



Tîm Awtistiaeth Cenedlaethol
National Autism Team

www.ASDinfoWales.co.uk

Annual Report 2018/19

"...Even though there are barriers it doesn't matter, if you have the confidence you can do anything."

"Being amongst so many autistic people was so lovely and freeing. This was a ground-breaking day of acceptance."

"We are not broken. We are not a collection of deficits. We are complex, beautiful, intricate beings with individual profiles of strengths and weaknesses, just like the rest of humanity."

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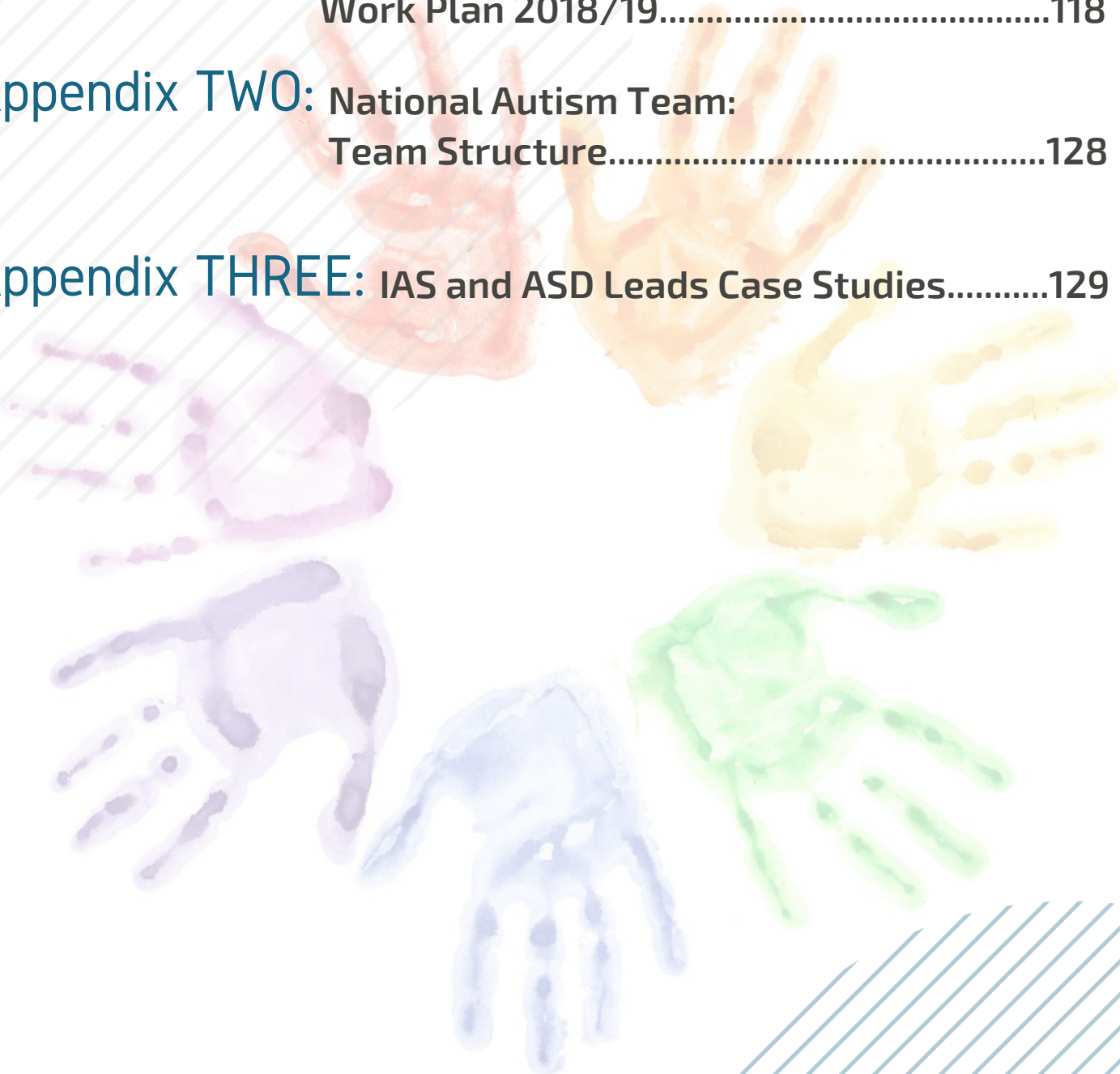
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Foreword

Our thanks to Welsh Government for the core funding to support the successful implementation of the National ASD Refreshed Strategic Action Plan and associated Delivery Plan, which includes the production of the Annual Report.

Our report provides an opportunity for the Team to reflect, with partners and stakeholders, on the work undertaken across Wales to improve the lives of autistic people.

I am particularly pleased to see the breadth of case studies included in the Annual Report, which provide some real and practical insight into the work of the ASD Leads across Local Authorities and the impact of Integrated Autism Services, as they become established.

I had the pleasure of being involved in the National Autism Wales Conference “Promoting Autistic Wellbeing” in Swansea, in April 2019 and it is good to read some of the positive outcomes and feedback from this co-produced event.

Cllr Huw David

*Spokesperson for Health and Social Care,
Welsh Local Government Association*

Foreword

The National Autism Team's Annual Report 2018/19 marks a considerable amount of partnership working across public services and a strong emphasis on engagement with autistic people and their parents/carers.

The team continues to work in partnership to produce high quality resources in digital and more traditional formats, as well as producing valuable training materials which are further highlighted. Use of the www.ASDinfoWales.co.uk web-site increased significantly in the past year and a steady growth in autism awareness is a further positive step towards increased understanding.

I am delighted to highlight the commitment made between the team's two host organisations – Public Health Wales and the Welsh Local Government Association in the form of a formal Memorandum of Understanding to underline our joint intention to work more effectively together for the benefit of autistic people and their parents/ carers.

Dr Tracey Cooper

Chief Executive, Public Health Wales

Introduction

The National ASD Development Team Annual Report 2018/19 provides Welsh Government (WG), as the Team's principal funder and the Welsh Local Government Association (WLGA) and Public Health Wales (PHW), as the Team's host organisations with a summary of the team's work but most importantly, reflects the considerable amount of activity undertaken in the past year, with key partners and stakeholders, including autistic adults, parents and carers of autistic children and young people and adults and professionals.

We joined the team in interim roles at the beginning of the financial year and were struck by the quality of the resources and by www.ASDinfoWales.co.uk in particular, but also by the commitment of the ASD Leads across Wales to improve the lives of autistic people and their families and carers through the provision of information, resources and training.

The Integrated Autism Services (IAS) were at a critical stage of implementation and development when we started as joint National Leads and we were encouraged by the high quality professional staff in health and social care being recruited to the IAS teams.

Introduction

We are both committed to engagement and participation and 2018/19 marked a subtle yet significant shift in emphasis to the Team's work, which we believe has resulted in even better resources, more ownership of the work undertaken and ultimately a better end result.

We have been committed to involving autistic adults in the production of resources, together with parents/carers and professionals, with a view to the "autistic voice" being heard and the experience of parents/carers being captured and acknowledged.

We have progressed key pieces of work that we had inherited from the Team's previous work plan with a refreshed emphasis on co-production. We are particularly proud of the "Parent-Carer Film" (Chapter 6) which includes several first-hand experiences and "stories" of people living in Wales.

Some of the autistic young people on the film found the experience of the filming an affirming and confidence building experience of itself. Many of the parents, family members and carers who were involved gave us feedback that they welcomed the opportunity to be heard and to share their experiences for the benefit of parents and carers of newly diagnosed children and adults.

Introduction

The Emergency Services training (Chapter 8) work has been progressed with professional advisors and staff working in the field to make it more robust and suitable for delivery which we will continue to pilot next year.

The refreshed Housing and Homelessness Guidance (Chapter 9) has been taken forward with a cross section of housing professionals, autistic advisors, parent/carer advisors and health and social services professionals. It takes considerably more time to work in this way but the feedback to date on the draft document is that it is more robust and more relevant than previous editions.

Working with Further Education colleges and Work Based Learning providers, together with autistic students, young people and professionals has provided worthwhile and valuable insight into the challenges faced at this significant transition in the lives of autistic young people and adults (Chapter 5).

We have encouraged the whole Team in the past year to re-engage and re-establish positive working relationships with key partners and stakeholders in the public, private and third sectors.

Introduction

Working more closely with National Autistic Society Cymru (NAS Cymru) around priority areas in the 2018/19 work plan including the housing guidance and the National Autism Conference has been a positive experience which we look to build on next year, as well as engagement at a local level with local NAS Cymru groups.

Further Third Sector engagement included support of the Autism Directory "Autism Shows" and linking in with the Autism Directory, as a "platinum member" of the Directory to ensure complementary links between their resources and those of ASDinfoWales. We also worked closely with key stakeholders such as the Autistic Women's Empowerment Project and Autistic UK in supporting key events which they led.

The WLGA and PHW reaffirmed their commitment to collaborative working and joint management of the National ASD Development Team through a Memorandum of Understanding, which is available to view on the ASDinfoWales website at www.asdinfowales.co.uk/national-autism-team. The Team also facilitated regular productive network meetings of the National ASD Leads and the IAS Leads through the year. The Adults Diagnostic and IAS Community of Practise (CoP) was given a new lease of life with an agreed work plan and several valuable CoP sessions to provide insight into good practice and learning from one another and other professionals across the UK (Chapter 1).

Introduction

We have also made efforts to engage with the Regional Partnership Boards which oversee Health and Social Care integrated working, and have a critical oversight role of the IAS's in their region.

Joint presentations with the relevant IAS lead provided the RPBs with a national strategic update, together with a progress report on the IAS activity. It was also an opportunity to consider the role of Regional Autism Champions being identified on the RPB (Chapter 1).

Collaborative working with Cardiff University's School of Psychology and the Wales Autism Research Centre (WARC) (Chapter 7) was further embedded by taking forward the SIGNS work and "The Birthday Party" film (www.ASDinfoWales.co.uk/autismchildsigns). We were delighted to support WARC in their work to engage with European partners in Latvia, Lithuania, Italy and Spain as evidenced on ASDinfoWales (www.ASDinfoWales.co.uk/european-versions).

At the time of writing the Annual Report we were also delighted to have won Cardiff University's 21st Innovation and Impact Award for health and partnership working with WARC. Winning the "People's Choice Award" was an absolute pleasure and a reflection of the importance of the work we are doing with our partners for the benefit of autistic people and their parents and carers, as well as professionals, for whom the film was originally intended.

Introduction

The National ASD Development Team has worked closely over the past year with the IAS that are established, and those working towards establishment and implementation. We were pleased that the Minister for Health and Social Care was able to confirm that all 7 IAS' were up and running by 1st April 2019.

It has been a challenging process to establish 7 new integrated teams of health and social care staff in each Regional Partnership Board/ Health Board footprint with all the practical considerations of recruitment, logistics and accommodation but they are now established.

We are pleased to be able to reference case studies as part of this report which provide clear and valuable evidence of the impact the IAS' are beginning of have across Wales for autistic adults, parents/carers of autistic people, as well as professionals. There remains a considerable amount of work to do but this year has been a genuine milestone.

Engagement and participation was made even more tangible with the production of a Strategy which went out for consultation with the community and will be taken further forward in 2019/20 (Chapter 1).

Introduction

The Team worked closely with professionals working in the field (local authorities, health) and autistic adults to provide robust and factual evidence to the Sports, Health and Social Care Committee's scrutiny of the proposed private member's Autism Bill. Subsequent to the Bill not being taken forward, the Team contributed to the progression of the Code of Practise for Autism Services and supported the WG led consultation exercises December 2018 – March 2019. We will continue to support the development of this important work in 2019/20.

We also engaged with as many ASD leads at a local level as we practically could in 2018/19. We met with colleagues in North Wales, Mid Wales and South Wales and encouraged those working "on the ground" to submit case studies to the Team to evidence the impact of the work being delivered at a local level.

Training was delivered (Chapter 4) across a variety of settings and our emphasis on evaluating the impact of the training is evidenced in the Annual Report. We continue to adapt the training and ensure it includes the voice of autistic people as well as professionals, as much as we are able.

We were particularly encouraged by the WLGA and Data Cymru reaching Autism Aware status as organisations in 2018/19 (Chapter 11) having made a commitment to do so at a strategic level. The feedback we had from the training was really positive.

Introduction

The National Autism Wales Conference 2019 – Promoting Autistic Wellbeing (Chapter 10) was a further illustration of co production, with the establishment of a Task and Finish Group that worked alongside us to produce an event for autistic adults which was described as “ground breaking” and one delegate noted, “[I learnt that there is a] wide range of experts and specialist services available to tap into for practical advice and guidance in day to day living.”

Genuine co production requires patience, resilience and commitment in facilitation but it is also hugely rewarding and the outcomes are so much better. We were delighted to have secured £14k in sponsorship in order to run the Conference free of charge for autistic people and their carers/ friends.

World Autism Awareness Week (Chapter 11) was something of a celebration for the National ASD Development Team, as it provided the conclusion and culmination of several key pieces of work which are referenced in the Annual Report.

We are pleased to share this report with you and we hope you will find it a useful and informative account of the work being undertaken by the Team, in partnership with our stakeholders.

Introduction

There remains a considerable amount to be done and the National Autism Team Work Plan 2019/20 will sit alongside this Annual Report as a commitment to make that further progress. 2018/19 has been a year of rewards and also of robust challenges.

Given the funding for the team has been confirmed by WG for a further three years, we look forward to working with you to continue to improve the lives of autistic people in Wales. To view a summary of the Annual Report against the Work Plan 2018/19 see Appendix ONE.

Sara Harvey

National Strategic Lead Autism

Wendy Thomas

National Professional Lead Autism



CHAPTER 1

National ASD
Development
Team and
ASDinfoWales



Tîm Awtistiaeth Cenedlaethol
National Autism Team

www.ASDinfoWales.co.uk

National ASD Development Team and ASDinfoWales

During 2018/19, the National ASD Development Team experienced significant changes at a leadership level and also within the team.

The National Professional and Strategic Leads commenced at the beginning of the financial year in interim roles seconded into the team to consolidate the Work Plan (<https://www.asdinfoWales.co.uk/resource/ASD-NatDevTeam-Work-plan-201819-04-final-v-02.pdf>) going forward and to review the team's activities and structure in the first 6 months, as well as to re-engage with key stakeholders.

The Leads worked with Academi Wales to facilitate Team development sessions and spent time with stakeholders to ensure a greater understanding of the work of the Team and also the work of partners and stakeholders.

It was a period of consolidation. WG, WLGA and PHW agreed to extend the interim period and the further 6 months allowed the Leads to further consolidate the work of the Team and to engage more proactively with autistic adults, parents/ carers of autistic people and professionals.

National ASD Development Team and ASDinfoWales

Emphasis was placed on co-production as a formally embedded approach to the work plan.

The leads endeavoured to meet with the ASD Leads across Wales “in situ” and to engage fully with the developing IAS teams. A “grand tour” of the 7 Regional Partnership Boards was undertaken in this period where the IAS’ and autism support and activity was further referenced and highlighted.

The high quality, freely available and professionally informed resources found on www.ASDinfoWales.co.uk are valued by many of our stakeholders.

The team produced a “resources leaflet” to summarise the web-site information and tools and also to provide a hard copy tool for ASD Leads and IAS teams to promote and engage with autistic people and parents/carers, where wi-fi may not be easily accessible.

National ASD Development Team and ASDinfoWales



ASDinfoWales Website

www.ASDinfoWales.co.uk is managed by the National ASD Development Team. The website is kept up to date and acts as a hub for all national autism developments.

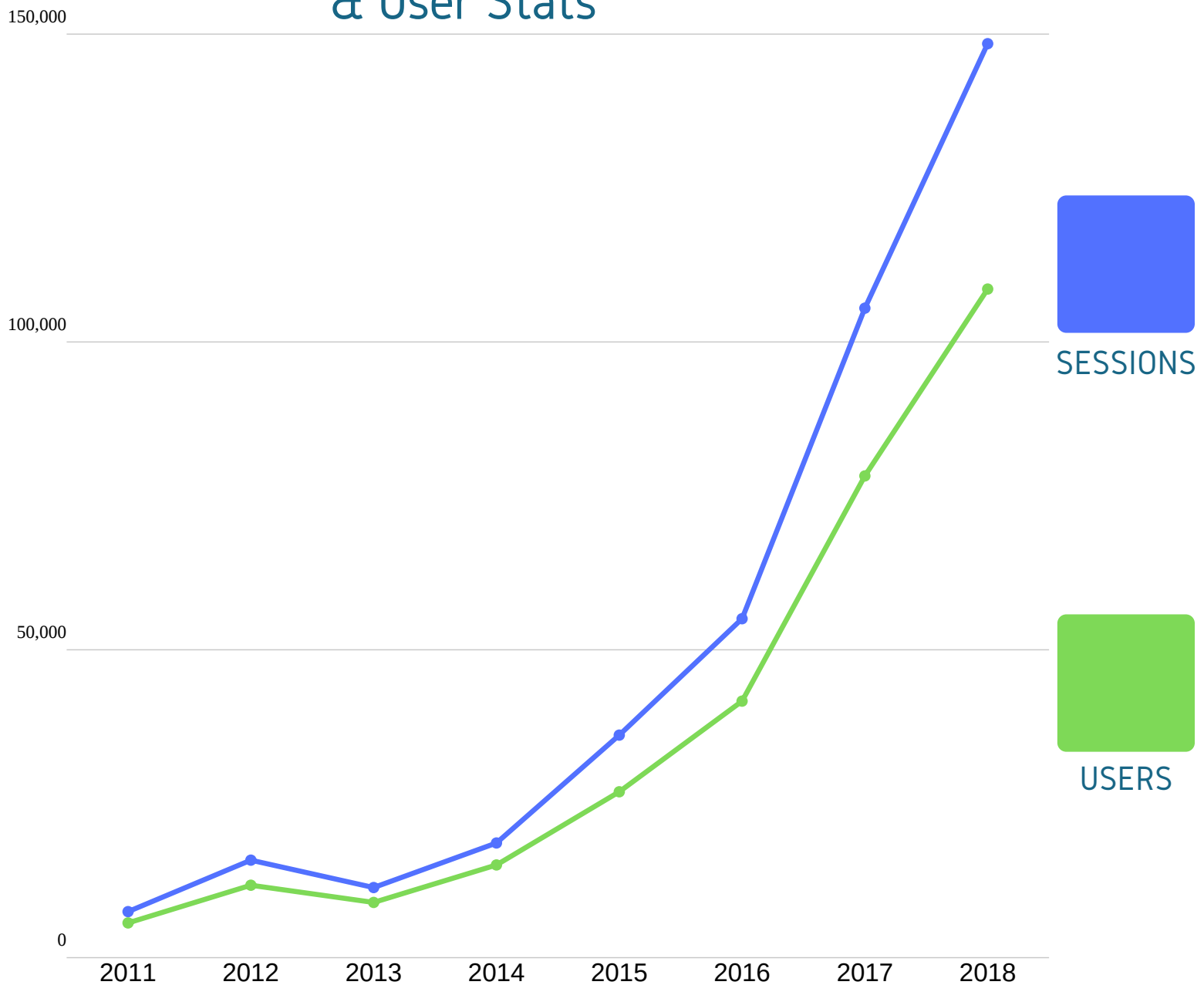
We have seen a **62% increase** in users of the website during 2018/19 compared to 2017/18. The number of page views in 2018/19 also increased to **649,301**. The website had an average number of **10,575 users per month**, which is over **3,500 more per month** compared to 2017/18.



