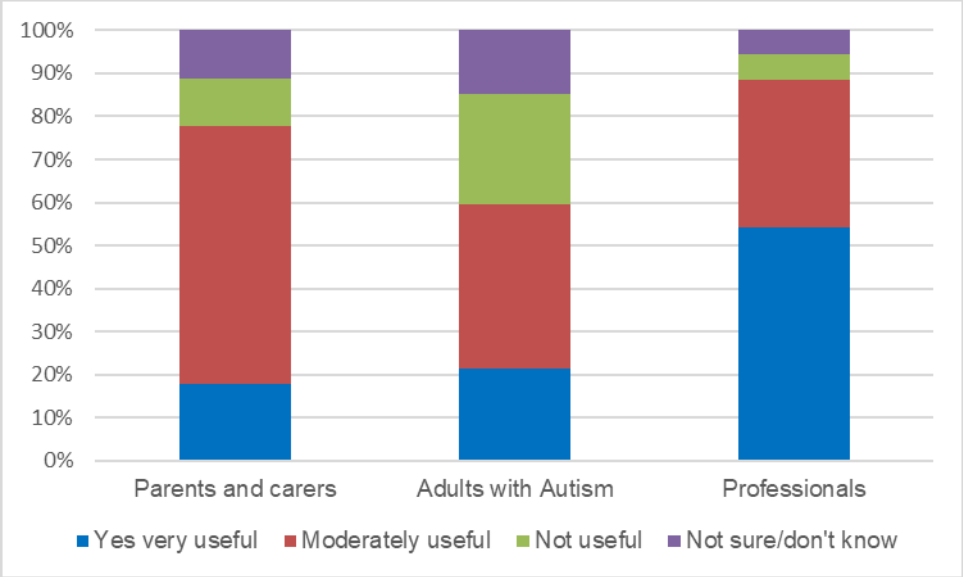
8.8. As graphs 16 and 17 illustrates, most of those surveyed and also most of those interviewed, who were aware of the web site, use it and find the information either very or moderately useful.

Graph 16. Parents' and carers', adults' with autism and professionals' responses to the question "do you use the ASD info Wales Website to find information?"



Source: People and Work parents and carers (n=90), autistic adults (n=47) and professionals (n=35).

Graph 17. Parents' and carers', adults' with autism and professionals' response to the question "do you find the information on ASDInfoWales website useful?"

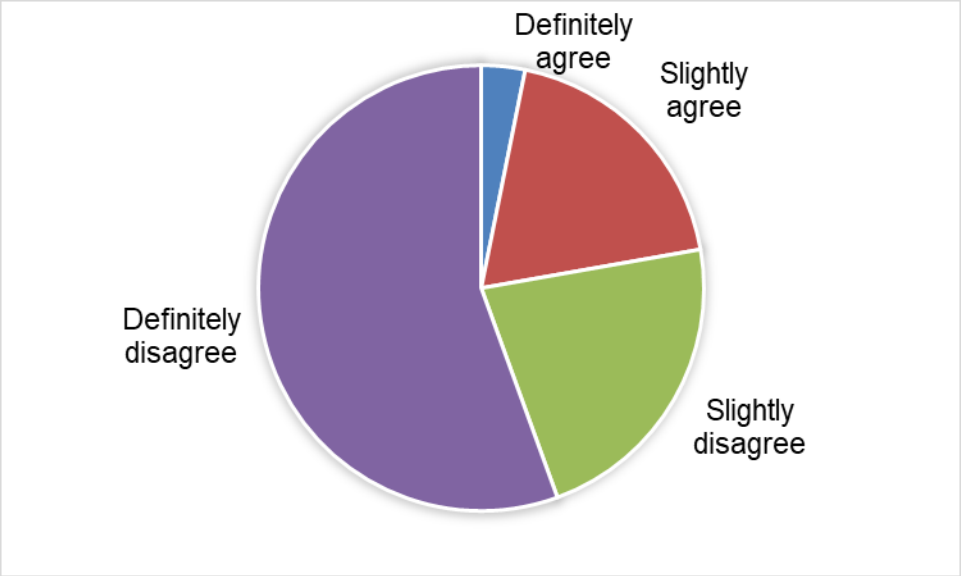


Source: People and Work parents and carers (n=90), autistic adults (n=47) and professionals (n=35).