Over 32,449 people have successfully undertaken our general ASD Aware scheme. Over 8,000 of these were during 2018/19.

National ASD Development Team and ASDinfoWales

ASDinfoWales Website Sessions & User Stats



62
PERCENT

INCREASE IN
USERS

649
THOUSAND

TOTAL PAGE
VIEWS

10
THOUSAND

USERS PER
MONTH

CHAPTER 2

Integrated Autism Service



Integrated Autism Service

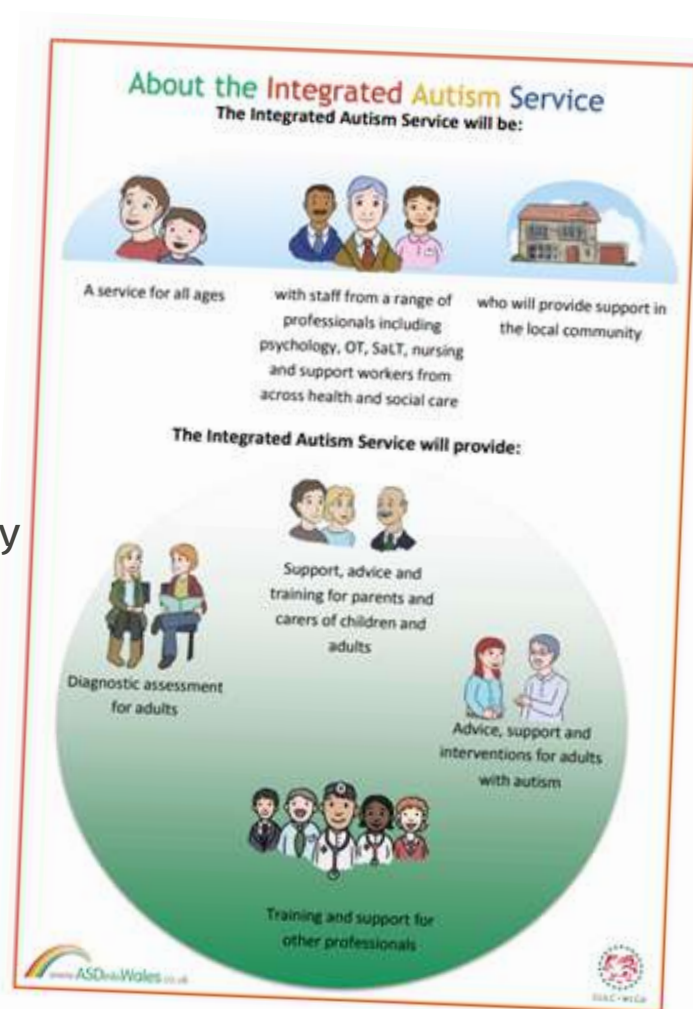
Background

The IAS was developed in response to a broad consultation across Wales in 2015 which highlighted a lack of support for autistic adults who were not eligible for statutory services.

In March 2017, the Minister for Health and Social Services announced an additional investment of £7 million to support the development of the Integrated Autism service for Wales. This takes the total funding for the service up to a total of £13 million.

The IAS was developed because autistic individuals, parents and carers told us they needed more support. They told us they can't access services because they don't meet the eligibility criteria. They told us they wanted support with:

- Behaviour issues
- Emotional issues, such as anxiety and anger
- Developing social and daily living skills
- Accessing leisure and recreational activities



Integrated Autism Service

We learned that autistic adults and children and their families' lives are severely affected because they can't access the correct support, that many can't leave the house on a daily basis and that parents and carers feel highly stressed.

We also heard that many adults who think they may have autism find it difficult to access a diagnostic assessment.

The service therefore provides: diagnostic assessment for autistic adults (sometimes jointly with other services); support, advice and guidance for autistic adults and parent-carers; training, consultation and advice to professionals.

Rollout

The rollout of the service has been done in two phases across the 7 Health Board areas in Wales, with the National ASD Development Team providing guidance and oversight to all IASs, as well as chairing the National IAS meetings which take place quarterly.

By April 2019, all 7 IASs are established across Wales, but some are still not fully staffed yet.

This year also saw Duncan Holtom from The People and Work Unit produce a report entitled "Evaluation of the IAS and Refreshed ASD SAP". The report's findings highlight that the IAS is largely delivering what was intended, however it has taken a significant amount of time to become fully operational – with some of the IASs still not fully staffed.

Integrated Autism Service

However, the experiences of people accessing the IAS has generally improved as services have developed. The evaluation reports that prospects for the future are encouraging, provided services can cope with demand, retain staff and secure funding for the service beyond 2021.

For further information on this report, please visit:

<https://gov.wales/evaluation-integrated-autism-service-and-autistic-spectrum-disorder-strategic-action-plan-final>.

Some quotes from the evaluation report:

“These teams are working in person-centred ways and developing their services to meet the needs of individuals and groups.”

“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 a previously unmet need.”

“Too early to judge the impact of the IAS. However, early evidence about the impact is encouraging and shows that it has markedly increased the capacity of adult assessment and diagnosis services.”

Integrated Autism Service

The total number of positive diagnoses via the IAS to date is more than 350.

Post-Diagnostic Programme

In 2019/20, all IASs will be rolling out a post diagnostic programme – a 6-week programme with a focus on many different areas, for example, relationships, health and wellbeing etc.

Outcome

In 2018/19, the National ASD Development Team worked closely with the IAS teams to gather case studies of examples of the impact of the IAS on autistic adults.

In 2019/20, the Integrated Autism Service Teams Team will implement an agreed outcome “star” measure tool which all of the IASs must follow to maintain continuity across the service.

For examples of case studies for each of the IASs and good practice across Wales, please see Appendix THREE. A further catalogue of case studies for all of the IASs is also available to view on the ASDinfoWales site.

Integrated Autism Service

Integrated Autism Service Training

In order to support the roll out of the seven IASs at a national level, a number of training courses have been arranged and/or delivered by the National ASD Development Team:

- In February 2019, a 2-day training course was delivered by the National Autism Leads to the North Wales IAS teams.
- During 2018/19, 14 staff from all 7 health boards benefitted from the DISCO Team's training. This Team derives from the NAS Lorna Wing Centre and stands for Diagnostic Interview for Social and Communication Disorders (DISCO). The service is used as both a clinical and a research instrument for use with children and adults of any age. This provides delegates with the skills to use this diagnostic tool within the IAS.
- Over 5 days in December 2018, and again in January 2019, the National Autism Team coordinated 2 combined Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview - Revised (ADiR) training courses. These sessions trained 24 staff members across 3 regional IASs. The training course was delivered by "BeginningwithA" and the course ensured staff were equipped to administer and code the ADOR and ADiR.



Integrated Autism Service

- During the latter part of 2018/19 a 2-day training programme on the Outcomes Star and Conversations for Change was commissioned and coordinated by the National ASD Development Team for all members of the IAS teams across Wales. The training and licences were provided by “Triangle Consulting Social Enterprise”, and the licences to access this online tool were created for 74 members of staff across Wales.
- In 2017/18 the National ASD Development Team commissioned specific Mental Health training for practitioners which continues to be rolled out across Wales. This training is being delivered by “Aspects - Adult Autism Psychology Ltd”, and they have held 32 1-day training sessions during 2018/19 and the roll out of the programme continues into 2019/20. The IAS teams will continue with this training and a “hand over” and Train the Trainer session has been arranged for June 2019.

CHAPTER 3 Training



Training

Introduction

Increasing the use of existing training materials and resources was a key priority for the National ASD Development Team in 2018/19, as a further means of consolidating the work of the Team.

In particular, supporting the increased use of ASD training and support materials developed by the National ASD Development Team in partnership with our stakeholders and supporting the roll out of the National Training Framework.

In 2018/19 the Team delivered the following training programs to various audiences across Wales and which will be detailed below, Autism Aware; Learning with Autism; Working with Autism and Housing Provider Training

Autism Aware Training

Welsh Local Government Association & Data Cymru

- Three sessions of autism aware training were held by the National ASD Development Team for 45 WLGA and Data Cymru staff, and we are pleased to report that both organisations achieved 'Autism Aware' status to coincide with World Autism Awareness Week April 2019.

Training

- Dr Chris Llewelyn, WLGA Chief Executive said:

“I am extremely pleased that WLGA has succeeded in fulfilling its commitment to become an Autism Aware organisation. The training provided by the National ASD Development Team to staff members was useful and practical in enhancing understanding of the condition, and to make us aware of the small steps we can all take to make our own day-to-day communication more accessible and inclusive. I would urge any organisation interested in becoming Autism Aware to get in touch with the National Autism Team.”

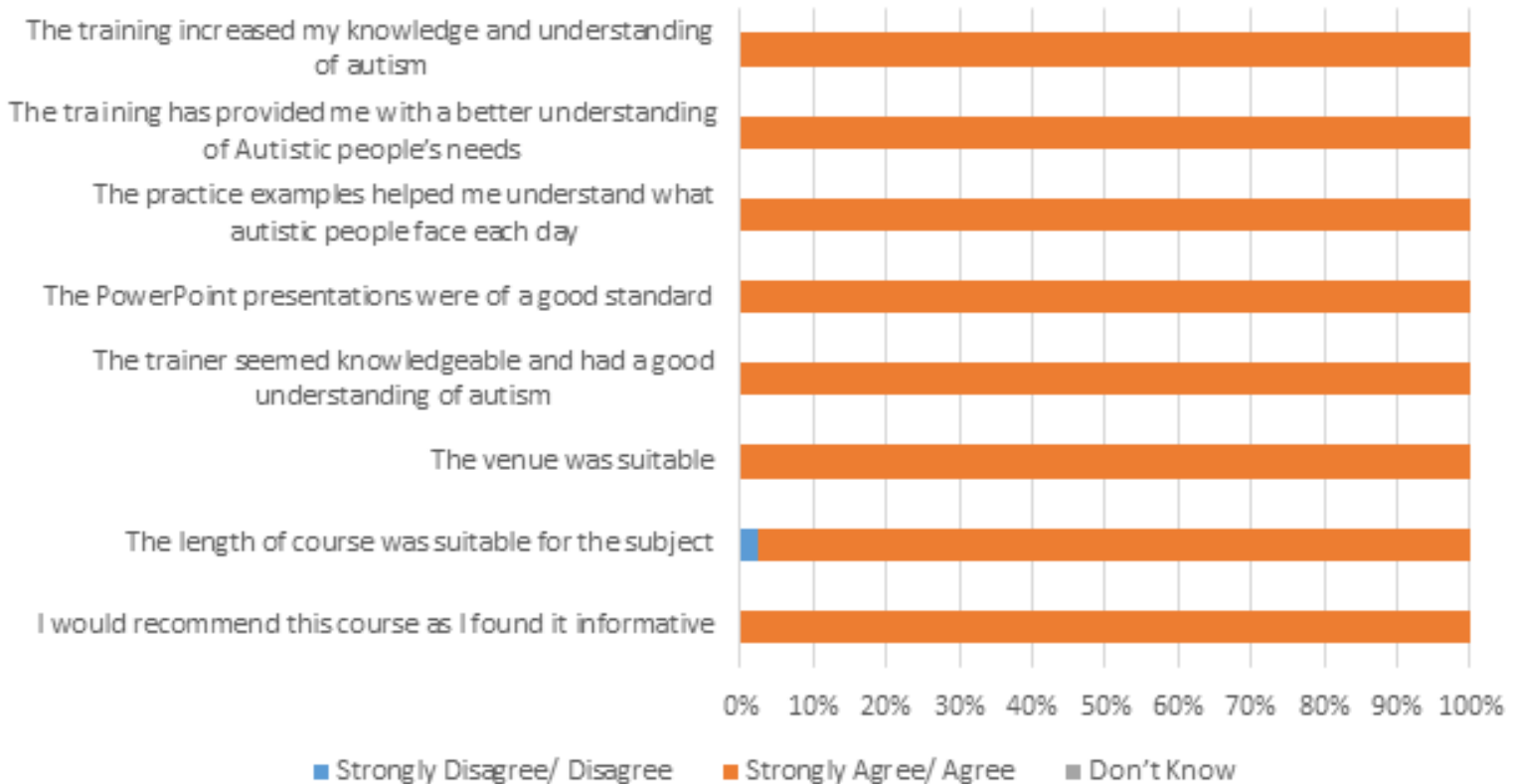
- Andrew Stephens, Executive Director of Data Cymru said:

“We decided to include autism awareness training as part of our staff development plan for 2018-19. Our staff found the training really useful, with much of it being directly applicable to our approach to dealing with our customers and colleagues. “We’re very pleased that we can now say that our staff are “Autism Aware”. The next step for us is to complete the HR scheme and become recognised as “Positive about working with autism.”

Training

The following responses were received from the evaluation sheets following the training:

WLGA and Data Cymru Autism Aware Evaluation Response



As can be seen from the graph, 100% of participants agreed, or strongly agreed that the training increased their knowledge and understanding of autism, 100% of participants agreed, or strongly agreed that the training provided them with a better understanding of autistic people's needs and a 100% agreed or strongly agreed that they would recommend the course as they found it informative.

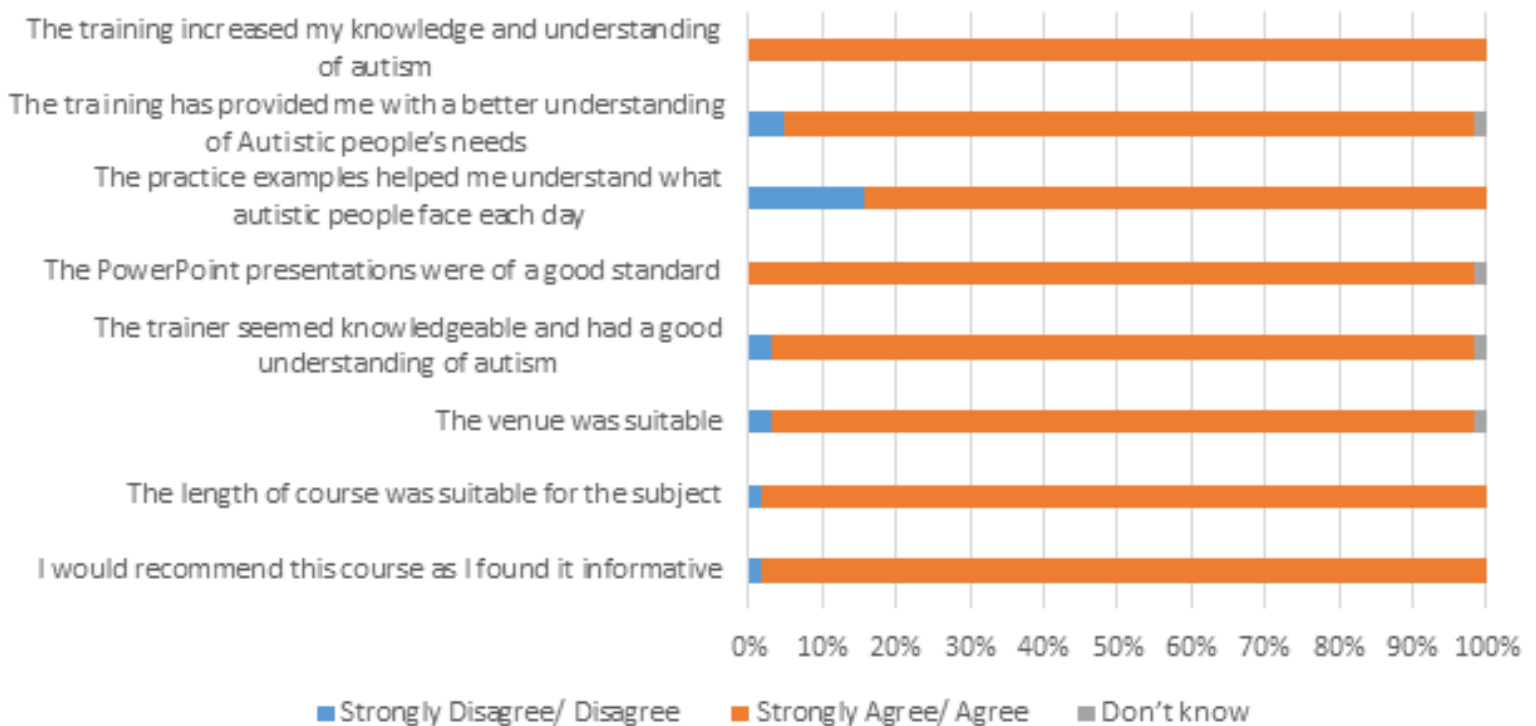
Training

Welsh Government

During 2018/19 the National ASD Development Team were pleased to provide autism awareness training for Welsh Government staff at 4 locations across Wales including Merthyr, Llandudno, Cardiff and Aberystwyth with 87 staff attending, as a pilot in conjunction with WG Organisational Development staff.

The following responses were received from the evaluation sheets following the training:

Welsh Government Autism Aware Evaluation Response



Training

As can be seen from the graph, 100% of participants agreed, or strongly agreed that the training increased their knowledge and understanding of autism, 94% of participants agreed, or strongly agreed that the training provided them with a better understanding of autistic people's needs and a 98% agreed or strongly agreed that they would recommend the course as they found it informative.

Quotes received following the sessions include:

"Will follow this up by looking at the resources on the ASDinfoWales website. Found this a very useful introduction."

"I enjoyed this session. As a family with a newly diagnosed young child these resources will be invaluable."