Access to information, advice and training

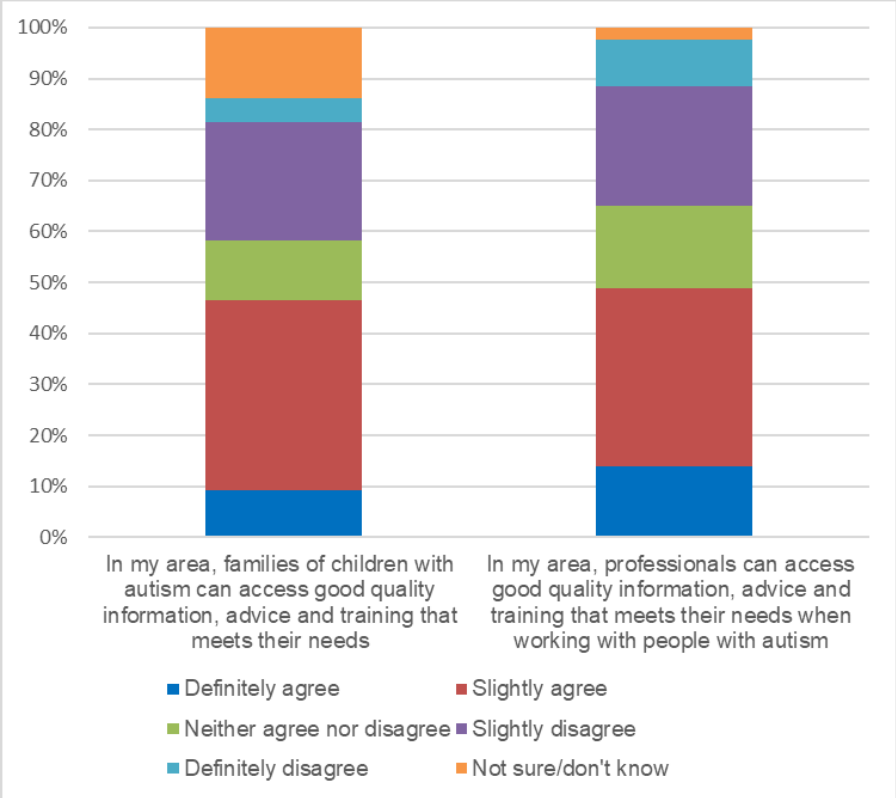
8.9. Overall the evidence indicates that whilst awareness is quite high, particularly amongst those adults and families accessing the IAS and also professionals, and the resources are clearly valued, particularly by professionals, the resources promoted by the National Autism Team are not of themselves sufficient to meet need; for example, as graph 18 illustrates, almost 80 per cent of adult respondents (n=49) felt they could not access good quality information, advice and training that met their needs. As Graph 19 illustrates, professionals were generally more positive about families' and their own access to information and advice, but still highlighted gaps for themselves and families.

Graph 18: Responses from autistic adults to the statement "I can access good quality information, advice and training that meets my needs."



Source: People and Work Adult with autism survey n=6

Graph 19. Professionals' responses to questions about their and families' access to good quality information and training



Source: People and Work survey of professionals n=43

8.10. While a valuable source of information, the website and resources are only part of the solution; for example, it was observed by one parent that: "the website is great, giving more information, but if you're in crisis, getting overwhelmed [that's not what you want – or need]". This reflected the desire for more face to face or telephone contact with support workers, as outlined in section 7. Similarly. as another family member put it:

looking after a disabled child doesn't leave much free time to filter through, digest, implement and assess the effectiveness of all the information available. It would help to have authoritative and practical guidance, more accessible to parents, to direct them to the relevant and reliable information on autism, related conditions (e.g. communication, behavioural, learning difficulties) and the strategies and resources available which are appropriate to the stage of development of the child and their environment. Unsure what format would be best for such a guide, but more frequent intervention and assessment by professionals who can visit to see the child in their home and school environments would be preferred to more online guidance or written materials.

8.11. Interviews and focus groups with family members and carers suggested a heavy reliance upon more informal sources of information and advice. When asked where they went to for information, family members and carers most commonly described asking other people they knew through the support group and/or via social media. One parent described how they were a member of ten social groups on Facebook and would post questions to people on these groups. It was also observed that when you are with your child you cannot easily get to a “drop in”, but that in the quiet two minutes when, for example, they’ve gone to bed, “you can pick up your phone at any time” or raise a question on an online social group. Smaller numbers described going to voluntary sector organisations like NAS Cymru or ASSC and/or their websites for information and advice.

8.12. Observation of parent and carers groups and online groups suggests that, while clearly valued, there are potential risks in family members’ and carers’ reliance upon them as sources of information and advice; for example, the sharing of negative experiences, which could be cathartic, could also influence the expectations of others, and fuel mistrust of services.

Learning with Autism

8.13. Earlier studies highlight the need to raise awareness of autism in schools (WG, 2015c) and, as section 7 outlines, interviews and responses to the questionnaires also highlight this. In response, Learning with Autism is a key part of the National Autism Team's strategy to ensure that all early years' settings and primary and secondary schools[76] become autism aware (WLGA, n.d.,b). Launched in March 2016, as table 6 illustrates, take up of Learning with Autism is increasing, but remains patchy across Wales.

Table 6. Take up of the Learning with Autism programme

	# Early years provision	# Primary schools	# Secondary schools
Blaenau Gwent	2	7	2
Bridgend	2	-	-
Caerphilly	-	18	2
Cardiff	2	1	-
Carmarthenshire	7	-	-
Ceredigion	1	7	2
Conwy	2	9	1
Denbighshire	1	5	-
Flintshire	-	9	-
Merthyr Tydfil	-	1	-
Monmouthshire	-	2	-
Neath Port Talbot	1	11	1
Newport	7	14	-
Pembrokeshire	2	6	-
Powys	5	5	-
Rhondda Cynon Taf	2	3	1
Swansea	2	3	-
Torfaen	-	4	-
Vale of Glamorgan	-	2	-
Wrexham	3	7	-
Total English medium	*31*	*92*	*6*
Total Welsh medium	*8*	*22*	*3*
Total settings	**39**	**114**	**9**

Sources: ASD info Wales January 2019.