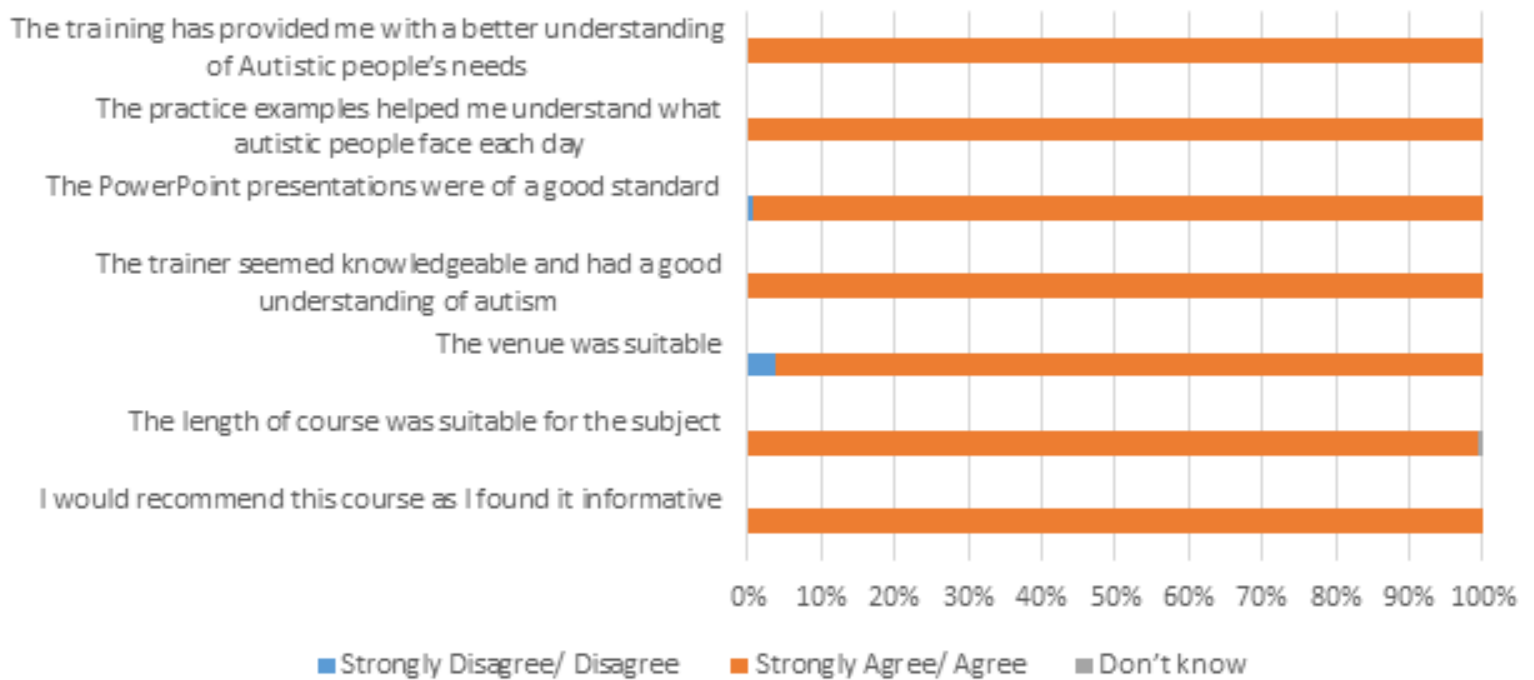
Third Sector and Other Organisations

Autism Aware Training sessions were also held with Third Sector and other organisations over the 2018/19 period including Community Voluntary Councils, Wild Elements, Shelter Cymru, Jobcentre Plus, Lifepoint Church,, the Coastguard and the Ospreys Community Foundation.

Training

166 individuals filled in evaluation sheets following the training, with the following data being reported.

Autism Aware Evaluation Response



As can be seen from the graph, 100% of participants agreed or strongly agreed that the training provided them with a better understanding of autistic people's needs and 100% agreed, or strongly agreed that they would recommend the course as they found it informative.

Training

Learning with Autism Training

Training in the Learning with Autism Programmes, Early Years, Primary and Secondary Schools, is provided in order for early years setting and schools to follow the learning with autism programmes and achieve the award.

The National ASD Team produced an Implementation Strategy for the LwA programme to increase the take up of this significant free resource across Wales. The strategy was supported by the National ASD Leads group and aims to take a two pronged approach to engagement with education professionals: “top down” through Directors and elected Members and “bottom up” through teaching staff, parents and school staff.



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www.ASDinfoWales.co.uk

Over the 2018/19 period 15 training sessions were held for the Early Years programme with 202 attending the sessions. 12 training sessions were held for the Primary Schools programme including 1 super schools. 2 training sessions were held for the Secondary Schools programme.

From the evaluation of the Early Years sessions 100% of attendees agreed or strongly agreed that the training provided them with a better understanding of autistic children's need's in early year's settings. In addition, 99% agreed or strongly agreed that the training films were useful and easy to understand.

Training

Quotes received following the sessions include:

"Excellent presentation, the programme will be well received by Flying Start Early Years Settings. I am looking forward to using the tools and resources within the settings and supporting them to adapt their practice where necessary.
Thank you."

"Great course, I will now feel much more confident when caring for a boy with autism in my care."

Very positive feedback was also received following the Learning with Autism Primary School setting training. These included:

"An excellent explanation of autism, and how to respond to children with the condition. Many useful strategies, thank you."

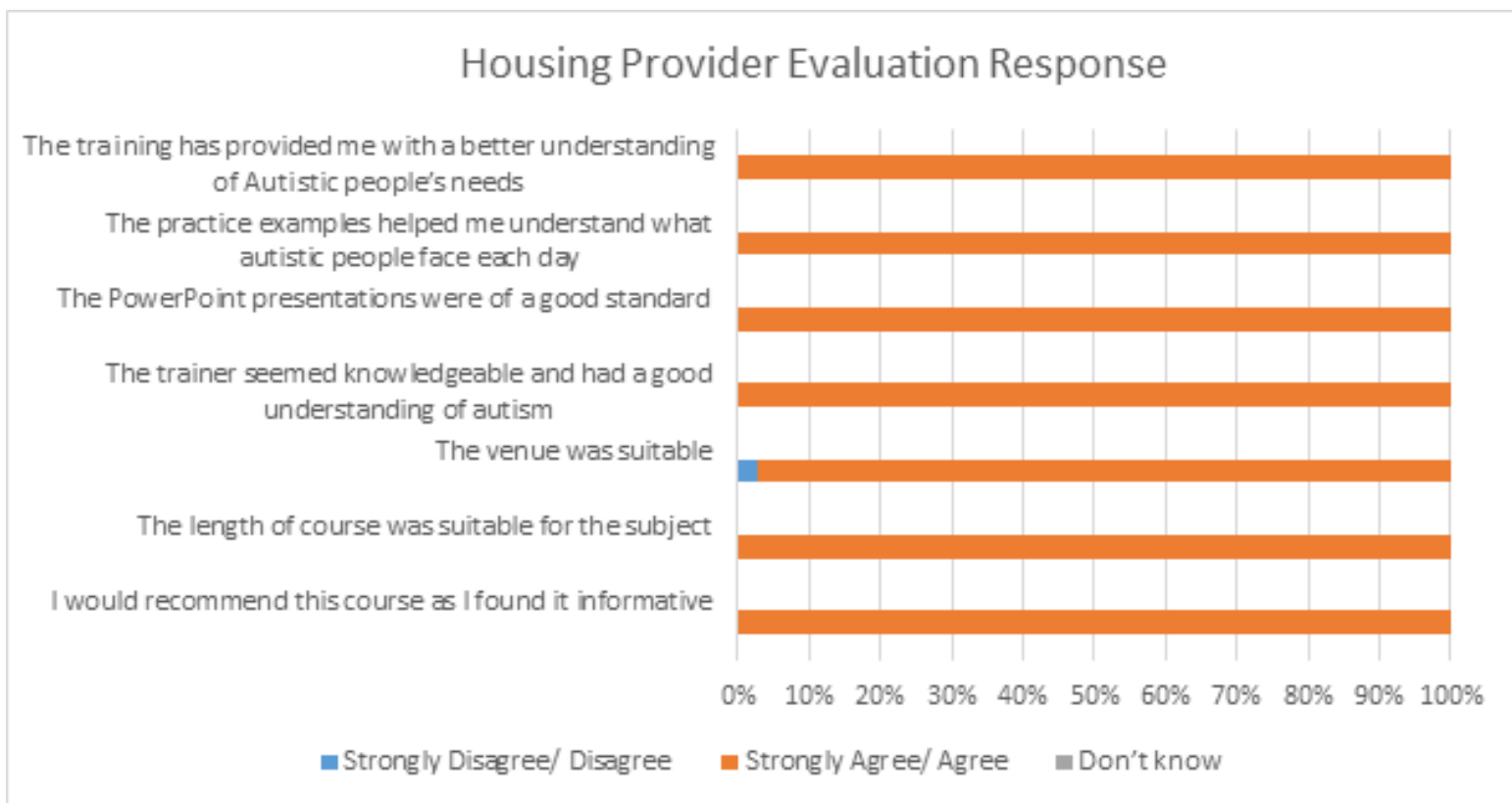
"Thank you very much, a very useful course. The website looks very helpful as well."

Training

Housing Provider Training

The National ASD Development Team have a Housing Provider Scheme which is aimed at helping housing provider staff increase their awareness and understanding of the needs of autistic individuals.

This training was provided over 5 sessions in 2018/19 with 70 staff attending, with the following data being reported through evaluation forms.



As can be seen from the graph 100% of participants agreed, or strongly agreed that the training provided them with a better understanding of autistic people's needs, a 100% agreed or strongly agreed that the practice examples helped them understand what autistic people face each day and a 100% agreed or strongly agreed that they would recommend the course as they found it informative.

Training

Quotes received following the sessions include:

"The activity was useful to understand more about autism."

"Very good awareness training."

Train the Trainer Sessions

The National ASD Development Team also provided "Train the Trainer" session with regards to the general autism awareness training in 2018/19 and delivered this to National Museum of Wales staff, the Ospreys Community Foundation staff team, as well as the Lifepoint Church in Swansea.

This is a strategy that the team is likely to employ more in the future in order to provide sustainable and resilient training across Wales. Ultimately, increasing the awareness and understanding of autism across Wales requires strong community engagement.

The National ASD Development Team responded to a request from a Christian Church in Swansea, whose priority has been on meeting the needs of children with learning disabilities and their families.

The team spent an afternoon delivering a full programme of training to the paid and unpaid staff in the church and received very positive feedback.

We will be looking to review this approach and rolling out with the support of the National ASD Leads in 2019/20.

Training

Quotes received following the Lifepoint Church sessions include:

“The training is extremely informative and gave me a great understanding of autism and how it affects individuals and how to identify signs and affects of autism. The trainers - Sara Harvey, Wendy Thomas, Fran Rees - are extremely knowledgeable of autism and deliver the training at a great pace and keep us engrossed in the presentation.”

“The stories, illustrations, definitely the film, and the power point were all very appropriate. The film made me think, "you've got it!". Very clearly communicated! And your ladies were warm, friendly and professional. Thank you for being so understanding. I'm truly grateful.”

“This training was vital, practical and precisely targeted to the needs of our organisation. The trainers were outstandingly informed, passionate about their subject, and really helpful in responding to our particular needs and questions. Our community will significantly benefit as a result of this training session.”

Training

Outcome

Case Studies from Swans Community Trust and the National Museum of Wales:

Swans Community Trust

The Swans Community Trust was a core sponsor of the National Autism Wales Conference. The Swans Community Trust is Swansea City AFC's registered charity, and is at the heart of the club and at the heart of the local community.

Through the Premier League & BT Disability Fund the Swans Community Trust provides a range of sessions to break down barriers to participation and encourage more disabled people to get involved, sessions include the Autism Spectrum Disorder (ASD) Football Club in conjunction with Cwm Wanderers.

Helen Elton, Head of Community at the Community Trust commented:

"Our mission is to use Swansea City AFC as a force for positive change within our communities, creating the conditions needed for communities to flourish. One of our five goals is to work for equality and inclusion, so it was very important to us to be part of the National Autism Conference - especially with its theme of Wellbeing which is an area in which we are confident we can add value."

Training

In addition to this, the Swans have developed a video which gives supporters with disabilities an idea of what to expect on a match day, which is particularly helpful to autistic supporters:

<https://www.swansea-city.com/news/swans-support-day-disabilities>.

They have also created a match day advice booklet for autistic supporters and their parents and guardians:

<https://www.swansea-city.com/sites/default/files/document/2018-07/Swans%20ASD%20Matchday%20Booklet%20Online.pdf>.

This is an example of the pro-active work the Swans and their registered charity, the Community Trust, have undertaken which is making a real difference to autistic supporters of the club.

Also, the Minister for Health and Social Services, Vaughan Gething, AM was pleased to announce at the National Autism Conference 2019 that the Swans had secured funding from the Premier League for a permanent sensory room at the Stadium, which will further increase the wellbeing of autistic football fans and their families across the region.

Training

National Museum of Wales

Outcome

DS was introduced to the National Museum of Wales (Cathays Park site) via his school. He was 15 years old and was being educated in a special needs unit in a local comprehensive school.

First Meeting

On meeting DS, along with his teacher, it was agreed that the placement would be for a six-week period for one day a week in a “shadowing role” so that DS could gain experience of visitor care, health and safety and security.

It was decided that his placement would be on a Friday from 9:30am until 5pm. At this point in his life, DS was unable to travel alone and was not left on his own at home – his mother couldn't work due to her being his full-time carer.

First Day

On DS's first day I gave him a basic fire evacuation briefing and explained what his duties entailed. I placed him with an experienced member of staff and I observed DS from a distance to ascertain if the role was suitable for him.

I quickly could see that DS was becoming uncomfortable as he started to rapidly pace the gallery whilst continually flicking his fingers, wringing his hands, and talking to himself. After taking him off the gallery and asking for his feelings on the placement, DS explained to me that the day was too long, and he needed time to get used to his first position of “Shadowing”.

Training

My solution was to reduce his day from 6.5 hours to 3 hours, and that I would meet with DS every day for 30 minutes before he started work.

In this 30 minute period, DS and I would talk about a variety of topics, as I quickly discovered that DS is stimulated by constantly researching a wide range of topics and he needed somebody to tell what he had discovered through his research.

Development

DS slowly progressed over the six weeks and although he still paced and occasionally flicked his fingers and talked to himself it did appear he was calmer in himself. As his placement drew to its planned end DS became quite upset as he didn't want it to end.

I contacted his school and his mother and offered to keep DS on the placement indefinitely, and the offer was accepted by all. DS has developed exceptionally over the seven years he has been with us – he now interacts with our staff and visitors really well and is extremely communicative, he no longer talks to himself, flicks his fingers or paces. DS took up karate and has progressed from Welsh to British and European and is now World Champion in his category, and if accepted into the next Olympics, DS will represent his country in the Paralympic.

DS's mother now has employment as DS can be left on his own, travel on his own, and attends college – all the things DS's mother thought wouldn't be possible and attributes it all to his placement in the museum and his role of being directly in contact with our staff and visitors and feeling a part of something.

Training

Today

DS is now nearly 23 and has developed to the point where I have had him trained as a “hands on” facilitator in special science exhibitions.

His flair for research has meant he excels at this and has no problem communicating with our visitors, and as special exhibitions opens, DS will continue as a facilitator.

I still spend time with DS and he helps me with any I.C.T problems – he is highly computer literate! DS has also had a beneficial effect on my staff – it has acted as a learning experience for them by breaking down barriers and challenging stereotypes often linked to Autism.

DS's inclusion has been the upmost for me to arrange autism awareness training and further autism champion training.

This training has been open to all staff and has been well received throughout all 7 of Amgueddfa Cymru sites.

CHAPTER

4

Learning with Autism



www.ASDinfoWales.co.uk

www.ASDinfoWales.co.uk

Learning With Autism

Building on the success of the Primary Schools Learning with Autism programme launched in March 2016, the Secondary Schools programme launched at the beginning of September 2017 and the Early Years programme was launched at the end of September 2017.

The National ASD Development Team developed many resources to support these training programmes, which highlights some of the challenges faced by autistic children during a normal school day.

Each programme adopts a whole school approach and the training is designed to stimulate discussions and increase understanding with all staff and pupils across the school/setting.



Learning With Autism

Below is an example of the three different learning schemes for the children/pupils that constitute the programmes:



The Early Years scheme consists of Teifi and Friends – an animated film showing how children in early years settings can be kind and accepting towards peers with additional needs.

For the Primary Schools programme, the pupils have the opportunity to become “Autism Superheroes”. There are two versions, one that is suitable for foundation phase and the other for KS2 pupils, both of which are available online and as a printed book.



The pupils are shown positive role models for children providing autism awareness. Each pupil can then take a pledge online to achieve their certificate to become an Autism Superhero.



The Secondary Schools scheme encourages pupils to watch the Sgilti film which shows some of the challenges faced by young autistic people during a normal school day.

The pupils complete a pledge online and achieve a certificate for becoming autism aware.

Learning With Autism

Each programme has a different **online certificated scheme** for the various staff and pupils within the school, which includes: teaching staff; learning support staff; pupils; and other staff (such as administrators, school governors, maintenance, domestic and catering staff, et cetera).

Every 3 years the school will be invited to re-apply ensuring there is a rolling programme for pupils within the school and new members of staff are able to undertake the scheme as part of their induction in order to keep their setting/school Autism Awareness certificate valid. All resources are freely available on the website and hard copies are also sent to those schools who have undertaken the programme(s).

The National ASD Development Team provides the administrative support to validate certification of the scheme across each of the three LwA programmes.

Learning With Autism

Early Years



www.ASDinfoWales.co.uk

Since its launch at the end of September 2017, 1141 staff have undertaken the training programme and 45 Early Year Settings have received their LwA award, 39 of these were during 2018/19.

In the last year, feedback following the evaluation forms from these settings have shown that 100% agree that 'the LWA programme increased their understanding of autism' and 100% agreed when answering 'Do you feel the programme has had a positive impact on children?'

Furthermore, 95% agreed that 'the learning with autism programme led to changes in the way [they] help children play and learn.'

Learning With Autism

Primary Schools



www.ASDinfoWales.co.uk

This programme was launched in March 2016, and during 2018/19 a further 47 schools achieved their LwA award, contributing to a total of 127 schools across Wales, and the following have been undertaken this year:

- 2206 Teaching staff (5192 in total)
- 1735 Learning support Staff (5219 in total)
- 10,534 Autism Superheroes (28,650 in total)

The feedback from the evaluation forms from these schools have shown: 96% agreed when asked 'Has the programme increased your ability to recognise any particular signs of autism that you might have missed before?'; 87% agreed to the question 'Has the Learning with Autism programme led to changes being made to a child's IEP?'; and 100% agreed that they '[Would] recommend the Learning with Autism Programme to other schools.'

Learning With Autism

Secondary Schools



www.ASDinfoWales.co.uk

Since its launch at the beginning of September 2017, 2814 staff have undertaken the training programme, and 12,390 pupils have received the Sgilti lesson and taken their pledge. A further 6 schools across Wales have received their LwA award this past year, which takes it to 9 in total.

The feedback from the evaluation forms from these settings have shown 100% agree that 'the LWA programme increased [their] understanding of autism', and 100% also agreed to the question 'Has the programme increased your ability to recognise any particular signs of autism that you might have missed before?'

Moreover, *all schools* have stated that they would recommend the programme to other schools.

Learning With Autism

The usage of other resources developed to support the Learning with Autism programmes continues to increase:

Children's picture cards – a simple, interactive resource, where a parent/ carer can search, select, download and print from a series of bilingual picture cards to create a structure chart for an autistic child, providing a daily structure or support for specific activities, such as toilet training.

Child personal profile – an online resource tool, where a parent/ carer, school staff or other professional can build a personal profile to highlight an autistic child's strengths and difficulties and let those around them understand how to support them in an easily accessible way.

This is especially useful if the child has a new teacher or joins a new club, as it ensures that there is consistency and continuity of care for an autistic child. Once completed, this resource can be downloaded from the ASDinfoWales website into Microsoft Word, so that the individual can alter, edit and personalise the document before printing and distributing.

Teen profile – this resource works in the same way as the child personal profile. The main difference is that it offers further, more relevant information for the pupil to add to their profile and distribute accordingly.

Learning With Autism

Learning with Autism Implementation Strategy

Given the quality of the LwA resources and the mixed picture of take up of the programme across Wales in 2017/18, combined with the strategic policy context of the Additional Learning Needs and Education Tribunal (Wales) Act, the National ASD Development Team produced an Implementation Strategy to support the roll out of the LwA programme.

This recognises the importance of engaging with the Local Authorities and in particular, the Association of Directors of Education in Wales (ADEW) to promote the scheme and its value and impact. Presentations have been given to the ADEW Joint Heads of Additional Learning Needs/ Improvement Group, to Additional Learning Needs Coordinators Groups and Educational Psychologists.

The following training has been delivered by the National ASD Development Team to support the implementation and use of the Learning with Autism resources, as well as presentations to Association of Directors of Education in Wales Heads of Inclusion group, ALNco's and educational psychologists:

- Learning with Autism:
 - **Early Years:** In total, 14 training sessions across Early Years settings across Wales.
 - **Primary Schools:** 12 training sessions, including 1 super schools across Wales.
 - **Secondary Schools:** 2 training sessions have been undertaken this year.

CHAPTER 5

Further Education & Work-Based Learning



Further Education & Work-Based Learning

Background

The Further Education (FE) and Work Based (WB) Learning schemes were funded by the Welsh Government's Education Department to increase the scope of the National ASD Development Team's Learning with Autism (LwA) resources, and also to tie in with the Additional Learning Needs and Education Tribunal (Wales) Act 2018, which states that people working within education need to increase their knowledge and experience around additional learning needs (which includes autism).

Unlike the other LwA schemes, in the FE and WB Learning schemes, the certification will rest with the providers.

The National ASD Development Team will implement the scheme by using a Train the Trainer model, and then it is for the colleges and the work based learning providers to work out how they will roll out the scheme themselves

Both schemes focus on 3 aspects:

1. Before the autistic learner goes to college/ work placement
2. Whilst they are in college/ on a work placement
3. What happens after leaving college/ work placement/ where to go afterwards

Further Education & Work-Based Learning

Description

Further Education

- The resources for the FE scheme have been co-produced with: ColegauCymru, FE colleges, autistic learners, and parents/carers across Wales.
- A generic “What is Autism?” film is shown at the beginning of the training.
- Following this, there is an FE-specific film which is shown. This mirrors the advice sheets provided, which follow the journey for the college staff and the learner and their parent/carer.
- Advice sheets are provided for staff and for the autistic learners themselves. These offer practical suggestions on how to adapt the working environment, equip students with the tools they need to effectively engage and achieve in FE. These are presented in a folder so that any updated future information can be added with ease. There is a file available for staff, and another separate file for the autistic learner.
- The resources follow the journey for a learner/student on how, where, and what they choose to study; what is put in place for them to be there; their time at college/ on placement; where and how they’re helped to move onto the next step of training or employment.
- The aim is to rollout the FE scheme within the next academic year – starting in September 2019 in partnership with the colleges/ WBL providers and ASD Leads across Wales, as well engaging with the IAS Development Workers

Further Education & Work-Based Learning

Work-Based Learning

- This scheme is for employers/trainers and autistic learners/apprentices who engage within a professional, workplace environment.
- The National ASD Development Team worked with the National Training Federation for Wales, Keith Ingram (Cardiff & Vale ASD Lead), and ACT (Associated Community Training Limited) to produce this resource.
- Similar to the FE Scheme, there are resources available for the training provider who works directly with the autistic young person, and resources for the autistic young person themselves.



- The film again follows the journey of the trainee/apprentice through the work based learning process: from how to pick the most appropriate placement/apprenticeship; through to how to manage the workload/how assessments will work, and so on.

Further Education & Work-Based Learning

- There are also “Advice Sheets” in this scheme which are provided in folders to the employers/trainers/staff and a separate folder for the autistic individual/apprentice to support them in their placement/ studies.
- The aim is to launch the Work Based Learning scheme simultaneously with the FE scheme in September 2019.

Outcome

A high level rollout and embedding of the Further Education and Work Based Learning schemes will take place in 2019/20, with the view that the way in which the Team facilitate the implementation of the schemes is just as important as creating the resources.

There are case studies to both schemes which can be found in the films themselves. These will be available to view on the ASDinfoWales site in 2019/20. Below are some of the case studies from the films, with thanks to ACT for the case study examples:

Little Tigers Day Care

We are very proud as a nursery to announce that our apprentice Ellie Curtis aged 18 years was announced as ‘Apprentice of the Year’ 2017 by Monmouthshire business awards at a lavish awards ceremony at the Celtic Manor on Friday 6th October.



Further Education & Work-Based Learning

Ellie was chosen out of over 200 candidates over the whole of Monmouthshire.

Ellie joined us in September 2015 as a young 17 year old apprentice who was about to step into the scary (but enjoyable) world of working with young children.

Ellie fresh out of college came with her own personal issues that she was clearly striving to work against and manage, for Ellie has Autism, Dyslexia and Irlen Syndrome.

Does she let his stop her... NO she doesn't. As her manager I have never met such a determined and focused young lady who is set to prove everyone wrong (especially her previous schools), that she CAN achieve and gain a career that she has always wanted.

Ellie did her training via ACT in Cardiff as well as working closely with her supportive colleagues.

Ellie has completed numerous courses such as Speech and Language, Foundation phase training, First Aid, Food Hygiene, Additional needs training and working alongside children with ASD.

Due to her own personal knowledge and that gained on training it became clear who our Additional needs co-ordinator should be... Ellie.

She took over as our designated ALNco in September 2016 and she has been able to work wonderfully alongside children and their families to ensure focused care and education is received as well as specific support.

Further Education & Work-Based Learning

She attends all meetings with other professionals and directs the way forward for children who need that little bit more support.

We are all exceptionally proud of Ellie and all she is achieving. She has always said that she “wants to help and support children like her” – well she is certainly putting that into practice.

Since Ellie won the award in 2017 she has completed her Level 3 playwork qualification and has now enrolled onto level 5 management.

Darren James Success Story

A self-confessed 'petrol head', eighteen year old Darren James from Pontyclun is well on his way to achieving his dreams of becoming a heavy vehicle diesel fitter.

After completing a Traineeship programme with Wales' leading training provider, ACT, Darren is now thriving as an Apprentice with one of Wales' Premier tour operators, Edward Coaches.



Darren loves working with vehicles, but having been home-schooled throughout childhood he was unsure of what opportunities were available to him.

Further Education & Work-Based Learning

“I was home schooled with my brother, until I was 15 and a family friend suggested ACT as a way for us to get into college. We looked in to it for my brother first and then when we saw he was doing well, I followed him a year later.”

After researching the many different routes available, Darren joined ACT's Traineeship programme, a Pre-Apprenticeship training programme that prepares 16-18 year olds for the world of work. With a keen interest in motor vehicles, he chose to enrol onto a Level 1 Traineeship in Vehicle Maintenance Repair, working hard to overcome the many barriers to learning he faced.

Darren's commitment and drive did not go unnoticed by his tutors, and in 2017 he was nominated for the 'Traineeship of the Year' award at ACT's internal awards in the Motor Vehicle category.

Commenting on the accolade, Darren said:

“I was shocked and very surprised to win the award as I was not expecting to be put forward for it but I am so grateful to the tutors for nominating me.”

Ros Smith, Care, Support and Guidance Co-ordinator at ACT, who nominated Darren for the award and played a key role in his learner journey said:

“Since joining ACT, Darren's really come out of his shell and he's worked hard to build his employability skills. What an achievement for a learner who lacked confidence.”

Further Education & Work-Based Learning

Darren had initially struggled to adapt to the new work and social situations he found himself in, but was determined to persevere and overcome any obstacles he faced.

His tutors were incredibly supportive and encouraged Darren to take part in a pilot scheme, which enabled him to gain access to an educational psychologist for an assessment.

The outcome resulted in Darren being officially stated as having Special educational needs and gaining additional support from his Motor Vehicle tutors via an ALS worker (Additional Learner Support) who provided excellent one-to-one support for Darren during his qualification.

Ros was successfully able to progress Darren onto a Level 2 Heavy Goods course with Cardiff and the Vale College, which later led to an Apprenticeship with Edwards Coaches. All this within a 3 year period.

Darren Gould, ACT Motor Vehicle Sector Lead and Darren's tutor commented:

"I'm very proud of Darren for overcoming his barriers and realising his dreams. He deserves all of the success for all his hard work and efforts."

Darren himself added:

"I couldn't believe it at first when Edwards offered me the Apprenticeship. I was so excited. I now go to college one day a week and work with a brilliant group of men who 'take the mick' a lot but who also take time to teach me the job."

Further Education & Work-Based Learning

Jason Campfield, Fleet Engineer at Edward Coaches commented:

“Darren’s been with us since September and he’s settling in really well. He gets his head down and cracks on with the tasks at hand, which is brilliant. Of course it’s the early stages of his Apprenticeship but he’s learning a lot and there are plenty of opportunities for him to continue to progress and develop his skills and knowledge further so he can take on even more responsibility. We support our Apprentices every step of the way and we’re currently also putting Darren through a driving course so he’ll hopefully have his licence soon too. We also keep in regular contact with the college, so we’re always aware of how he’s doing on his course.”

Apprenticeship schemes have been an excellent resource for Edwards Coaches, who use their Apprentices to grow and nurture a skilled workforce to suit their business needs. They currently have around 10 Apprentices working across their business.

Jason added:

“As a company we massively benefit from Apprenticeship schemes as it means we get to mould our learners to our specific needs. There are plenty of car mechanics out there but working with buses is very different so it’s not always easy to find mechanics who have the experience and skillset we need. We would definitely recommend Apprenticeship schemes to other businesses as they allow you to train your workforce to fit your specific requirements.”

Further Education & Work-Based Learning

Darren is one of thousands of Apprentices who is benefiting from the chance to specialise and develop his skillset, and he is looking forward to taking advantage of the many opportunities that lie ahead for him. Reflecting on his journey to date, he said:

“If I hadn’t gone to ACT and began my Traineeship, I wouldn’t have had the chance to learn about motor vehicles till later on in college - if I had even made it there to begin with. ACT has given me a huge amount of support and I would highly recommend them to absolutely anyone.”

Talking about his future plans, Darren added:

“I’m looking forward to completing the Apprenticeship, including the additional improver year I’m currently doing, and working towards my goal of being a fully qualified heavy vehicle diesel fitter. I’m really excited for what the future holds.”

CHAPTER 6

Parent-Carer Film



Parent-Carer Film

"This film will lead the way
to changing the narrative."

- *Emma Durman*

Background

The Parent-Carer Film was launched on **1st April 2019**. The National ASD Development Team's Leads inherited this piece of work when they came into post in 2018 which had been previously agreed with the Welsh Government.

The aim of the film was to complement the Parent-Carer hard copy Guide and the various films that the Team have created to increase awareness and understanding and provide advice to parents/carers, including the first Parent-Carer film, the Birthday Party film, and the Can You See Me? film.

It also derived from feedback from autistic people and other stakeholders who indicated that there was a gap in support in the period immediately following diagnosis.

Description

The Parent-Carer Film aims to support parents and carers with newly diagnosed autistic children. It is a **resource** that clinicians and professionals can use to signpost parents and carers to upon the child's diagnosis. It is also easily accessible online at the ASDinfoWales site:
<https://www.asdinfowales.co.uk/tv>.

The film covers a range of topics, including discussions with parents and carers, autistic individuals, and professionals.

Parent-Carer Film

Approach

The National Leads wanted to change the format that had been previously agreed for the film, from a 'One Show' format, where a panel of professionals would discuss the various topics autism for the benefit of parents and carers, to a more holistic approach.

The National Leads wanted to co-produce the film with autistic young people and their parents and carers, and subsequently shift the focus of the film to be about their lived experiences and individual journeys that would capture the voice of autistic people and parents and carers.



Rather than following a script, the film was shaped by a series of conversations with people around autism and its impact.

Parent-Carer Film

The Team facilitated individual interviews with autistic people and their parents and carers at a filming session, which was held for families in a bowling centre in Carmarthenshire. Further informal interviews took place in people's homes and informal settings.

Framing these clips of the autistic individuals and their parents and carers at the bowling centre was the panel, which followed the original 'One Show' format.



This section of the film sees the presenter, Trystan Ellis-Morris, asking questions to a panel comprised of one consultant clinical psychologist, a specialist speech and language practitioner, and two members of the National ASD Development Team, who discussed the resources available and the professional support and guidance that is available to all parents and carers across Wales.

Parent-Carer Film

Challenges

The challenge of filming in this particular way also happened to be the most rewarding aspect of the work, which was to work alongside autistic people to co-produce something that would have been beneficial to them at the point of diagnosis. This approach can often be an emotional experience for all involved.

The approach also extended the time period that such a project can be undertaken within. There needed to be respect towards the diversity of all involved, and although it was often challenging trying to meet every participants' needs and views, the outcome was far greater. Emyr Jenkins, a member of the *Injan* filming crew that worked with the National ASD Development Team to create the film in such a pioneering way, had this to say:

“Whilst working with the National ASD Development Team on the Parent-Carer film, we all felt it was important to reflect the experience of real parents and carers who the viewers could identify with, and from there it was a natural step to also include the perspective of the young autistic people receiving their care. We're very proud of the way the film has allowed people to share their stories in order to help others in the same situation, and by adding to the mix the invaluable explanation and advice of experts and practitioners in the field, and bringing this all together in an easy-to-watch television-style format, we hope we've created a resource that will inspire parents and carers to seek out all the help that's available and to develop a positive outlook on the future, both for themselves and for the autistic children and young people in their care.”

- Emyr Jenkins

Parent-Carer Film

It takes courage for people to be so truthful and open on camera, especially when the subject matter is such a personal one. As a Team, we want to continue to foster a culture where people respect this approach and to be mindful of what the individual has to say.

Outcome

When producing a film, it can be viewed in its entirety (in this case, 48:56), but also has value in being shown in short clips and sections to add to people's understanding of autism from a first-hand perspective.



Before the official launch of the film, the Team held a screening of the film so that all of the people who had been involved in the filming could see the end product before it was launched during **World Autism Awareness Week 2019**.



The feedback from the autistic individuals, their parents and carers, and professionals who took part in the film was overwhelmingly positive. Parents in particular felt that it gave a good introduction to parents and carers of newly diagnosed children, and also that it was exciting to hear the views of autistic people themselves in a positive and effective way.

Parent-Carer Film

Comments Following The Screening

"I thought the film was really honest and to the point. Hopefully it will help people understand autism a bit better in the future... and if not, watch it again until you understand!" - *Luke Messaggio (autistic adult)*

"The film shows that there is a light at the end of the tunnel. It is informative because it covers all aspects, including the challenges, but it is also hopeful." - *Wendy Messaggio (Luke's mother)*

"As a grandmother, you feel for your daughter and what she's going through as well as your grandchild who is autistic – but the film gives hope." - *Annette Charles (Luke's grandmother)*

"My favourite part of the film was the body language of the people in it – you can see that some of us were nervous but we are all clearly having a good time and so it is positive without hiding the truth."
- *Mia Durman (autistic child)*

"The language used was perfect – it's not a 'disorder', it's a condition." - *Emma Durman (Mia's mother)*

Parent-Carer Film

"Mia was nodding along while watching it, which shows how important it is for everyone to watch the film and be able to relate to it and see themselves in it." - *Phil Durman (Mia's father)*

"[The film] was very informative, and it will be very useful to parents with newly diagnosed children." - *Claire Evans (Issac's mother)*

"People will be able to dip in to the film. They will be able to relate to it."
- *Fiona Rogers (parent)*

"To involve families was imperative, because they are the experts. The quality of the film is excellent, and I loved the filming nights because people could relax together in a safe environment."
- *Amanda Roberts (Mencap Cymru)*

Parent-Carer Film

On the day of the screening, as well as the day of filming at the bowling centre, autistic individuals were granted a “safe space” to enjoy, be themselves, and celebrate their autism.

The Team continuously strive to provide opportunities for individuals to get involved and experience such joy. For example, one of the autistic delegates performed his favourite songs at the screening. It was exhilarating to see a young autistic man perform with such talent, especially as he had been non-verbal until he was 8 years old.

It is important to let autistic people have the same opportunities as everyone else.

Usage

Following the launch of the film, the Team will now go on to update the parent-carer guide that the film is based upon.

To rollout the film, it will be publicised across the Children's Neurodevelopmental Services and shared across the Team's stakeholders.

The film will also be broken down into smaller sections in order to be easily accessible by topic.

Lessons Learned

It takes far longer to co-produce work projects with “real people” but it is certainly worth doing, and the Team are committed to continuing with this meaningful and successful approach.

CHAPTER 7

The Birthday
Party film
and SIGNS
work



The Birthday Party Film

Background and Description

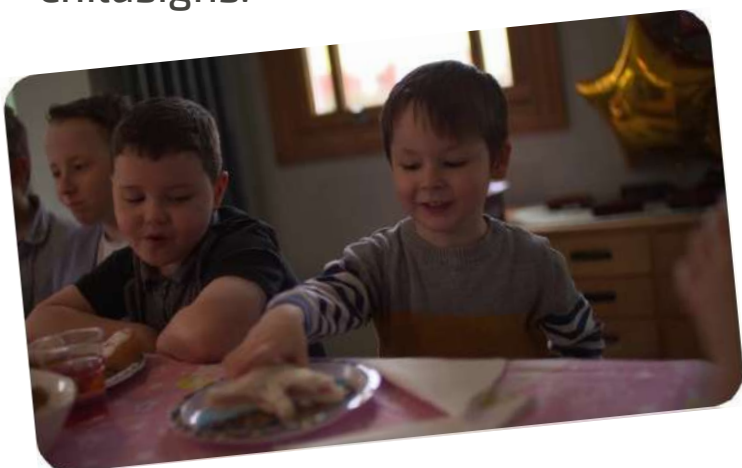
The first edition of The Birthday Party film launched in June 2017¹ as a partnership project between the **Welsh Local Government Association, Cardiff University, Aston University** and clinical psychology partners.

Its aim is to improve front-line professionals' understanding and awareness of autism in children and is available to view on the ASDinfoWales website:

www.ASDinfoWales.co.uk/autismchildsigns.



Following a call for the film to be translated and rolled out in European countries, Professor Sue Leekam and Dr Catherine Jones, then Co-Directors of the Wales Autism Research Centre (WARC) at Cardiff University, applied for and were awarded funding by the Economic and Social Research Council (ESRC) in order to respond to these international interests. The National ASD Development Team was an external partner on the application.



¹ www.ASDinfoWales.co.uk/news/wlga-press-release-film-collaboration-aiming-to-increase-awareness-of-autism-signs-in-children

The Birthday Party Film

Professor Sue Leekam and Dr Sarah Carrington, School of Psychology, had originally identified and published a set of essential signposting items from an assessment known as the Diagnostic Interview for Social and Communication Disorders (DISCO).

Further research conducted by the Cardiff team led to the creation of SIGNS – a way for frontline professionals to identify and understand autistic behaviours in children.



The 18-minute training film, which is based on SIGNS, is an example of international best practice and is now available in Latvian, Italian, Lithuanian and Spanish thanks to the work being taken forward by WARC, Auspicious and the National ASD Development Team.