[76] Equivalent package for further education and work-based learning.

8.14. There is only limited evidence of the impact of Learning with Autism at this stage. There has been some limited self-evaluation of the programme in a small number of settings and (positive) anecdotal evidence. When discussed by interviewees for this study, people were either positive about the study or frustrated that they had it not been rolled out in more schools in their area.

8.15. It is therefore likely that the programme is making a difference, but given the pace and spread of take up, the impact has been fragmented. Moreover, while there is a clear need for awareness raising with staff to provide "core skills", this needs to be complemented with steps to ensure that when they need it, staff have "advanced", and "specialist skills" in relation to autism. This goes beyond the ambition of the Learning with Autism programme and will require a different approach, based upon collaborative professional learning within settings and between settings and/or specialist SEN services. This will range from a discussion with a colleague about a particular pupil's needs, to more formalised models, such as professional learning communities and lead practitioner arrangements that may tackle whole school or systemic issues (ibid.). The case study below provides one example of this type of model.

SEN/ALN Team within Services for Schools, Ceredigion Local Authority

Using the Welsh Government's ALN Innovation funding, a team of specialist staff liaised with staff from other agencies and services in order to create and deliver a specific training package to create Autism Champions within all of Ceredigion's secondary schools and all the county's larger primary schools.

The role of the trained Autism Champions is to provide advice and

strategies for pupils with autism and their teachers within their schools. They are also expected to work with the SENCO/ALNCO on the Learning with Autism project and to achieve the National Autism Awareness certificate for their schools over the coming year.

The training course was delivered over five half days to nominated teaching assistants. Individual sessions were delivered by drawing upon the skills of staff in a range of specialist services: educational psychology, speech and language therapy, and occupational therapy, as well as advisory teachers and teachers from specialist resource centres (SRCs) within Ceredigion.

Adapted from the National Autism Team Case Studies Library

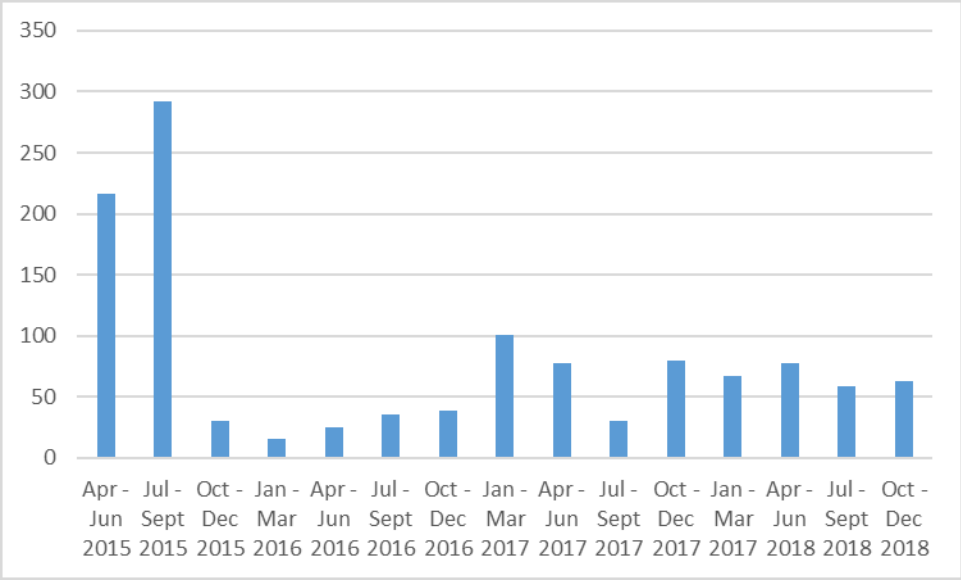
Training and resources for professionals and employers

8.16. The national team has developed a national training framework, which has informed the strategies IASs have taken (discussed in section 5), and is trying to shift from a reactive to a more strategic training model. Professionals interviewed for this study were generally very positive about the quality of resources and training framework. One described how they had used a film: "with gob smacking effect to train nurses", describing it as "very effective" in helping professionals to empathise and understand the needs of autistic people and to identify what practical steps they could take.

Training and resources for employers

8.17. Resources for employers, such as Positive about working with Autism and the Working with Autism programmes have been developed. As graph 20 illustrates, take up of the Working with Autism programme, launched in May 2015, has been relatively modest, and has plateaued after the launch.

Graph 20. Take up of the Working with Autism programme (number completed, 2015-2018)



Source: WLGA

8.18. It is not possible to evaluate the impact of the work, beyond observing that the limited take up suggests impact will be equally limited and fragmented. Some professionals interviewed for the study reported that awareness in other services was increasing, and that services were more willing to make reasonable adjustments. However, beyond individual case studies, such as the one below, it was difficult to attribute this to a particular programme.