*On 27th September 2018² there was a joint re-launch of the film between WARC and WLGA in its six different languages – Welsh, English, Italian, Latvian, Lithuanian and Spanish – an example of **Wales' pioneering collaboration with four European countries.***

2 www.ASDinfoWales.co.uk/news/recognising-signs-of-autism-welsh-autism-awareness-film-rolled-out-across-europe

The Birthday Party Film

Co-Production

Throughout the project, a novel approach was used to achieve the aims of the collaboration – Cardiff University and The National ASD Development Team worked very closely with the autism community (parents; autistic people) at various stages of the film’s development.

The autistic community in turn gave important feedback, as well as being active in sharing and disseminating the film. The success of the European collaborations was underpinned by research-charity partnerships in each country, where an academic team was paired with an autism charity.

Through these pairings, each country worked closely with an advisory group from the autism community to give feedback on the initial translations of the film script. The result of this has been an important university-practitioner platform of communication, facilitated by members of the autism community.



The Birthday Party Film

How did the European countries get involved?

WARC played an integral role in administrating the project and its translation processes, as well as having the contacts with the different countries.

Latvia

Liga Berzina visited WARC in 2014. Her charity, the Autism Association of Latvia, had just been set up and resources were few.

She joined a parent conference that WARC held and was immediately interested in the resources and research activities that WARC were creating for families.



Welsh



English



Italian



Latvian



Lithuanian



Spanish

Once Liga saw the ASDinfoWales site she wanted to make similar resources in Latvia.

In February 2017, Liga brought a delegation of teachers for a visit to Wales, to whom Sue Leekam and Jo Manikiza (the National Lead for the National ASD Development Team at the time) presented the work that was being developed for The Birthday Party film.

Liga and her team were so impressed that they asked if a translation was possible.

The Birthday Party Film

Arrangements were made to translate the film into Latvian without funding (a student did the voice-over), and a few months later the film was presented to 400 people at a professional's conference in Latvia.

The evaluation was very positive, and it has since been adopted into teacher training in Latvia.

Lithuania

While Sue Leekam was at the Latvia conference, two parents disclosed their Lithuania-based charity to her which desperately required the film to be translated into Lithuanian, again because they had hardly any resources of their own and attitudes in schools and clinics needed changing.



As a result of this, Sue Leekam and Catherine Jones wrote a funding application to the ESRC. Jo Manikiza was their partner through Auspicious Wales, and Tracy Hinton was their partner at the WLGA.

The film is now used widely in Lithuania by charity partners Valdona Judickaite and Kristina Radžvilaitė, Lithuanian Autism Association, and the academic partner there, Dr Renata Geležinienė, Siauliai University has incorporated it into the training for speech and language therapists and teachers.

The Birthday Party Film

Spain

While Sue and Catherine were planning the funding application, Sue was invited to give a seminar to a university in Madrid. After talking about the film, the academic colleagues told her of the interest from the national charity Autism Spain for the film in Spanish.

The film was therefore extended into Spanish with partners Dr Carmen Nieto and Dr Ruth Campos from the Autonoma University of Madrid, and Ruth Vidriales, Autism Spain.



Dr Claudi Ferre

The Spanish version of The Birthday Party film has been used at Autonoma University for the training of medical students and psychology students. The national charity Autism Spain (Autismo España) report that, after its release, it was in the top five most viewed items on their blog. With thanks to WARC at Cardiff University for sharing the photographs.



The Birthday Party Film

Italy

Another colleague in Italy, Dr Marcella Caputi, Vita-Salute San Raffaele University, Milan, Italy, with charity partner Silvia Montanari, Associazione Autismo Pavia Onlus also asked for translation, so that the film could be available in Italian.

Since then, Dr Caputi has won an award from Italian charitable foundation to travel to Cardiff in July and October 2019 to continue the partnership work, and she will present the work at the Autism Europe Conference in September 2019.



Dr Daniela Brazzo

S = Social Interaction and verbal communication

I = Imagination

G = Gestures or non-verbal communication

N = Narrow range of interests, routines and repetitive behaviours

S = Sensory responses

The Birthday Party Film

Outcome

Since its re-launch in September 2018, the project has received several positive feedbacks, which Cardiff University have provided below.

Feedback from Practitioners

"As a teacher with experience of [autism] I found this resource remarkable as it opened my eyes to the wider and more varied ways that children with [autism] experience life...

The resource will certainly help me to a better practitioner." - **Primary School Teacher**

"This is a very clever teaching tool... it would suit all of our clinical team, including reception staff who observe patients in the waiting area. Really helpful!" - **GP**

"The film is very informative and will be a useful tool to incorporate into training new and mainstream school staff. The film highlights an important discussion point regarding the subtleties of ASD in girls and how best to support them appropriately." - **Head of ASD Specialist Resource Base**

"An amazing resource which debunks stereotypes and explores the many ways autism may show up with both sensitivity and respect for difference." - **Learning and Development Consultant**

Feedback from Parents

(NB. both parents with children seeking diagnosis at time feedback provided)

"I think this video is great not only for professionals but as a parent of a child who is yet to be diagnosed it will be great to show my family/friends to give them an insight into what autism means for children." - **Parent**

"Love this film!! So very powerful, showing the different signs. I wish we could educate staff and children about invisible disability right from a young age, with clips like this!" - **Parent**

Cardiff University and the WLGA jointly submitted an application to Cardiff University's "Innovation and Impact Awards 2019" in 2018, for their work on the SIGNS and Birthday Party film. At the time of producing the Annual Report, the project had won the "Innovation in Healthcare" award and the "People's Choice" award.

CHAPTER 8

Emergency Services



Emergency Services

Background

The Emergency Services film was created in conjunction with Emergency Services in Wales and the filming company, Injan, in April 2018. The training involves: showing the film and presenting case studies.



Precedent cases nationally and internationally had highlighted the vulnerability of autistic people and their risk of involvement within the Emergency Services.

Initial consultation was carried out in July 2017 following requests for autism training from Emergency Services partners to develop a better understanding of autism and to influence practice. The National ASD Development Team undertook a scoping exercise to ascertain the current provision and needs across Wales.



As part of this work, an online survey for Emergency Services employees was created. In addition, the Regional ASD Development Officers contacted 3 Fire and Rescue Service, 4 Police Services and the Welsh Ambulance Service to further the scoping work.

Emergency Services

This work identified a real need for autism training in emergency services throughout Wales, in order to develop a good understanding of autism. Respondents felt that training would be useful to their role, and that they would be committed to undertaking training.

Description

This scheme will be run as a “train the trainer” form of training, where members of the National ASD Development Team will train a few people, who will then take the training out more widely across Emergency Services in Wales. The training will be adapted and specific to the kind of cases the different areas of emergency services are involved with.

So far, the train the trainer sessions and the training package for the Police and Fire and Rescue services are being used as pilots, with a vision to disseminate to all emergency services across Wales in 2020/21.

- The Police have a complex, more front facing contact with autistic people. This training was rolled out in November 2018 to Dyfed Powys Police.
- Fire and Rescue services training will be rolled out in the Summer 2019 to South Wales Fire and Rescue Service.
- The Ambulance and Coast Guard training will be completed in the Autumn 2019.

Emergency Services

South Wales Fire and Rescue Services

The goal is for the Fire and Rescue services in South Wales to all undertake the train the trainer sessions during the Summer/Autumn 2019.



Ashley Collins, Sally Chapman, Sara Harvey, Tony Jackson and Huw Jakeway QFSM



Huw Jakeway QFSM, Rebecca Meredith and Vaughan Gething AM

Dyfed Powys Police (DPP)

The DPP piloted the Emergency Services train the trainer sessions during November 2018.



Emergency Services

Here is an overview of the feedback that Dyfed Powys Police received from the community (before and after the Train the Trainer scheme):

The individual in question is autistic and agoraphobic. At a time where they were threatening to self-harm, a particular police officer showed understanding and respect towards them. The following message was received by the Force:

“Hello, I just wanted to write to say many thanks to the Police Officer who attended the minor car incident yesterday morning, where another driver drove into the back of my car. I'm afraid I didn't get their name, but they made an unpleasant experience much easier. I particularly wanted to write because I have autism, which made the influx of interactions especially taxing. Your officer was friendly, clear and they told me what would happen step by step, which was enormously helpful when processing what had happened. Your officer didn't know that I have autism, so it was pleasing to see that the procedures you have in place are neurodiversity-friendly. Whilst it will still take a few days for my over-taxed brain to bounce back fully, your officer's demeanour helped me put off a possible period of "shutdown". Thank you for your time.”

Emergency Services

“Today we visited a carnival in the DPP area, there were two officers there. I just wanted to say a huge thank you for making my child's day. My child has autism and is utterly obsessed with policemen (ambulance/firemen too) and these two took time to explain everything; what they wore and why etc. My child can be very “in your face” and doesn't know boundaries and I never know whether to explain about their condition or not. I chose not to as I thought they were being bugged enough haha but these two really touched my child's heart and so I wanted to just say thank you!”

An employee of a mental health charity wishes to praise both officers' conduct while undertaking a recent interview with a person suffering with Asperger's syndrome, who is on the autistic spectrum, and who also has paranoia and ADHD.

Emergency Services

A member of the public wanted to pass on a thank you to the officer currently dealing with their child's case. The caller was the parent of an assaulted victim and they advised the officer that their child was autistic, but the officer wasn't patronising. They stated that the officer was polite, courteous and very professional.

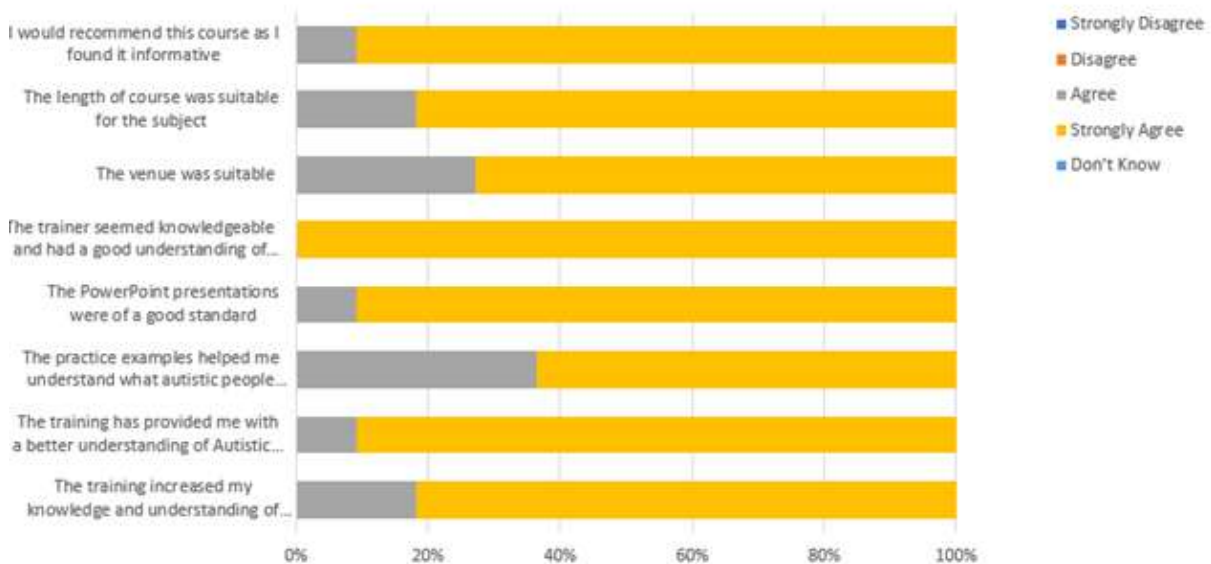
The caller explained that their child is autistic and had come out of a shop after buying a cake, when a police car drove past, and their child was staring at the officers in the car. The caller explained that their child was wearing tracksuit bottoms and their hand in their pocket. The officers stopped the car and approached the caller's child. The caller stated how their child was so pleased with the officers' attitude towards them, stating they were very cheerful, friendly, nice and professional. The caller also stated that their child was extremely pleased the officers didn't ask them to take their hands out of their pocket.

Emergency Services

Statistics

The National ASD Development Team delivered two pilot Train the Trainer sessions for DPP. The following response was received from the evaluation sheets following the training.

Emergency Services Pilot DPP



As can be seen from the graph, 100% of participants agreed or strongly agreed that the training increased their knowledge and understanding of autism, 100% of participants agreed or strongly agreed that the training provided them with a better understanding of autistic people's needs and a 100% agreed or strongly agreed that they would recommend the course as they found it informative.

Quotes received following the sessions include:

"Really needed within the service and other emergency services."

"Excellent summary, engaging, well worth attending."

CHAPTER 9

Autism: A Guide for Practitioners within Housing and Homelessness Services



Autism: A Guide for Practitioners within Housing and Homelessness Services

Background



The Autism: A Guide for Practitioners within Housing and Homelessness Services has been written and produced in 2018/19 in response to the Housing (Wales) Act 2014 and the Social Services and Wellbeing (Wales) Act 2014.

Following these Acts, it was recognised that the previous guide that was in place from 2011 needed to be refreshed and significant policy areas needed to be changed.

The Guide is also a response to the consultation that the National ASD Development Team facilitated on behalf of Welsh Government in 2015, as well as the reports commissioned by Shelter Cymru³⁴ at this time. In the consultation, autistic people and professionals highlighted the issues and challenges faced by autistic people in relation to housing, and Shelter Cymru reported that there is a higher proportion of homeless people who are autistic.

The aim of the Guide is also to ensure that autistic people know what their rights are in relation to housing, housing support, and benefit housing claims. As the social model of disability suggests, reducing the barriers autistic people may face in the housing sector could mean they reach the best possible outcome in housing and consequently overall well-being.

³ <https://sheltercymru.org.uk/wp-content/uploads/2015/05/Jacqueline-Campbell-Shelter.pdf>

⁴ Autism - The prevalence of autistic traits in a homeless population (Alasdair Churchard, Morag Ryder, Andrew Greenhill and William Mandy) - <https://journals.sagepub.com/stoken/default+domain/IAmuFddNNmeCRNV5RWXY/full>

Autism: A Guide for Practitioners within Housing and Homelessness Services

Description

The Guide was co-produced by the National ASD Development Team, autistic advisors, several Housing professionals, and colleagues who work with autistic people across Wales. There was a Task and Finish Group established to complete the Guide, as well as a smaller Writing Group.

The Guide is split into themed chapters which align with those in the Housing (Wales) Act 2014 for practicality and ease of reference.

A diagnosis of autism does not necessarily mean that a person is unable to cope with living independently, but rather that they may require additional consideration in the choice of housing, in the way the property is managed, and in the way the tenant is supported.



Outcome

This Guide will be fully published by July 2019. There is a high level implementation plan to establish the Guide and it will be available to professionals and providers across Wales through the ASDinfoWales site.

There are “Top Tips” at the end of the Guide that can be printed out by practitioners for ease of reference and can be used by practitioners at all levels.

Autism: A Guide for Practitioners within Housing and Homelessness Services

Overview of Housing Case Studies (which are included in Autism: A Guide for Practitioners within Housing and Homelessness Services):

Wales and West Housing Early Intervention

B had a very bad perception of the Housing Association from previous experience of interacting with them.

He felt that the Housing Association told him what to do in his accommodation rather than allowing him to make decisions about his property.

One of the first times the housing officer met with B it was over a complaint about a neighbour's dog barking. B was told that the neighbour would be given 10 days to resolve this issue. B felt that this was not acceptable or reasonable and it led to an argument between B and the housing officer rather than a reasoned conversation.

Working in a different way and finding out "what matters" to the tenant has enabled issues like this to be dealt with differently.

B is a very intelligent gentleman and he sees his autism as making him evolutionary superior. Therefore, it is important to acknowledge this and speak to B as at least an intellectual equal. This has drastically changed B's reaction to conversations as housing officers don't "talk down" to him anymore but relate to him on his level.

Autism: A Guide for Practitioners within Housing and Homelessness Services

On one visit the housing officer noticed a Marvel poster in the property and found out that B has a very keen interest in comic book characters and films.

A new way of recording has allowed this information to be shared with other staff within the Association and enables repairs staff, for example, to find common ground with B and strike up a conversation with him rather than a repairs visit being confrontational as it might have been in the past.

B is now keen to have conversations and will talk about the latest film or computer game and often calls the housing officer up to do this.

Wales and West Housing what matters conversation

G was living with his mother in the front room of her house and only had access to very dated amenities. His mother was moving on and G had to move out of the family home.

When the housing officer first met with G he found it very difficult to converse with him and G didn't laugh at his jokes. G stated that he didn't need "support" – the word "support" had very bad connotations for him. The terminology used was very important and G received "assistance" going forward.

G had no income of his own as he had always been provided for by his parents. He didn't even have a bank account for any new benefits to be paid into. Although G promised the housing officer that he would set up a bank account, he failed to do so. As the housing officer continued to meet with G and get to know him he was made aware that G had Asperger Syndrome.

Autism: A Guide for Practitioners within Housing and Homelessness Services

The housing officer obtained leaflets about a range of basic bank accounts and left these with G. On the next visit the housing officer found that G had read the leaflets and opened his own account.

This helped the housing officer understand that G responded better to written information rather than verbal instructions. It also led the housing officer to a change in practice, enabling people to open accounts or make benefit claims rather than just taking the person's word for it that they will do it. G was assisted to make a benefit claim in order to receive income and pay his rent.

G was then given a step by step written guide to help him pay his rent from his income. G had sustained his tenancy for over 4 years with very little need for further assistance.

When G's benefit claim switched to Universal Credit he mistakenly thought from things he had heard about "not signing on" that he wouldn't need to go to the Job Centre any more. G took things literally and needed things explained to him in a specific way.

G had no phone of his own but is able to access "assistance" by going to a nearby extra-care scheme and letting the staff know that he wanted to meet with the housing officer.

Any assistance was then based on demand from G but the housing officer worked hard to understand what had led to this demand. When the housing officer needed to meet with G he was very clear in his correspondence about this and when he would be meeting him.

Autism: A Guide for Practitioners within Housing and Homelessness Services

Keeping to an appointment time was very important to G. This information was also shared with other staff within the organisation who may have also been setting up appointments with G.

Cardiff in-house homelessness support provision

C is a 60-year-old male who has multiple health needs which affect his ability to “take in” and retain information in traditional forms (letters, action plans, benefit updates online etc.).

He was living in temporary accommodation due to domestic abuse within his family. C had been looking for private rented accommodation but had not been successful and was struggling to cope with the temporary accommodation due to his support needs. I tailored my support to his individual needs generally working in the following way:

- Before meeting C, it was important to thoroughly research his case and gather information from his initial assessment. This information could be verified in the first meeting but allows the first contact to be more conversational and focus more on C’s needs and aspirations. We needed to identify and secure private rented accommodation, set up and then maintain this tenancy, maximise benefits including UC and PIP, and ensure that direct payments of UC were paid to the landlord.

Autism: A Guide for Practitioners within Housing and Homelessness Services

- The action plan drawn up contained both long and short term goals, which included setting limited time, achievable targets building a rapport and helping C to stay motivated and increase confidence. Complex tasks (applying for benefits for example) were broken down into smaller parts so as not to overwhelm him.
- Any written communication was provided in as straightforward a manner as possible and was always followed up with a call or visit to make sure that it had been understood. I arranged for C to receive long-term floating support and ensured this was in place before closing his case.

C is now in a secure, sustainable tenancy, with support in place, and is making links with his local community through his mosque. Long term sheltered accommodation will become available in the future should C's support needs increase. Floating support is in place to support C through the next few months of his tenancy.

At the beginning of my involvement, C was under a lot of stress and had no confidence that he would be able to sustain a private rented tenancy. The work we did has allowed him to live comfortably and independently whilst addressing his previous arrears. C gave positive feedback at sign off:

"I am very happy with the support and what you have done for me.
Thank you very much."

GOFAL Housing Advice Pontypridd

M is 28 and was living with his dad but was about to be homeless as his dad was moving out of the area and M did not want to go with him. M did not want to pursue the option of supported accommodation and wanted to live independently.

He was referred to the support service by Housing Options. They were satisfied that M was a priority need.

M had been diagnosed at the age of 4 with autism and had also been diagnosed with ADHD, OCD, anxiety, depression and Insomnia.

He had taken medication over the years and had received support from mental health services, however at the time of interview and during the support he declined any referral back to the Community Mental Health Team as he felt he was managing fine and wanted to be as independent as possible.

During the assessment, care was taken not to overload M with all the advice and information generally given as it was apparent the situation was stressful enough without adding to this.

It was decided to give the information required to make choices and understand the process in order of priority for completion.

Autism: A Guide for Practitioners within Housing and Homelessness Services

M was always telephoned to ensure he understood things and encouraged to write things down if he needed to so that he could ask the next time he saw the support worker.

Only one task was dealt with on each visit. M was always seen by the same support worker as continuity is essential for building relationships and trust with people, especially those who have autism.

M worked for 12hrs a week while living with Dad but had no other income, so it was clear from the start that on a wage of £60 a week the tenancy was going to fail very quickly. It was explained that he would not afford his own tenancy unless a claim for benefit was submitted, however this was not easy as it was not something he had ever needed to do and did not really think about this when choosing to live independently.

M's job was hugely important to him, so it was essential that any benefit claim requested was able to incorporate him continuing to work. Working was the only time he saw people other than at home, and was part of his routine, so it was essential that the property he was allocated was within walking distance of his job as he would not go on public transport.

Another appointment was given to M to go over again the reasons why he needed to claim benefit and then he was supported to do this over the phone. A request was made by the support worker under the work permitted rule guidelines.

In order for the completion of the benefit to be processed a one to one appointment was requested which M managed well as it was explained prior to attending and whilst there.

Autism: A Guide for Practitioners within Housing and Homelessness Services

It was essential to obtain and submit bank statements ahead of submitting to housing benefit (before allocation of property). M was not forthcoming as he did not understand why they were required.

This needed to be explained in simple terms several times, however by the time we had to submit the housing benefit forms M was ready to obtain them.

When M was allocated his property, a referral was submitted immediately for Tenancy Support and requested that this could continue with the same support provider to ease the transition and to initially do some joint working.

The reason behind this was for M to feel less anxious about leaving the current support worker.

As neither M nor his family had the financial means to purchase any essential items for his new home, a Discretionary Assistance Fund application was made. This provided him with white goods for his new home. The utilities were set up, change of address with DWP was made, support to change address with GP, employer etc. was also provided.

The role of the agency is to provide housing advice and crisis re-settlement. Without a referral into tenancy support this would have failed if M had received no ongoing support.

Care was taken when withdrawing support in this case and telephone contact continued in order to provide reassurance and to discuss any concerns M may have had.

To date the tenancy has been a success.

CHAPTER 10

National Autism Wales Conference 2019



3rd April 2019
Liberty Stadium, Swansea

Follow us on  [@ASDInfoWales](https://twitter.com/ASDInfoWales)
and join in the conference discussion at [#promotingautisticwellbeing](https://twitter.com/promotingautisticwellbeing)
www.ASDInfoWales.org.uk/NAWC2019

National Autism Wales Conference

Cynhadledd Genedlaethol Awtistiaeth Cymru Hyrwyddo Lles Awtistig
National Autism Wales Conference Promoting Autistic Wellbeing

Background and Context

The aim of the first National Autism Wales Conference “Promoting Autistic Wellbeing”, held on 3rd April at the Liberty Stadium Swansea, was to increase the wellbeing of autistic adults who are not necessarily in regular contact with public or third sector services, but for whom an event about wellbeing and increasing their capacity to cope with day-to-day life would be beneficial and positive.



Jules Robertson and Gemma Smith

The Conference was coordinated by the National ASD Development Team, hosted by the Welsh Local Government Association and Public Health Wales.



Emma Durman

National Autism Wales Conference

The approach to the Conference was to provide a variety of keynote addresses, workshops, exercises, tools and tips that would all help to promote emotional, physical and/or social wellbeing for autistic people aged 16+ and for those that care for them/their guests.



Amara Tamblin, Gerraint Jones-Griffiths and Cllr Huw David

The Conference was self-funded through a mixture of core sponsors and co-sponsors. The core sponsors included Swansea University, the Swans Community Trust, Ospreys in the Community, the Welsh Local Government Association, and Public Health Wales, while the co-sponsors comprised Hacer Developments, The Autism Directory, and Welsh Government's Social Services and Health Directorate.



National Autism Wales Conference

Task and Finish Group

Once a business plan had been agreed by WLGA and PHW and sponsorship secured, the National ASD Development Team established a Conference Task and Finish Group to co-produce the event. The Group comprised of x5 autistic individuals, x5 parent/carer representatives, x5 professionals including the National Autistic Society Cymru, and representatives of the National ASD Development Team.

The Group met every three weeks for two hours in the five months leading to the Conference, and was chaired by the National Strategic Lead for Autism. The Group informed and agreed the title of the Conference, its aims and themes, and the detail of the workshops being offered.

Welcome and Support Team

The Task and Finish Group also provided a fundamental role on the day of the Conference as part of the Welcome and Support Team, which also included core sponsors, staff members of the Integrated Autism Services (6 teams) and the full National ASD Development Team.

The purpose of the Welcome and Support Team was to support delegates and ensure the smooth running of the whole event on the day.



Frances Rees, Gerraint Jones-Griffiths, Sara Harvey, Tracy Hinton, Wendy Thomas and Linda Pilgrim

National Autism Wales Conference

There was at least one member of the Team situated in every workshop; others were dispersed across the building to help direct the delegates to the allocated rooms of the workshops, plenary sessions, and breaktime; there were also two members of the Team in the **Sensory Room**, the **Calm Down Room**, and the **Quiet Room** continuously throughout the day, all dependent on a scheduled rota.

The Welcome and Support Team welcomed the delegates on their arrival and, assisted by Public Health Wales, registered delegates, handing out badges with the delegates' names and workshop choices, the Conference Brochure, and communication stickers. The Support Team were recognisable by green sashes.

Description

The Conference had two autistic keynote speakers – Emma Durman (Director, Outside) and Jules Robertson (Actor, most famous for his role in *Holby City*) – as well as autistic co-chairs, Amara Tamblyn (Law Student) and Gerraint Jones-Griffiths (Lead Ambassador, Engage to Change All Wales People First).

In the morning plenary session, the Minister for Health and Social Services, Vaughan Gething AM, also spoke and provided a scene setting to the event, while the afternoon plenary session had Cllr Huw David, Welsh Local Government Association Spokesperson for Health and Social Care, providing insight into the work of the National Autism Team and the planning of the Conference itself.



Vaughan Gething AM

National Autism Wales Conference

Furthermore, the Conference gave autistic delegates the option of choosing two workshops in the morning and two workshops in the afternoon from the below list, all of which focus on wellbeing:

Morning Workshops

1 : Autism and Eating – tackling eating difficulties in autism

Dr Jacinta Tan, Consultant Child Psychiatrist,
Aneurin Bevan University Health Board

2 : Getting on Well: into middle age and beyond

Cos Michael, Autism & Ageing Consultant

3 : Improving Alcohol Support for People with Autism

Andrew Misell, Director for Wales at Alcohol Change UK and Professor Mark Brosnan,
Bath University

4 : Interpersonal Empowerment: practical tips to improve your relationships

Dr Freya Spicer-White, Principal Clinical Psychologist, North Wales Integrated Autism Service

5 : Thriving at University

Sara Hounsell and Gemma Price, Specialist Autism Spectrum Conditions (ASC) Practitioner and Advisors, Swansea University

6 : Let's Keep Moving! – physical activity and autism

Ospreys in the Community, Swansea City Community Foundation, and Disability Sport Wales

7 : Gentle Flow Yoga

Huriyah Sisuvie, Yoga Instructor

Afternoon Workshops

8 : An Autistic Guide to Creativity Rhi Lloyd-Williams, Writer and poet

9 : Autism and Employment

Gareth Tarrant, Operations Manager, The Autism Directory

10 : Skills for Life and Getting Things Done

Lucy Wells, Highly Specialist Occupational Therapist, Cardiff & Vale Integrated Autism Service

11 : Digital Technology – the Pros and Cons

Professor Phil Reed, Department of Psychology, Swansea University

12 : Managing Anxiety including Embracing Safe Stim

Emma Durman, Director, Outside

13 : Let's Keep Moving! – physical activity and autism

Ospreys in the Community, Swansea City Community Foundation, and Disability Sport Wales

National Autism Wales Conference



“Being amongst so many autistic people was so lovely and freeing. This was a ground-breaking day of acceptance. Thank you so much! PLEASE DO IT AGAIN!” -
Autistic Delegate

Rhi, your workshop at the #ASD conference today was exceptional. It was a delight to be invited and encouraged to be beautifully ourselves with no agenda other than the joy to be found in creative self expression. You are a wonderful presence and influence.

5:10 PM - 3 Apr 2019

The National ASD Development Team produced an Accessibility Guide, which was endorsed by the Task and Finish Group, and distributed to all registered delegates one week ahead of the Conference.

This document provided the following information to delegates: how to reach the Liberty Stadium; photos of the rooms that will be used for the purposes of the Conference; the existence of a Sensory Room, a Calm Down Room, and a Quiet Room, which will be available continuously all day for everyone; and an explanation on how to use the communication badges that delegates can choose to wear in order to signify the level of interaction they wish to have (which can be changed and amended throughout the day).

National Autism Wales Conference

Outcome

Many positive comments were received by the autistic delegates who attended the Conference, their guests, and professionals. For example, **95%** of delegates who had completed the evaluation form agreed that **the Conference had been beneficial to their own autistic wellbeing or understanding of autistic wellbeing.**

These comments, alongside the feedback received from various members of the Welcome and Support Team, the speakers, and the workshop leads, are a testament to the **overarching success** of the Conference.

This was one event among a series planned for various needs and interests.

A website page was created on the ASDinfoWales site one week following the Conference: <https://www.asdinfowales.co.uk/NAWC2019>

Here, the delegates can access the workshops' PowerPoint presentations and handouts; a video of the plenary sessions; the endorsement video clips from various influential individuals in the autistic community (including the autistic speaker, trainer and singer, Dean Beadle, and the autistic content creator and entrepreneur, Katy Gough); and further documents from the day.

Following the Conference, the National ASD Development Team produced a draft Evaluation Report, which will be reviewed and endorsed by the Conference Task and Finish Group. The Team will be using the Evaluation Report to inform future events.

CHAPTER 11

World Autism Awareness Week 2019



World Autism Awareness Week

Introduction

Throughout World Autism Awareness Week, the Team worked with the WLGA's Communications Department to release regular press releases, celebrating different aspects of the Team's work throughout the year.

Monday 1st April

Launch of Parent-Carer film in support of parents and carers following a child's diagnosis (for more information, visit Chapter 6)



Tuesday 2nd April

Launch of consultation concerning a Participation and Engagement Strategy at the Going for Gold Event led by Willow Holloway at the Senedd, and chaired by Mark Isherwood, AM (Chapter 1)



Wednesday 3rd April

National Autism Wales Conference "Promoting Autistic Wellbeing", Liberty Stadium Swansea (Chapter 10)



World Autism Awareness Week



Thursday 4th April
South Wales Fire and Rescue Service to promote their commitment and intention to be Autism Aware as a Fire Service (first in Wales) as a part of the pilot for the Emergency Services Programme (Chapter 8)



Friday 5th April
WLGA and Data Cymru celebrate the achievement of becoming Autism Aware organisations with over 80% of staff achieving Autism Aware certification during 2018/19 (Chapter 3)



WAAW also marked the Team's change of name from 'National ASD Development Team' to the 'National Autism Team' in response to the autistic community's preference for a more generic term than 'disorder' or 'condition.'

World Autism Awareness Week

WLGA Press Releases

01/04/2019: WLGA Press Release - More Support For Parents And Carers Of Newly Diagnosed Autistic Children

A new film is being launched today by the National Autism Team which aims to support parents and carers of newly-diagnosed autistic children.

Feedback from autistic people and other stakeholders has indicated that there is a gap in support and guidance in the period immediately after diagnosis.

Clinicians and professionals will be able to signpost parents and carers to the film upon their diagnosis, and it is also easily accessible as a reference point online.

The film was commissioned by the National Autism Team – formerly National ASD Development Team – which is funded by Welsh Government and hosted by WLGA, in close partnership with Public Health Wales.

World Autism Awareness Week

Councillor Huw David (Bridgend), WLGA Spokesperson for Health and Social Care said:

“For parents and carers, their child being diagnosed with autism can often be a bewildering experience due to a general lack of understanding of autism as a condition.

“The film was commissioned by the National Autism Team in direct response from autistic people that there isn’t enough support and guidance immediately after receiving a diagnosis. I hope this film will help to offer reassurance to parents and carers, and to show that there is information available that can really help them understand what the diagnosis means and practical advice about day to day living.”

“In addition to the film, the National Autism Team have an array of useful materials available on www.ASDinfoWales.co.uk to support autistic individuals and those around them.”

www.ASDinfoWales.co.uk/tv

World Autism Awareness Week

03/04/2019: WLGA Press Release - First Of Its Kind Event To Promote Autistic Wellbeing

Autistic people came together on Wednesday, coinciding with World Autism Awareness Day, at Swansea's Liberty Stadium in an exciting event to learn more about wellbeing and how to live independent lives.

Over 150 autistic people were welcomed to the conference, which was developed and co-produced by autistic individuals.

The packed agenda for the day featured a range of sessions contributing to improve understanding of good overall wellbeing, including mental health, physical exercise, further education, yoga and ageing well, to name but a few.

Delegates at the event also heard from Holby City actor and autistic advocate Jules Robertson, who discussed his own experiences of the condition.

The conference was coordinated by the National Autism Team (formerly National Autism Development Team) in partnership with National Autistic Society Cymru, Public Health Wales, the Ospreys, Swansea City FC and Swansea University.

World Autism Awareness Week

Speaking before the event, Councillor Huw David (Bridgend), WLGA Spokesperson for Health and Social Care said:

“I am delighted that after many months of planning, the first National Autism Wales Conference – Promoting Autistic Wellbeing is taking place as part of World Autism Awareness Week.”

“Autistic individuals have consistently said that they feel ‘invisible’ as far as key events go for them in the community. This feedback has been heard clearly by the National Autism Team, and the conference – developed and co-produced by autistic people, for autistic people – is a direct response.”

“I sincerely hope that the agenda offers something for everyone and will offer helpful and practical advice in terms of promoting wellbeing and how to live independent lives.”

Also speaking before the event, Vaughan Gething AM, Minister for Health and Social Services said:

“Today’s event provides a welcome opportunity to discuss the unique challenges many autistic people face in their day-to-day lives and to look at ways to maintain and promote well-being. The Welsh Government is continuing to invest in the development of new integrated services to improve support for autistic people and their families.”

www.ASDinfoWales.co.uk/NAWC2019

World Autism Awareness Week

05/04/2019: WLGA Press Release - WLGA and Data Cymru Achieve Autism Aware Status

The WLGA and Data Cymru have both achieved 'Autism Aware' status, following successful completion of a training programme by the National Autism Team.

For an organisation to successfully achieve 'Autism Aware' status, it must have demonstrated its commitment by ensuring that a significant proportion of its staff members have undertaken and successfully completed the Autism Aware Certification scheme.

It is estimated that 1 in 100 people are autistic. Registering as an Autism Aware organisation will support autistic people to better access its services, and will increase staff members' awareness of the condition.

Dr Chris Llewelyn, WLGA Chief Executive said:

"I am extremely pleased that WLGA has succeeded in fulfilling its commitment to become an Autism Aware organisation. The training provided by the National Autism Team to staff members was useful and practical in enhancing understanding of the condition, and to make us aware of the small steps we can all take to make our own day-to-day communication more accessible and inclusive. I would urge any organisation interested in becoming Autism Aware to get in touch with the National Autism Team."

World Autism Awareness Week

Andrew Stephens, Executive Director of Data Cymru said:

“We decided to include autism awareness training as part of our staff development plan for 2018-19. Our staff found the training really useful, with much of it being directly applicable to our approach to dealing with our customers and colleagues.”

“We’re very pleased that we can now say that our staff are “Autism Aware”. The next step for us is to complete the HR scheme and become recognised as “Positive about working with autism.”

To find out more about the Autism Aware scheme, please visit www.ASDinfoWales.co.uk.

Appendix ONE – Annual Report Summary against Work Plan 2018/19

ASD National Development Team Annual Report Summary against Work Plan 2018 – 19

The work plan for 2018/19 set out the high level priorities for the National ASD Development Team produced by the team for WG review and agreement. It was supplemented by a more detailed activity work programme and a budget summary.

The Autism Spectrum Disorder National Development Team supports the delivery of the ASD Strategic Plan and Delivery Plan in conjunction with key stakeholders. The team has worked with partners across Wales in response to engagement with autistic individuals and parents and carers, together with professionals, to produce an extensive set of resources to increase awareness of autism and to support autistic adults and children, professionals and service providers. The 2018/19 work plan and work programme was a consolidation of this work and included the ambition to rollout out the resources across Wales in an effective way with the support of partners and stakeholders. The work plan built on a foundation of a number of years of work among partners with a commitment to supporting and responding to the needs of autistic individuals and children and their parents and carers.

The implementation of the Integrated Autism Service across Wales was a further key priority and the team worked with the 7 Regional Partnership Boards (Social Care and Health) to support the effective establishment and delivery of these services for the benefit of autistic individuals, children with autism and their parents and carers in the context of existing services. The resources referenced above represent an important underpinning of the IAS delivery. The priorities in the work plan 2018/19 were based on a combination of priorities identified by Welsh Government; on-going discussions and informal feedback from stakeholders; the Evaluation of the IAS and ASD Strategic Action Plan Interim Report ¹ and the knowledge and experience of the National ASD Development Team, building on previous and existing work.

The work plan included an informal review of the role and structure of the National ASD Development Team and the WLGA implemented recommendations/ changes required.