Case study provided by Cardiff and Vale

Contact was made by the HR department of a national pub / restaurant chain. They had an autistic employee in the region who was on the brink of being dismissed from his role. They were seeking some specialist input and support for the manager in the premises, with a view to the employee keeping his job. Two short meetings took place, one with the manager only and the second with the manager and staff member. The employee had not completed a mandatory online training

module that was a requirement for continuing work. The meeting highlighted some areas of information around awareness that the manager and his staff needed to take on board. The ASDinfoWales site was recommended and accessed by the manager for further reading. The meeting further highlighted a difficulty in communication. The manager was being kind and alluding to the consequences of non-compliance. What was needed was speaking plainly and informing the employee that if he failed to complete the module he would be dismissed by Friday.

As a result, the employee understood the importance of completing the training, and feedback from the manager was: “thanks so much for coming, he finally gets it now and he’s really flying, and will get it all completed by Friday.” The employee did complete and he retained his job.

Adapted from the National Autism Team Case Studies Library

9. Conclusions and recommendations

The case for the national IAS

9.1. As the interim report (for this evaluation) outlines, given the weakness and inconsistencies in access to assessment and diagnosis for adults, and post-diagnostic support for adults and families across Wales, there was a strong case for action. (Holtom, and Lloyd-Jones, 2018). The need for action was unanimously supported by stakeholders interviewed for this study.

9.2. There was a strong case for creating an integrated service that brings together health and social care services. This was also almost unanimously supported by stakeholders interviewed for this study. Poorly co-ordinated care is associated with poorer outcomes, delays, multiple assessments and transfers, and lower levels of patient satisfaction (Parliamentary Review 2017; Williams, 2014). The decision to make the IAS an integrated service created additional challenges when establishing the new service. These challenges slowed progress, but they have now largely been overcome.

9.3. There was also a strong case for national leadership in establishing the IAS. Stakeholders interviewed for this study stressed their concerns about “post code lotteries”, where access to support differs depending on where you live, and supported the vision of a national service offering consistency across Wales. As outlined in section 3, earlier initiatives, such as the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults, led to important improvements which created islands of good practice, but failed to drive systemic change across Wales (Holtom & Lloyd-Jones, 2016). Given the evidence of ‘what works’ (NICE, 2012) there was a clear case for national action to drive up standards and ensure good practice

was adopted across Wales (Parliamentary Review 2017[77]; OECD, 2016; Williams, 2014)[78].

Progress establishing a new integrated service

9.4. Establishing a new service (like the IAS) is challenging. It requires new systems, approaches and recruitment, and it takes time, skill (including, in particular, effective leadership and communication) and resources.

9.5. The initial developmental phase, during which the IAS model was developed, was arguably too rushed. As outlined in the interim report (Holtom and Lloyd-Jones, 2018), announcements about the service were made, raising expectations, before all the details had been worked out. This meant that some families and some autistic adults projected their hopes upon the new service, and managing people's expectations continues to be a key challenge for the IAS. It also led to a misplaced perception amongst some services that the IAS would "take care" of autism in each region.

9.6. In addition, forecasting the demand for the IAS, whilst inherently challenging, was not well developed, and some stakeholders expressed concerns that the development process lacked transparency; and although informed by an extensive consultation exercise (WLGA, 2015), further opportunities for direct stakeholder engagement during the design phase were missed. As outlined in section 5, it was only once the national model had been agreed and

[77]The Parliamentary Review of Health and Social Care in Wales identified the need for: "stronger national direction and a better balance across the continuum of national direction and local autonomy in generating change" (ibid. 2017, p.7).

[78] For example, as the Williams review identified: "a co-ordinated and nationally-led programme of service change can lead to major improvements. … Where there is clear evidence that adopting good practice would demonstrably and consistently lead to better outcomes, it is incumbent on service providers to adopt that practice, and on the Welsh Government to ensure that they do so. Where reasons are there why a particular service-provider cannot adopt a specific good practice approach, that needs to be fully justified. That is particularly important in areas where there are wide disparities in performance now; and especially if that persists, the Welsh Government needs to consider compelling the adoption of good practice" (Williams, 2014).

services were already partly established that engagement was restarted, limiting the scope for co-production with autistic adults, families and services.

9.7. Conversely, the implementation phase, during which teams were established, took much longer than planned. The availability of funding enabled action, but the decision to adopt a standardised national model, while it has many strengths, meant ownership did not grow organically from RPBs. National leadership and communication was initially had some weaknesses, delaying progress and contributing to disagreements about the vision in Cardiff and Vale, Cwm Taf,Gwent and Western Bay. Moreover, in all areas, even once senior leadership "buy in" was secured, practical problems linked to establishing a new and integrated service, such as recruitment, finding suitable accommodation and difficulties integrating health and social care staff and systems, slowed progress and the original timelines were missed.