¹ Evaluation of the Integrated Autism Service and ASD Strategic Action Plan: Interim Report, Dr Duncan Holtom and Dr Sarah Lloyd Jones, People & Work, ©Crown, 01/03/2018

1. Increasing use of existing training materials and resources	
Activity	Achievement/ Outcome
<p>1.1 To support the increased use of ASD training and support materials that have been developed by the National Development Team in partnership e.g. Learning with Autism, Working with Autism and Can you See Me?</p>	<p>Rolled out a train the trainer model in partnership with LAs, National Museum of Wales, community groups etc.</p> <p>Developed a strategic implementation plan for the LWA programmes</p> <p>Delivered a wide range of training sessions across a variety of sectors – Coast Guard, DWP, Colleges, Sports groups, Community Trusts etc.</p> <p>Began to scope out the impact evaluation of LWA programme</p>
<p>1.2 To make necessary adjustments to resources and materials taking into account feedback from stakeholders and those who have used the resources</p>	<p>Engaged with a wide range of stakeholders to gain views and suggested changes to existing resources e.g. some of the Autism Awareness questions were amended following feedback.</p> <p>Feedback responses have been collated to help inform some of the team’s work in 2019/20 and 2020/21</p> <p>A mailing list of stakeholders - including autistic adults and parents and carers has been developed to work on updating and revising existing resources in a planned and phased way.</p> <p>The team has changed its name in response to feedback</p>

<p>1.3 To continue to maintain and further develop the ASDinfoWales website as an integral resource for autistic children, autistic individuals, parents and carers and professionals.</p>	<p>The usage of the website continues to grow (<i>see stats in Chapter 1 of Annual Report document</i>)</p> <p>A specific “Resources leaflet” was produced that helps people navigate the website more effectively and assists professionals working with autistic people</p> <p>Website content has been continually maintained and updated</p>
<p>1.4 To support the roll out of the National Training Framework</p>	<p>Work begun on mapping existing training against the framework this has included: Health colleagues, IASs, Education Professionals, Social Care Workers.</p> <p>Initial work undertaken to look at possible accreditation of resources against the framework. Linked to CPD hours.</p>
<p>1.5 To complete Emergency Services resources package</p>	<p>Pilot training package completed and to be rolled out in two pathfinder areas – Dyfed Powys Police and South Wales Fire and Rescue in 2019/20</p> <p>Train the trainer model developed as part of the package development</p> <p>Implementation plan produced</p>
<p>1.6 To support Mental Health Training Adults</p>	<p>Aspects specific adult mental health training has been rolled out across Wales</p>
<p>1.7 To scope an evaluation of the Learning with Autism scheme</p>	<p>Initial work re proposed model, impact measures, pilot settings etc. has been undertaken. The framework and method have been finalised to roll out in 2019-20</p>
<p>For further information, please see Chapters 1,2,4 and 8 of the Annual Report 2018/19</p>	

2. Training including development of new resources	
Activity	Achievement/ Outcome
2.1 To develop new resources concerning behaviour management training for parents/professionals	<p>Initial scoping undertaken re issues. Linked with IASs that had delivered specific behaviour management training to look at uptake and future developments. Further research is needed in this area to ensure that any development does not duplicate existing provision, is effective with a strong evidence base and can be used by parents.</p> <p>Some IASs areas already rolling out Parenting Behaviour Management courses – the feedback and outcome information will be used to inform work in this area in 2019-20 and 2020-21</p>
2.2 To develop new resources in relation to increasing knowledge and understanding of co-occurring mental health and autism in Children and Young People (within CAMHS and Children’s Social Services / Education teams - Powys work)	<p>Initial scoping with autistic young adults who had been in contact with specialist CAMHS services was undertaken. In addition, meetings have been held with autistic adults who have developed long and enduring mental health issues to look at what could have helped them when their difficulties began. This work has taken longer than anticipated as those involved needed additional time to feel comfortable discussing their lived experiences.</p> <p>Meetings with Hywel Dda and Powys ND Services have been held to look at possible model and roll out. Specification in draft</p>
2.3 To develop an access to leisure programme - adults	<p>This has been rolled out via the “Can You See Me” campaign and in partnership with IASs and ASD Leads. The team have also trained such groups as the Ospreys, Swansea City Football club, and the National Museum of Wales.</p>
2.4 To further develop post diagnostic support for the parents / carers of autistic children/ young people	<p>The parent carer film has been produced – this involved parents and carers and autistic young people in addition to professionals.</p>

	The project took longer to complete because it was co-produced but the end result was worth the extra time.
2.5 To develop a Further Education and Work Based Learning programme	<p>The “What is autism?” FE and WBL films produced – co produced with autistic people, parent carers and professionals.</p> <p>Task and finish groups established – via Colegau Cymru and NTF Wales.</p> <p>Resource packs for professionals and autistic people produced in draft. To be completed and rolled out for the new academic term in September 2019</p>
2.6 To review and develop appropriate post diagnostic support for Adults	<p>Post Diagnostic programme has been produced by 21 High Street and IASs (C&V and Gwent). This has been distributed to all IASs via the National ASD Development Team.</p> <p>Scoping work re the existing adult guides has begun. Feedback has been sought from some autistic adults and IASs. A much larger exercise is planned for 2019-20 to look at content, format and distribution</p> <p>A mapping exercise has been undertaken via the Community of Practice to look at existing post diagnostic support, sharing of best practice and any significant gaps.</p>
2.7 To further enhance early years resources with “Ble Mae Teifi?” campaign	A small catalogue of “Teifi” photographs have been collected to be used to promote the Early Years Scheme.
	For further information, please see Chapters 1, 2, 3, 4, 5, 6 & 7 of the Annual Report 2018/19

3. Supporting further development and embedding of Integrated Autism Services	
Activity	Achievement/ Outcome
3.1 To further support the effective implementation of the IAS across Wales	The IAS leads meetings and the Community of Practice have been facilitated throughout the year by the team with a strong focus on effective implementation and delivery. Specific training for the IASs has been developed by the National Team and is being rolled out across Wales. All 7 IASs are developed and operational across Wales
3.2 To review and update the guidance for IASs	The guidance has been reviewed and updated in collaboration with IAS leads
3.3 To develop and support the implementation of a data / performance monitoring system	A key data set has been developed to be rolled out in 2019-20 to be facilitated via Data Cymru. <i>The resource and time required to achieve this agreement with the IAS leads should not be underestimated.</i> The “Outcome Star” distance travelled planning tool is being utilised in every IAS. A full programme of training has been commissioned and delivered. An all Wales outcomes model is being developed and implemented. A suit of group interventions and outcome measures is being discussed to be implemented in 2019-20.
3.4 To review the ICF Reporting Framework	This has been completed as part of the data set and reporting framework work and will be incorporated into that system.
3.5 To increase awareness and understanding of the IAS across Wales	The IASs remit, background etc., form part of our core presentation that has been presented at conferences, RPBs, Head of Inclusion Forums, and at all our awareness raising or training events.

	The National Leads have engaged with many Local Authorities during 2018/19 in every region
	For further information, please see Chapters 1, 2, 3 and 10 of the Annual Report 2018/19

4. Facilitating Networks

Activity	Achievement/ Outcome
4.1 To facilitate the National ASD Leads Forum	<p>This has met 4 times in 2018/19 – one session was a joint meeting and exchange of practise session with the IAS Leads. There was a clear work plan for the year to explore such topics as:</p> <ul style="list-style-type: none"> ○ The role of the ASD Lead ○ The Autism Bill ○ The Code of Practice for Autism Services ○ How to roll out the resources in an effective and sustainable manner ○ Knowledge and good practise exchange
4.2 To facilitate the National IAS Network	<p>This has met 4 times in 2018/19 – one session was a joint session with the IAS Leads for knowledge exchange. There was a clear work plan for the year to explore such topics as:</p> <ul style="list-style-type: none"> ○ The data set ○ The interface with existing services ○ Reporting mechanisms ○ Measuring outcomes ○ Issues and concerns regarding the IAS model ○ Best practice
4.3 To develop and establish a community of practice for adult diagnosis and IAS implementation	The Community of Practice has been established. Via the group the following have been agreed:

	<ul style="list-style-type: none"> ○ Adult diagnostic pathways ○ Agreed quality standards ○ Post diagnostic support ○ Guidance ○ Referral routes <p>In addition, the group has shared best practice, fed into research and learned of the latest research from a range of universities and individuals.</p> <p>Established an effective space to share experience, discuss issues and share solutions.</p>
4.4 To progress engagement with housing providers in order to highlight specific issues to be considered in providing housing for autistic people (social housing sector and PRS) and ensure any specific needs of autistic people can be met by housing providers	<p>A task and finish group of autistic adults, parent carers and professionals (housing and autism) was established.</p> <p>Revised Housing guidance aligned to the Housing (Wales) Act has been produced.</p>
	<p>For further information, please see Chapters 1, 2, 5, 7, 9, 10 & 11 of the Annual Report 2018/19</p>

5. Working with partners and stakeholders, including Welsh Government	
Activity	Achievement/ Outcome
5.1 To develop an engagement strategy, with a focus on co-production	<p>The engagement and participation strategy was co- produced and the draft was launched at the Going Gold Event at the Senedd on World Autism Day.</p> <p>The strategy was shared on ASDinfoWales for consultation.</p> <p>A mailing list of autistic people and parent carers who wish to be involved in the process has been compiled. This will be continually updated and amended depending on the focus of the work.</p>

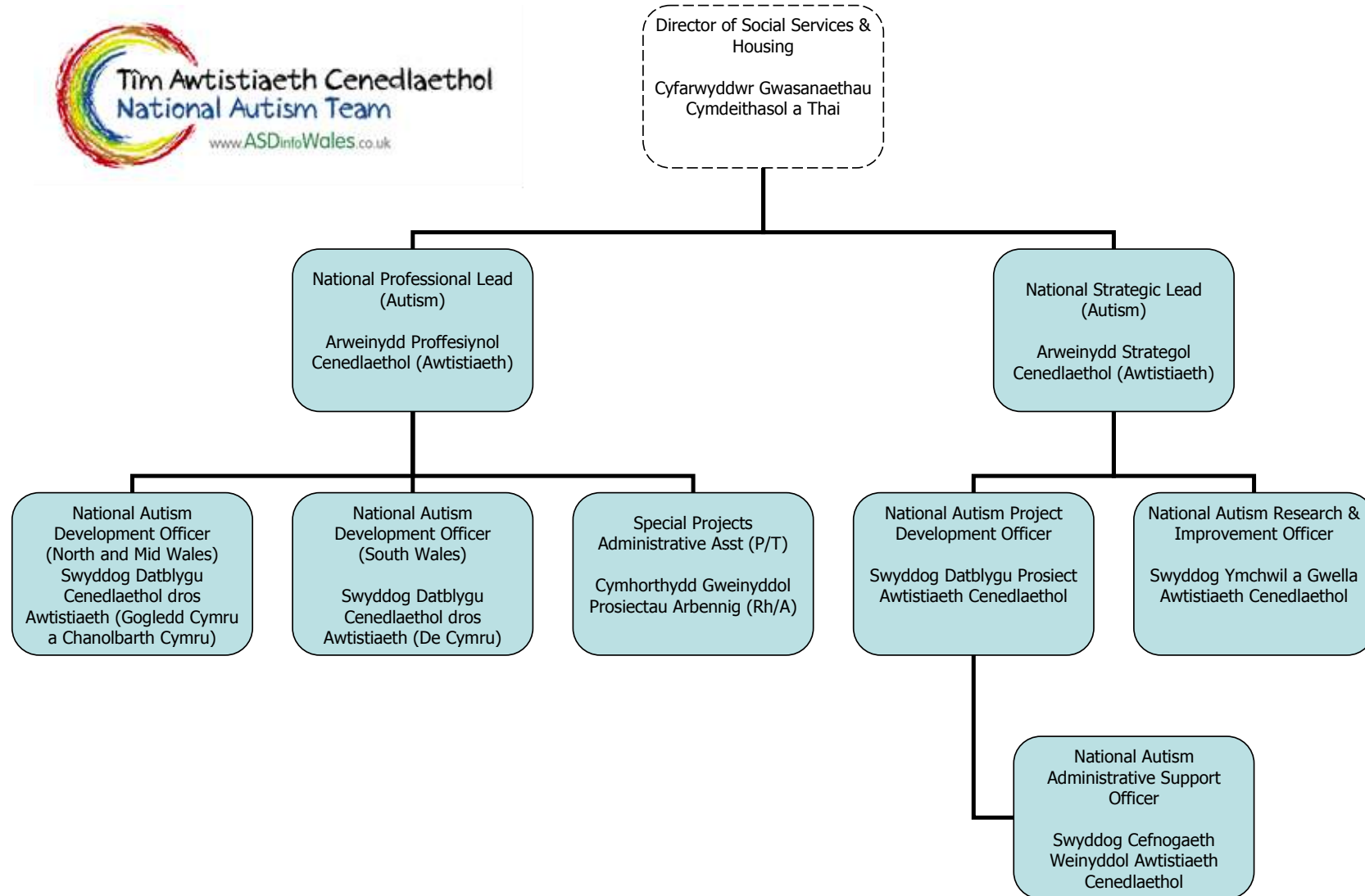
<p>5.2 a. To support the development of WG Code of Practice on the delivery of autism in Wales and work with local authorities, health boards and other partners in implementing the requirements of the Code when published</p> <p>b. To maintain an overview on the progress of the proposed Autism Bill and support its development, if appropriate, through highlighting the positive on-going work on autism across Wales</p>	<p>a) the team helped facilitate the Code of Practice consultation events</p> <p>b) the team helped to coordinate the response to the proposed Autism Bill – this included giving evidence to the Health, Social Care and Sports Committee</p>
<p>5.3 To establish and facilitate new governance arrangements/advisory board to oversee delivery of work of the National Development team and to drive improvements in identified priority areas for ASD</p>	<p>Initial work has begun on establishing the board and management group (terms of reference drafted etc.,)</p>
<p>5.4 To progress an awareness raising campaign for autism in Wales</p>	<p>This has been the cornerstone of our awareness raising, training and engagement work.</p> <p>The team has presented at a number of conferences, awareness raising and other events including the Autism Shows, the Education Show, Housing events, Professional networks etc.</p>
<p>5.5 To support and enable development of stronger links between Regional Partnership Boards and ongoing work at local and regional levels on autism</p>	<p>The Strategic Lead has met with each RPB, with each IAS lead and presented on the work of the Local Authorities at a local level, the IAS and the wider autism agenda. This is ongoing work.</p> <p>The team have attended regional events, stakeholder groups, steering groups, planning days, awareness raising days etc. all over Wales</p>
<p>5.6 To further contact with other sectors to raise awareness of IASs and achieve senior level buy in and commitment to contributing to work on autism as appropriate</p>	<p>The team have met regularly with 3rd sector partners e.g. the NAS, the Autism Directory.</p> <p>The team have also made key strategic links with elected members and senior officers in Local Authorities, senior officers in Health Boards, Universities, etc.</p> <p>The team have developed a MOU with Public Health Wales and developed a joint work plan which has been agreed between the WLGA and PHW.</p>

<p>5.7 To coordinate an Autism Wales Conference in partnership with PHW, NAS and other key stakeholders</p>	<p>A national conference was held during World Autism Week “Promoting Autistic Wellbeing” in Swansea at the Liberty Stadium. The Event was co-produced with autistic people, parents/ carers and professionals. It was a self-funded event and £14k of sponsorship was secured from public, private and third sector partners.</p>
<p>5.8 To support National, European and International Exchange of Good Practice</p>	<p>The work with Cardiff University’s School of Psychology, Wales Autism Research Centre has continued with increased engagement with European partners in Italy, Latvia, Lithuania and Spain. The SIGNs project / Birthday Party film won Cardiff University’s Innovation & Impact Award for partnership working in Healthcare in 2019, including one that was the “People’s Choice”</p>
	<p>For further information, please see Chapters 1, 2, 5, 6, 7, 8, 9, 10 & 11 of the Annual Report 2018/19</p>

June 2019

Sara Harvey – National Strategic Lead for Autism
Wendy Thomas – National Professional Lead for Autism

Appendix TWO – National Autism Team: Team Structure



Appendix THREE – IAS and ASD Leads Case Studies

The following case studies have been collated from examples of practice across Wales during 2018/19. They range from examples of general intervention in support of individuals with autism and parents and carers by the ASD Leads, to case studies specific to the Integrated Autism Services (IASs). Further case studies can be found on the ASDinfoWales website.

Cardiff and Vale IAS

The Integrated Autism Service Clinical Psychologist and Highly Specialist Occupational Therapist (OT), diagnosed a man in his fifties with Autism Spectrum Disorder. In the post-diagnostic follow-up session, he and his wife spoke about their autistic son who was in his twenties. They said that he was diagnosed a couple of years ago and had not received support. The son was living at home with them and struggling with significant anxiety and problems in the workplace. The OT suggested they tell him about the IAS and ask if he would like to come to meet to discuss his support needs. The son agreed and accessed the IAS with support from his mother. Unfortunately, soon after he began accessing Occupational Therapy, he and his father were the victims of a physical assault which caused significant trauma and a worsening of his anxiety and deterioration in functioning at home and work. The OT provided the following interventions over several months:

- Information about autism to the client and mother to understand some of his difficulties and behaviours
- Occupational Therapy and Sensory Processing assessments to help identify triggers for anxiety
- OT Interventions to develop anxiety management strategies which utilised sensory activities and skills.
- Liaison and recommendations to the court and victim support in order to ensure that the client and his family were supported appropriately when giving evidence about the assault
- Using information gained in the OT assessments to produce guidance and recommendations for the client's employer. A joint meeting with the client and his manager led to increased appropriate support at work and significant changes to his work hours
- Sign-posting the client to leisure activities to help him build his confidence and self-esteem

Outcomes:

- The client gave evidence at trial which would not have been possible without support.
- He returned to work and is significantly less anxious.

- A significant reduction in his anxiety which meant that he no-longer felt a need to access specialist trauma support with IAS Clinical Psychologist.
- An observable improvement in his confidence and feedback that he is much happier in his life, enjoying work, and doing things that he enjoys.
- Feedback from his mother that he is coping better with problems and needing less support from her.

Feedback:

“It would be my pleasure to give feedback on the service which I have received from the IAS. I don't have any negative views regarding the help with you have given me, everything was positive even though at times I was really suffering from extreme chronic anxiety so I wasn't taking it all in at times. Since my extreme depressive episode last Christmas I feel I have become a totally different person, with the fantastic new working pattern which I was granted thanks to the IAS, my confidence has doubled & I feel my assertiveness/speaking out has really improved since I started work again. I am planning to see my close friend Aidan on regular occasions & my spark has certainly come back too! When I went on the sick over Christmas I felt my life was over, I thought I had lost my job; suicidal thoughts did enter my mind on occasions when I was at my lowest & I wasn't interested in anything even communicating with my worried friends & family. My whole self worth & care totally vanished, without your consistent help Lucy & supportive manner I honestly believed I could have not made it through that horrible time that I certainly don't want to revisit ever again. My employer & my family/friends are now more aware of my autism at its worst & I am more aware in recognising the signs of my anxiety coming back — not eating properly, sleep deprivation, tightening chest upper muscles, not communicating as much as I usually do & not thinking straight/logically but if they do arise I know how to manage & deal with them more effectively from the techniques shown by my therapist.