9.8. As a consequence, there has been confusion and sometimes frustration at what the IAS can and cannot offer, and with the delay in establishing the service. People's expectations of the IAS were often high, and cannot always be met because, for example, it is not resourced to provide long term, ongoing support, or to work directly with children. It is crucial that the IAS's role, and reasons for the delays in becoming fully operational, are communicated to, and understood by, professionals, autistic adults, their families and carers. Greater transparency and, as one stakeholder put it: "openness and honesty" about the difficulties inherent in establishing a new service will be important in managing expectations in the future. Sharing this report, and updates on progress in the future, are both likely to be important here.

Recommendation 1. The Welsh Government and the National Autism Team should review the communication strategy, to provide clarity about the IAS role and remit.

Recommendation 2. The Welsh Government and the National Autism Team should identify how more information about the progress in establishing the IAS, the challenges encountered, and its performance, can be appropriately shared with (i) stakeholders involved in the development and establishment of the IAS (e.g. through the National Advisory Implementation group and the community of practice) and (ii) autistic adults, children and young people and their families, and the general public, through, for example, ASDInfoWales and local ASD steering groups.

9.9. Despite these challenges, considerable progress has been made in establishing the National IAS. The first four services, Cardiff and Vale, Cwm Taf, Gwent and Powys, have consolidated their teams, established assessment and diagnosis and support services, and begun working with other services, although this remains a "work in progress", and Cwm Taf (which started later) is less established than the other three services. Each service is also working in person-centred ways, developing and adapting their services to meet the needs of individuals and groups. The established services face challenges, however, in managing demand for assessment and diagnosis. The North Wales service is now operational, although there were delays before it started offering assessment and diagnosis, and good foundations for the service in West Wales and Western Bay have been laid.

Recommendation 3. The Welsh Government, National Autism Team and RPB Autism Champions should continue to monitor the continuing development and performance of the first five IASs (Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales) and the establishment of the two remaining services (Western Bay and West Wales).

Recommendation 4. The Welsh Government, National Autism Team and RPBs should review the adequacy of overall funding for the IAS, given the demand for assessment and diagnosis, support and collaborative work with other services.

Progress in establishing a national service

9.10. A key challenge for programmes like the national IAS is how to ensure consistency and meet national standards without stifling local innovation, initiative and ownership Parliamentary Review, 2017). As the interim report outlines, in the initial phase, too much emphasis was placed upon standardisation, and this contributed to disagreements that delayed the establishment of the IAS in Cardiff and Vale, Cwm Taf and Gwent (Holtom and Lloyd-Jones, 2018). Since then, relationships between the IASs and the National Autism Team have improved markedly, enabling a much more collaborative approach to development and fostering greater innovation and ownership.

9.11. Despite the national model and standards, some contributors to this study and to the Health and Social Care Committee, in relation to the Autism (Wales) Bill stage one scrutiny (NAfW, 2018) voiced concerns about increasing inconsistences in the service and the support offered by the IAS. As section 4 outlines, the five operational services all work to the same national standards and offer broadly the same service. There are differences though, reflecting a number of factors including:

- differences in funding, with some services like Cardiff and Vale benefiting from additional funding from the LHB and LA, and some services like Western Bay complaining that the apportionment of funding across areas is inequitable and does not adequately reflect differing levels of demand;
- differences in the pace of development, with services like Powys, Cardiff and Vale and Gwent having the benefit of the longest time to establish their teams and relationships with other services;
- differences in service provision in each area, which means the partners IASs can work with differ, and which poses particular challenges in rural areas; and
- differences in people (including differences in the roles, skills and interests of different teams[79]), structure and ethos, with some, such as North Wales and to a lesser degree Gwent, adopting a more "social" model, compared to the more "medical" model of Cwm Taf and Cardiff and Vale.

9.12. These factors, coupled with differences in the individual needs of autistic adults, and family members and carers, means that the support that individual adults or family members or carers received, differed. Although the services will never be identical, it is important that, as far as possible, outcomes for autistic adults and their families, do not depend upon where they live.

Recommendation 5. The National Autism Team should ensure that monitoring consistency through compliance with the IAS's national standards, is complemented by a benchmarking of outcomes across IASs. This should be done intelligently and the reasons for differences in outcomes explored; for example, differences in resources and context are likely to impact upon outcomes. Improvements in the measurement and reporting of outcomes using Outcome Stars will be crucial to enable this.

[79] For example, only Cardiff and Vale and Cwm Taf have a dietician as part of their team.

Recommendation 6. The Welsh Government and National Autism Team should review the apportionment of funding to each IAS in the light of the evidence of the demand for each service.

The interface between the IAS and other services

9.13. In some ways, the IAS is a service, rather than person-centred, model. Although it seeks to work in person-centred ways with users, it has strict criteria about who can and cannot access the service and prescribed service standards about what it can and cannot do. This makes it an efficient model, filling gaps between services (minimising duplication). However, it means managing the interface between the IAS and other services and, in particular, mental health services and social services, will be critical as the service develops. It is notable that despite the Social Services and Well-being Act and the IAS's status as an integrated service, the interface with social care remains underdeveloped.

9.14. The interface between services is important to set boundaries and manage demand for the IAS and to ensure that autistic adults can access the other services and support they need (e.g. in relation to housing, social care, employment and benefits). IASs also have a potentially important role to play as facilitators or intermediaries, helping autistic people, who often have communication difficulties, navigate and access other services. Networking, training, advice, consultation and collaboration with other services, and work to signpost, support and sometime advocate on behalf of individuals trying to access services, are all important to manage the interface, but have been shown to be time consuming. Given the other competing demands upon IASs' time and attention in relation to assessment and diagnosis and support for adults and families, there are risks that engagement with other services becomes reactive (e.g. driven by problems) rather than strategic, or side lined, if services turned inwards.

Recommendation 7. Each IAS should periodically review its work with other services to ensure that a strategic approach is taken, and that engagement with different services is prioritised (e.g. which services are engaged with as a priority) and planned. Opportunities to involve autistic adults and also family members in this review should be taken.

Recommendation 8. The Welsh Government, National Autism Team and RPB Autism Champions should examine how the interface between the IAS and other services develops, including, in particular, its impact upon access to mental health services and social care and upon outcomes for autistic adults and parents and carers.

Assessment and diagnosis

9.15. The national consultation that informed the development of the IAS (WLGA, 2015) identified the need for improvements in assessment and diagnosis. The investment in the IAS and children's ND services have increased capacity and the quality of assessment and diagnosis. Although long waiting times have developed for both children and adults, there is now a service for them, and the level of demand is evidence of the previously unmet need.

9.16. Diagnosis remains important for children, adults, family members and carers, although the impact differs and is not always positive. For young people, adults and family members and carers it can provide understanding and insight, but for some a diagnosis challenges their sense of identity. For children and parents and carers, it is often the key to accessing additional and appropriate support from education and children's services; for example, generic parenting courses may not be appropriate for families when the problems are linked to autism, rather than parenting *per se*. For adults, a diagnosis enables them to access the IAS and, in some cases, additional employment support,

benefits and social care. However, the impact and value of diagnosis for children, adults and families, depends to a large degree upon the availability of support, not only from the IAS and children's ND services (discussed below), but also from, for example, education, health and social care services and the voluntary sector.

9.17. In some areas, like Cwm Taf and West Wales, concerns were raised about staff's confidence to undertake assessment and diagnosis and the robustness of adult assessment and diagnosis carried out in parts of adult MH services. The IAS in, for example, Cardiff and Vale is working to address this, but it may represent a wider workforce development issue that the IAS cannot address on its own.

Recommendation 9. As outlined in the draft Autism Code of Practice, "Local Health Boards must ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles". As part of this, LHBs should review assessment and diagnosis practice in adult mental health and learning disability services and, where needed, invest in workforce development to address confidence and skill gaps.

Access to support following a diagnosis

9.18. The national consultation (WLGA, 2015) identified the need to strengthen support:

- for adults and, in particular, support for emotional and behavioural issues, ASD specific issues, life skills and access to social and leisure activities; and
- for family members and carers; in particular, timely advice, social activities and training, information and help to manage problems and behaviours.

9.19. The IAS was designed to do this and the Cardiff and Vale, Cwm Taf, Gwent and Powys and North Wales IASs, have largely delivered this (support for adults, families and carers has improved markedly, although access to social and leisure activities was less developed), and it is expected that the Western Bay and West Wales services will do so soon. This markedly increases the value of diagnosis, and the IASs were concerned that pressure to prioritise assessment and diagnosis in order to reduce waiting lists, could compromise their post-diagnostic support offer.

9.20. The IAS was envisaged as offering: "emotional, behavioural, low level mental health and life skills support" (WLGA, n.d. b). However, as outlined in section 7, many of the adults accessing the IAS did so after a crisis, and they appeared to often have quite complex needs. The IAS was providing much needed support to this group, but this may have drawn resources away from more preventative work to help ensure that the needs of others with less complex difficulties do not escalate. To date, improving access to social and leisure activities has had a lower priority than other types of support. A further challenge here appears to be how to provide support over a life course, when people needed it, without taking on a caseload. Some interviewees reported that the IAS had helped them overcome their immediate challenges, but felt they might need additional support in the future, when, for example, they were ready to start work again.

Recommendation 10. IASs should continue to monitor the profile of autistic adults accessing the service in order to assess how well suited the IASs' support offer is to the needs of different groups, such as autistic adults, those with mental health difficulties and those with sensory needs. This should be informed by analysis of data on outcomes.

Recommendation 11. IASs should assess the capacity of the service to respond to changes in people's circumstances and needs; for example, this could include monitoring the numbers of autistic adults who receive a short term, outcome focused intervention, and who subsequently re-engage with the IAS at a later point, when their circumstances or needs change.