Since I have been back in work I wear an Autism Awareness lanyard & pin badge to raise awareness of my condition, Sainsbury's my employer & customers are a lot more understating of me now which helps an awful lot. The IAS put me in touch with 21 High Street who is continuing to support me in work & even though I have now been discharged from the IAS if things do deteriorate again I know they are always on hand in the future to help.

I can't thank Lucy & the IAS enough for how these little changes have made my life so enjoyable again & worth living to the full. Thank you so much!”

Lessons Learned:

When working with a person with autism, support for the family, friends, employer and other networks is often the most helpful intervention.

Cwm Taf IAS

Beginning in January 2019, the Positive Behaviour Support (PBS) course for parents ran over eight weeks. The course was designed to provide strategies and methods to parents of children with ASD which could help understand and manage behaviours that challenge in the context of ASD.

A variety of topics were covered week-to-week, including self-care strategies for parents and carers, understanding reinforcement, sensory processing difficulties, communication and restrictive eating behaviours.

Parents were asked to complete an evaluation questionnaire at Week 1 and again in Week 8 to gain an understanding of how helpful the course was for them and share their experience.

Parents also completed an evaluation form at the end of Week 8 e.g. asking how they will apply the learning and if there were any improvements that could be made.

Feedback:

Some of the comments on expectations from the course taken from Week 1 include:

- *“Refresh memory on how to manage behaviour. Find socialising opportunities for my son to get out and about more.”*
- *“Looking for anything that will make life easier for my son and me.”*
- *“To have coping strategies and understand my son’s frustration.”*

Some of the comments from the evaluation form from Week 8 include:

- *“It has helped me to start to understand behaviours and the reasons for the behaviours and speaking to other parents and understanding their difficulties.”*
- *“To understand the behaviour better, speaking to other parents and share their opinions.”*
- *“The course should be longer so more time for discussion.”*
- *“Not being able to have more 1:1 advice”*

Lessons Learned:

At the end of the course, the team reflected on any lessons that were learnt. The initial idea of an introductory week focusing on behaviour that challenges proved too ambitious and was changed to focus more on self-care strategies. The possibility of setting

up a drop-in clinic for 1:1 advice on behaviour that challenges was raised. The small attendance of the course was a factor that made the team ensure that more parents were to be invited to any future courses.

Gwent IAS

I is a 19 year old young man who was diagnosed with ASD in 2017 by a Consultant Psychiatrist whilst admitted to a mental health inpatient unit. On discharge, he retreated into his own home, only going to friends' houses if he had a lift from door to door. He continued to use cannabis, developing an over reliance, which created additional issues. I had been discharged from secondary mental health services and a referral came into IAS via his social worker at the point of discharge. IAS supported I for a period of five months from November '18 – March '19.

I was reluctant to engage with 1:1 support due to previous failed contact with other services. The IAS support worker was able to gain his trust through a shared interest in rugby. I was then able to identify the following outcomes from using the service:

- Improved general health and overall well-being (by making changes to his daily habits)
- Re-built confidence to return to rugby training with realistic expectations of himself (previously he had been unable to return to play rugby as he knew he couldn't play to his previous standard and felt disappointed in himself)
- An increased insight into his diagnosis
- A new ability to make longer term goals, for example, regarding employment and education.

At the point of referral, I was too anxious to access the Post Diagnostic Course, and so his IAS support worker discussed this on a 1:1 basis for him to relate to personal barriers. Tensions at home also improved as I's mother attended the Post Diagnosis Course for Parents and Carers of Adults with ASD, which increased her understanding of autism and how to support I.

To support him with his anxiety, the service utilised the five-point scale to help him identify when he was getting anxious to enable him to put in interventions to stop it getting to crisis point.

Problem solving techniques and tools were used to support I to make a plan to return to play rugby for enjoyment and exercise.

I ate healthier meals.

I now completes a list of jobs left for him by his mother to help her.

I stated he now understands his autism and how it impacts upon his life and can use different interventions to cope so that his autism doesn't rule him or hold him back.

I is also realistic about the support he still requires but is able to access this through his mother, by playing rugby, and his now wider circle of friends to whom he has disclosed his diagnosis.

Rhondda Cynon Taf ASD Leads – Autism Awareness Training in Library Setting

Training in regard to Autism awareness for the Rhondda Cynon Taf Library Service was requested by the Head Librarian following an incident at one of the branches. Several pupils access public libraries either through school visits or with their families, making this training critical.

Three individual training sessions were held in Rhondda, Cynon and Taff. These were attended by 18 members of library staff. The training focused on awareness of Autism, traits, communication, visuals within the library and sensory needs. The staff were provided with an adaptable Social Story and strategies for helping a person with Autism.

Feedback:

- Libraries being mapped with colour coded visuals to support
- Designating a quiet area with low stimulation
- Small sensory objects that young adults or adults could access
- 'Autism Friendly' sessions, potentially also offering community links between families and provide information about other services

Staff were asked to complete both a pre and post impact evaluation form. Prior to the training, most staff rated their understanding, confidence and knowledge as either 'satisfactory or 'poor'. All staff indicated that these areas had increased to either 'good' or 'very good' by the end of the training, and 17 members of staff rated the training as 'very good'.

Some of the comments from the post-evaluation form included:

- *"I found out more about the traits of an autistic person, and the best ways to approach any difficulties or struggles they may have."*

- *“I have better knowledge of how to approach an autistic person and also to offer resources to help them adapt to the library environment.”*
- *“Making me more aware that we already meet many people on a day to day basis who may be AS and being confident in dealing with this.”*
- *“Continue with high-quality training as we received today, possibly with setting up the next step.”*

Following the first training session, staff were keen to develop their working practices and began discussing ideas that could be used with staff from other branches who had not yet attended the training.

Furthermore, Aberdare Library is set to trial mapping the library and using the social story, the ‘Autism Friendly’ sessions are being considered, and Pontypridd Library is due to relocate, so a social story and map would assist with the transition for library members.

Lessons Learned:

In terms of further scope for development, libraries may need support with individualising social stories for each library. The social stories are also to be shared with schools.

Torfaen ASD Leads – Sensory Life Team

Mr X has a severe learning disability and autism, which is a lifelong developmental learning disability that effects how Mr X relates to people. Mr X is also very sensory orientated/seeking. Mr X lives in a group home with two other individuals. Mr X had limited opportunities for social interaction and was not involved in any community based activities prior to attending day service. Mr X also has a very limited attention span and doesn't engage in any activity longer than 20 minutes. Mr X understands most simple instructions but needs structure and routine. If this is not followed Mr X will become agitated and has a tendency to abscond. A multidisciplinary team were involved in developing his intervention plan at the day service he attends, which included a health & safety officer, occupational therapists, social worker, as well as a close working relationship with day service staff and house staff. Due to Mr X's short attention span, building relationships and feeling comfortable in his new environment, his transition was a very slow and an in depth process. This started with Mr X visiting the day service to meet with specified staff and building relationships and the day, (from 5 minutes to a full day). Mr X has a very detailed person centred timetable with activities lasting a maximum of 15 to 20 minutes, in between these activities there are various items of interest available that occupy Mr X to keep him engaged. During the transition period 6 weekly multidisciplinary meetings were held to assess and gain successful outcomes for Mr X. Initially Mr X was supported by 2 day service staff members and 1 house staff member in one area. However, over year this has now been

reduced to 1 day service staff member and Mr X accesses all areas within the building. Mr X is successfully attending day service for 1 ½ days per week, ½ a day being in the community within a group setting with 1 x day service staff member.

Feedback:

Mr X has successfully transitioned into day service. Day service has received positive feedback from the individuals home, staff have reported that Mr X looks forward to attending. Mr X also shows this himself in a non verbal way to day service staff that he is happy in his new environment as he now trusts staff and accesses different areas within the building. Mr X is now accepting new activities, which include accessing community based projects, socialising within the community, using public transport and interacting with other people has increased. Mr X will also tolerate a small group of individuals in a group setting. As Mr X's transition has been successful, involvement from the occupational therapist, health & safety officer and social worker has been withdrawn at present. Mr X is settled in his daily routine which proves that the intervention received was hugely successful.

Lessons Learned:

We have learnt the importance of taking a person centred approach, at the individuals pace, with the co-production of a multidisciplinary team. An individual person centred structured timetable and setting achievable goals as well as having the correct environment has benefited Mr X to become more confident and raised his self-esteem, which in turn has enhanced his daily living skills. It is important to document, record and hold regular meetings with the staffing team to reflect on what has gone well and what hasn't gone so well in order to adapt and progress further. Continuity of a staffing team which have been skills matched and the importance of coproduction to achieve the best possible outcomes for the individual. It has also enabled the staffing team to develop their skills and use the information learnt to use with other individuals and progress other staff with the newly acquired skills. It has also enabled staff to identify their own individual training needs. Staff have grown in confidence to enable to develop the service further and are looking forward to new the challenges ahead.

North Wales IAS

An individual was referred to the IAS from the Community Mental Health Team for support. The individual had severe anxiety and periods of very low mood, which led to self-neglecting behaviours. The individual had difficulties with social communication and in social situations which was leading to problems at work. The individual felt that she was being victimised at work. The individual had suffered extreme trauma in her life and felt that she had no understanding of her autism.

The individual received 1-1 work around strategies to manage anxiety and low mood. Resources were provided and interventions were put in place, such as mapping anxiety levels and recording difficult social situations which were subsequently talked through. The individual alongside the IAS worker created social stories for difficult social interactions, which the individual created and drew up herself. The individual applied these in her workplace.

Following the support, the individual reported that she is happy in the workplace and has the confidence to openly discuss with her colleagues when she is unhappy or doesn't understand something. The individual states that she is happier in mood and now interacts socially and has developed a larger social network. The work around developing a better understanding of her ASD has led to her gaining enough confidence to discuss it with people.

Feedback:

Feedback was given verbally and through written communication throughout the support. The individual in question was pleased by the involvement of the IAS, and especially the flexibility of appointments that fitted in with her.

A comment from the individual in question.

"I've really found going through situations and analysing them with you useful, I've also found your way of explaining things super beneficial to me whereby you go step by step rather than delivering a huge amount of information that leaves me feeling overwhelmed. Would also like to say a special thank you for your dedication to helping and not giving up on me like so many people have before! Thank you again."

Lessons Learned:

A person-centred approach when supporting an individual is vital. It has shown that there is a need to work collaboratively with the individual and to make sure that they feel happy to meet at a time and place that they feel comfortable in.

Conwy ASD Leads – Conwy Connect

Conwy Connect for Learning Disabilities was set up in 1997 to help promote the rights of people with a learning disability living within the County of Conwy in North Wales. Its aims include ensuring people have equality of choice and opportunity in the community they live in. The service offered musical freedom for adults, and then youngsters with a diagnosis of autism within Conwy. The sessions consisted of 2 musicians. A drummer / percussionist and a guitarist. Each session lasted for 1½ hours and lasted

for a period of 18 sessions over 5 months. The intention behind each session was to allow members to have the opportunity to express themselves musically. The members were offered a selection of percussion instruments / Tom Tom drums / box drums / rain makers/ electric guitars / acoustic guitars / bass guitars and a slider guitar. As confidence grew members created their own musical beat which others joined in with, and also began to utilise their voices for musical interpretation.

Those that wished to were also able to learn and develop their guitar skills.

The sessions were held on a weekend and were addressing inclusion, avoiding isolation, encouraging socialisation, confidence and the opportunity to learn new skills.

Individual outcomes were measured by their evident enthusiasm. The way that they spoke to other members encouraging participation. Attendance each week. Music was recorded within the sessions to highlight the levels of enjoyment.

Social interaction improved as well between members who have not previously appeared to have interacted within other activities.

Feedback:

The sessions have raised a huge amount of awareness regarding autism for the musicians in particular. They have both shown how well they are able to adapt to individual needs, have a high level of respect and patience for our members and their enthusiasm to work with autism again. I believe this will also have a positive reflection upon work with Connect Buddies and other musical sessions they organise and participate with in the community.

The sessions have seen members grow in confidence and mix with other members that are not usually attending the same activities. A lovely example is that two of the members began creating their own beat, sharing the drums, and singing their own tunes together bouncing off one another. They were having such a great time everyone else was laughing and joining in with them. Other members who have initially appeared shy have also had a real enjoyment for the session and their confidence has grown considerably.

Lessons Learned:

The sessions opened up to children who had enquired part way through the time period following confirmation this would be allowed. The sessions had a healthy mix of children and adults within them which worked really well. It would have been good to have had the confidence to have done this from the start.

The members who enjoyed the guitars developed each session they attended as they were taught further skills and their confidence was evidenced through asking for the PA system to be louder so they could be heard, through starting a set or ending one and through wanting to play solo. Members have so many skills and talents. To have the opportunity to help people embrace that is fantastic, and that all would like this to happen again is amazing and hopefully this can be made to happen.

Powys IAS

An introductory drop-in workshop session in Newtown was arranged for anyone with an interest in autism – autistic individuals, parent-carers, and professionals – to explain what the IAS does (and doesn't!) do. It was also a chance for people to ask any questions they had about autism and the provision of services. The aim was to provide good quality information to a number of people in a short space of time (a one-hour session) and also to referrals for issues that could be resolved by face to face contact with one of the team in the workshop. Feedback was taken verbally, and attendees also completed a form asking them what topics they would be interested in attending future workshops in, if indeed they felt that workshops would be beneficial to them.

Feedback:

There were some initial reservations from participants around things regarding the length of diagnostic waiting lists, and expressions of disappointment at some of the things that the IAS is unable to provide. However, the overriding feedback was appreciation that the service exists and is operational and making efforts to improve things. Attendees said that being able to talk to someone in person made a difference, and they appreciated getting answers to their questions, both about the service, autism in general and wider issues such as the SEN system, benefits system etc. Everyone expressed an interest in attending further workshops and obtaining more information from the service, and gave a number of ideas for topics they would be interested in. E-mail addresses were collected via the attendance sheet and one family was given a referral form as they were interested in direct support from the service.

Lessons Learned:

The workshop was held at the premises of Siawns Teg, a charity in Newtown who were pro-active in promoting it amongst their autistic clients. Posters were also put up at NHS venues and other charities in the area, which helped. The purpose of the workshop could have been clearer, but with such a generalist event it was always going to be difficult. The over-riding lesson from the workshop, is that getting 'out there' and seeing people face to face, so that people can literally put a face to the service, is of

great benefit to the service and to the perception of the IAS by others. It is also a way of 'nipping in the bud' potential referrals by the provision of good quality information.

Western Bay IAS

I was attending a well-being event in the Bridgend area, a teenager came over to look at some of the information we had and asked if she could borrow the "SIGNS" poster. A little later whilst I was circulating I noticed her and her mum in the corner and she was gesturing at herself and pointing at the poster. I went over to check if they were ok and the young lady said that she has thought for a while that she may have autism. Her mum described her as bright and lovely to be around but that she struggled in several areas of her life. The young lady said that this scared her. I spent time chatting to her about why she was scared, and explained that diagnosis can be very positive and that many people with ASD have brilliant skills that can be used in many ways. I then shared my own positive story about a family member who was diagnosed with ASD. At the end of our chat I told her that if she does get a diagnosis not to be sad or scared but to throw a party to celebrate how awesome she is.

Feedback:

The young lady was reassured and left our conversation smiling and chatting with her Mum. She came back to visit our stall several times over the course of the event and enjoyed chatting to the team. The young lady's mother thanked me for chatting to them both.

Lessons Learned:

Pay attention to the people around you at these events. I felt like I touched the lives of that young girl and her Mum even if it was only in a small way, had I not been looking and circulating she would have left the event still feeling scared about getting a possible diagnosis of ASD.

West Wales IAS

An individual submitted a self-referral into the Integrated Autism Service for support in her home, specifically around using appliances. The individual was having difficulties recalling information relating to essential activities of daily living (routine and structure). This was increasing anxiety and impacting on functioning throughout the rest of the day. It also had an impact on

support networks around her, increasing dependency on family members. With the aim of reducing anxiety and encouraging independence, visual aids were introduced to assist with retaining specific information and steps to support executive functioning enabling everyday tasks. The individual now has more independence at home and does not require support from family members.

Feedback:

The individual gave excellent feedback and was eager to try using the additional accessibility documents created. The individual's confidence has increased, they have more autonomy in their home.

Lessons Learned:

Provide the individual with written/ pictured information/ diagrams on the steps to use appliances effectively.

Carmarthenshire ASD Leads – Carmarthen Adult Autism Advice (CAAA)

The CAAA social groups have been running for over 4 years, when the project first started it was identified that there was a need for a social/support group for autistic adults who were not accessing services elsewhere. The initial aim was to form a group for autistic young people to meet up twice a month with other autistic peers. We chose to use the bowling centre as many people were very anxious about socialising and didn't feel comfortable talking to others. It provided a clear activity to take part in, organised in a structured way, keeping to the same routine, sitting down initially as people arrived to have a drink, paying and collecting your shoes, putting the names up on the screen etc. This helped anyone who was very anxious to feel that they knew what was going to happen next. Very quickly people formed friendships and by the end of the first year, the group was having fun, there was lots of chatting and interaction. One of the strategies used to support people with their social interaction skills was through demonstrating in a real life setting. The lead of the group would always go first by paying and collecting shoes, ordering food etc, this gave the young people the opportunity to follow the lead whilst still feeling independent. Many of the young people were not comfortable showing that they needed support, this gave an ideal opportunity to become more confident. The second aim was to use the bowling group as a starting base to develop other groups and projects. Once people were comfortable in this setting, CAAA suggested and organised other activities and projects for smaller groups, whilst still continuing to run the bowling sessions. As the young people already knew each other and felt more confident, they were keen to be involved in other activities. Some examples of the other projects which CAAA has organised and run are; a photography project at a local farm/garden, volunteering in a local garden, a healthy eating cooking course, art club drop in, charcoal making project at the National Botanical gardens, and an animation project – making a short film. Outcomes for the individuals can be measured by a rise in

confidence in the young people. Some of the young people have gone on to pass their driving test, find employment or go back to college, and now also participate in other projects across the county.

Feedback:

- *"The service has been invaluable and that it has boosted my son's self-esteem and confidence by him being able to enjoy social activities without the fear of being judged."*
- *"The service is the only service that hasn't failed me and allows me to spend time with like-minded people."*
- *"K's clubs, art, bowling and the projects she arranges give like-minded people a pleasant atmosphere 2 have fun and gain knowledge without worrying about upsetting people by certain behaviour issues such as not talking or even too much! They give a sense of wellbeing. May they continue."*

Pembrokeshire ASD Leads – Pembrokeshire Early Years Additional Learning Needs for non-maintained settings

Following Learning with Autism - Early Years training received by the National ASD Development Team we have been able to share information from the ASDInfoWales website and the Learning with Autism in Early Years pack with Early Years non-maintained settings. This information has supported the settings with strategies to use with children with ASD and who may require adaptations to their learning and daily environment. The supporting resources have also been helpful for Early Years settings in recognising the signs of ASD in children without a diagnosis. Toileting is an example of an area where advice was given to support the setting and to link with the parents to ensure the same phrase/signal was used at home and in the early years setting. This ensures a consistent approach minimising frustration for the child.

Feedback:

Feedback from the settings has been positive and the training has allowed the setting to adapt their approach to managing a common area of difficulty.