9.21. The evidence base in relation to interventions for autistic adults is still developing. Therefore, although the IASs' offer is clearly informed by the national consultation and NICE Guidelines, there is scope to develop and strengthen the evidential base about "what works". As outlined in section 3, the NICE guidelines identify that: "…. there is little evidence to guide the establishment and development of …a team" like the IAS (NICE, 2012, p.40). The investment in the IAS therefore provides a valuable opportunity to advance knowledge in this area. The IASs could also be used to help better understand the wider needs of autistic people, just as the data garnered by the community monitoring and support projects was used in the national consultation (WLGA, 2015) that informed the IAS.

Recommendation 12. The National Autism Team and IASs should continue to monitor and evaluate the extent to which the interventions and support they offer for adults and parents and carers meets their needs. Where gaps in support are identified, consideration should be given to whether IASs should develop their offer and/or work with others services to meet the need.

9.22. By working with other services and supporting and signposting people to them and, in a small number of cases, working jointly with them, the IASs have also helped ensure that people can access the other services they need and are entitled to. Overall, the impact has been greatest with MH services, and to date, quite limited with LD services, where there is seen to be less need, and social care, where a small group of adults have struggled to have their longer term need

assessed, identified and provided for. There is also a need to work with other services, such as leisure, employment and housing services. There are examples of work here, but the IASs have neither the capacity, nor always the expertise, to work with all statutory and voluntary sector services. Trying to engage with too wide a range of services may also dilute the support provided.

Recommendation 13. The National Autism Team should work with IASs, RPBs, voluntary sector and service users, to consider the scope and ambition of the IAS; for example, should the IAS (i) focus its work upon a small number of services such as mental health, learning disability and social care services, or (ii) should it seek to take on a more ambitious agenda, to also work systematically with other services such as leisure, employment and housing services? This should consider both which organisation/s are best placed to deliver this, and their capacity to do so.

The impact of the Integrated Autism Service

9.23. Although it is still too early to judge the impact of the IAS, as even the five operational services are still developing, data collection has been problematic (contributing to stakeholders' uncertainty about the impact of the IAS), and many impacts should be invisible to services users[80], the emerging evidence is encouraging. In particular, the IAS has:

- markedly increased the capacity of adult assessment and diagnosis services[81]. Although demand has outstripped capacity, in doing so it has shone a light upon the latent unmet demand for

[80] In many ways, the test of the IAS will be not only how many adults and families it helps directly, but also how much capacity it can help build in other services that also support autistic people/their families. As a consequence, people may never be in contact with the IAS, but still be (indirectly) supported by it.
[81] The Adult Network was funded to do 125 assessments a year across Wales, and in comparison, in 2018, just one IAS, Cardiff and Vale, had already accepted 91 adults for diagnostic assessment.

assessment and diagnosis for adults. In many areas, it has also improved the quality of assessment and diagnosis by ensuring they are NICE compliant and, for example, that multi-disciplinary assessments are undertaken.

- provided a vital service for adults without an LD or severe mental health difficulties, which was previously only partially available in some areas, such as Cardiff and Vale and Ceredigion, and not available in others.
- provided an important service for family members and carers, filling gaps in support for adults and their families or carers and helping compensate for the pressures upon children's ND services, which have very limited capacity to provide post-diagnostic support to parents and carers. This complements the more informal social support offered by online and face to face support groups.
- provided a focal point for consolidating and sharing autism expertise, which had previously been fragmented across services, and a resource for joint working, consultancy, advice and training to raise awareness and upskill other services; activity which had been piecemeal and limited before the IAS was established.

The wider experiences and expectations of children and autistic adults and family members and carers

9.24. As section 7 outlines, the experiences of autistic adults before they had had contact with the IAS was often poor, and sometimes extremely fraught. Levels of mental ill-health and unemployment are high. Levels of disability often increase as young people struggle to make the transition from school or college or university, to work (Holtom and Lloyd-Jones, 2016), or when adults can no longer cope with the demands of living and conforming to a 'neuro-typical' world, and have a breakdown. Many of the adults who contributed to this study were not diagnosed as children, and had not accessed a service until they hit a crisis and then, typically, came into contact with mental health services.

As one interviewee put it, those accessing services are probably just the: “tip of the iceberg” (given historically low rates of diagnosis), while others had found that a diagnosis in childhood had not unlocked the support they wanted, particularly after leaving education.

9.25. The experiences of many family members and carers who contributed to this study were similarly poor, and sometimes extremely distressing. Most reported a constant battle to access services and support for their children and themselves. Some had sacrificed their own aspirations in order to meet their children’s needs and were worried about what will happen as they grow older and can no longer provide this support. As the population ages, this challenge will increase and many parents were concerned that their adult child was not engaged in planning for the future.

9.26. It is difficult to assess how representative these experiences are. They came from a small group of people and there were also people with positive experiences, but there sometimes appeared to be reluctance to share these in group discussions, given the difficulties others in the groups had faced. There may also have been selection bias, with those with more polarised experiences (be they good or bad) becoming more motivated to share them with the evaluation, compared to those with less vivid experiences. Nevertheless, the difficulties reported are consistent with other research and, at the very minimum, point to the severe difficulties that some adults and some families and carers experience.

9.27. Given the difficulties they face, there is often a gulf between the expectations of family members and carers in particular, but also of some adults, and the services and support offered. The expectation gap is rooted in the severity of the impact of autism upon children, adults, their parents and carers and partners; as one interviewee put it: “life can be bloody hard”, and their sometimes unmet demands for support to help them cope and live with a degree of independence and

wellbeing. Part of the problem, as one interviewee from an IAS put it, was that for family members and carers: “everyday will be really hard; people want a cure and we can’t fix it”. There were also people whom IASs and others services struggled to support, as they could not agree with the service users how best to meet their needs. However, this was only part of the problem, and many adults and parents and carers were realistic about what they wanted and apparently reasonable in their requests, but frustrated by services failures to provide for them. These failures were caused by a range of challenges, including severe financial constraints and rising demand (Williams, 2014), inflexibility, and sometimes limited awareness and understanding of autism, which made it difficult for services to adapt to the needs of autistic people and respond to people’s expectations and needs.

9.28. The IAS was developed to address priorities identified by the national consultation (and confirmed by this evaluation), and it has dominated the autism agenda in Wales in the last 18 months and drawn in time, energy and resources, but the IAS is not a “silver bullet”, it cannot meet all needs, nor can it work directly or indirectly with all autistic people. There is a need for both specialist services like the IAS, and a transformation of more mainstream services (SCIE, 2017). To be effective, the IAS needs to be an integral part of a broader approach to supporting autistic people including, but not limited to, learning disability, mental health, employment, leisure, education and housing services. The IAS has a key role to play here, but cannot be expected to drive the transformation required on its own and national, regional and local actions in other areas identified as priorities in the refreshed ASD Strategic Action Plan, such as employment and access to social care, will be vital. The proposed Autism Code of Practice (WG, 2018a) should also have a key role to play here.

9.29. The Welsh Government has a clear role and responsibility in developing and delivering the national autism strategy in partnership with others. However, at a regional and local level, It is not clear where

the responsibility for taking on this wider agenda should lie; for example:

- the National Autism Team is quite well placed, given its joint sponsorship by the WLGA and PHW, but its capacity is limited (given the size of its team and resources). Its links to the wider sector have been limited, although they are strengthening, and it has been focused, in the last two years, primarily upon establishing the IAS and, to a lesser degree, awareness raising, information and training;
- in some respects, ASD leads' roles in many areas have been somewhat side-lined by the development of the IAS, and also their skills, knowledge, time and seniority (and consequently capacity to drive change) differs markedly; and
- autism does not sit neatly in any existing health, education or social care services and, although a feature of Population Needs Assessments (PNAs), it has struggled to gain ownership in PSBs or RPBs, as it cuts across service boundaries and responsibilities. This might suggest that autism policy's natural home ought to be a collaborative body, but autism remains a small part of either PSBs' or RPBs' agenda, compared to issues such as care for older people.

Recommendation 14. The Welsh Government and National Autism Team should work with other stakeholders to explore where responsibility for regional and local ASD policy development should lie.

9.30. The evidence gathered by the evaluation also indicates that action to address other priority areas in the refreshed ASD SAP, like access to education, employment and social care, which are often reliant upon programmes still under development (like the Employability and ALN Transformation programmes) is required.

Recommendation 15. As the IAS becomes firmly established, the Welsh Government, National Autism Team, RPBs, PSBs and Local ASD Leads should work with autistic adults and their families, and the voluntary sector, to identify the next priorities for action; for example, support in education, for transitions and employment appear to be key unmet needs, but is too early to judge if actions in the refreshed autism strategy are sufficient to address this.

Recommendation 16. The Welsh Government should ensure that the impact of the new Autism Code of Practice is evaluated and that, for example, the impact upon access to social care is considered. This should include assessing the extent to which Information, Advice and Assistance Services have the appropriate skills to assist autistic people; assessors have the knowledge, skills and understanding of autism necessary to identify care and support needs; and the extent to which eligible care and support needs are felt to be identified (in assessments) and provided for.

Recommendation 17. As far as possible, future evaluations of other key elements of the autism strategy, such as the Employability Programme and ALN Transformation Programme, should be required to identify and report on their impact upon autistic people.

The long-term sustainability of the Integrated Autism Service

9.31. Where established, the IAS is largely delivering what it was intended to do. Although it took time to get working, the experiences of people accessing the IAS generally improved as services developed. The prospects for the future are encouraging, provided services can cope with demand, retain staff, and secure funding for the service beyond 2021.

Recommendation 18. Local Health Boards and Local Authorities hosting IASs should monitor staffing and the impact of decisions about terms, conditions and pay upon services' budgets and their ability to recruit and retain staff.

Recommendation 19. IAS should work with the National Autism Team and RPBs to ensure the evidence needed to inform decisions about the long term funding is available.

Recommendation 20. The Welsh Government should make its expectations about long term funding of the IAS clear; for example, whether the expectation is that if the model is proved cost effective, it will continue to be funded through the ICF, or if, for example, LHBs and LAs will be expected to fund the service after March 2021.

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