

WLGA Briefing

Driving improvements in services for Autistic People in Wales



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Autism in Wales

Autism affects approximately 1 in 100 people in Wales and the UK and can have significant impacts on the lives and well-being of individuals and families. The aim of the Refreshed Strategic Action Plan (2016)¹ is for autistic children, young people and adults and their families and carers to have their needs identified, understood, and to be supported to achieve their well-being outcomes. The priority areas of the Refreshed Strategic Action Plan are:

- Assessment and diagnosis;
- Meeting support needs;
- Awareness raising, information and training.

The Refreshed Strategic Action Plan provides a framework for an agreed programme of work to achieve these priorities and is supported by an associated Delivery Plan (2016-2020) and the Together for Children and Young People Neurodevelopment Diagnostic Assessment Workstream and Pathway.²

Integrated Autism Service

Wales' vision for an **Integrated Autism Service** (IAS) is one that helps to meet the unmet support needs of autistic people, where other services cannot meet those needs. It is helping to fill the 'gap' in the jigsaw of existing services. The IAS is a collaboration between health and social care, a truly 'integrated' service. To achieve the vision the IAS works closely with education and other services both statutory and non-statutory

Through consultation it was identified that many autistic people have unmet support needs, yet are not eligible for support from services and many adults fall into a gap between mental health and learning disability services. It was also identified that many children are not accessing the support they need in education and parent carers felt that they required

¹ www.ASDinfoWales.co.uk/refreshed-autism-spectrum-disorder-strategic-action-plan

² www.ASDinfoWales.co.uk/children-diagnostic-pathway

more support in meeting their child's needs. Often being unable to access support means that needs escalate - leading to crisis, including emotional / mental health problems for both the autistic person and those who support them.

Working closely with Welsh Government (WG), local authorities and health have established, or are in the process of establishing, 7 regional IAS's. They are funded by WG through the Integrated Care Fund, based on the Health Board footprints with oversight by the 7 statutory multi agency Regional Partnership Boards focusing on integrating health and social care. The IAS's collectively contribute to what can be seen as a national service with similar and consistent standards and practice, providing advice, guidance and offering practical solutions to a range of challenges.

During 2017/2018, Cardiff and the Vale, Cwm Taf, Gwent and Powys IAS's were launched in the first phase of development and became operational, while North Wales launched in June 2018. West Wales and Western Bay continue to make progress in readiness of launching later in March/ April 2019 and there will be an operational IAS in each region by April 2019.

The **National ASD Development team** played a key role in supporting the creation and formation of an IAS for Wales. The team is hosted by the Welsh Local Government Association and works in partnership with Public Health Wales. The National ASD Development Team has supported the creation and establishment of the IAS and will continue to do so for those areas not yet fully operational.

The team, facilitated the establishment of the National IAS Leads Network which works collaboratively with the Team and WG to, for example, finalise reporting ICF templates for the next financial year to ensure that information collected provides information on the outcomes and impact of the services. Further work to align data collected in the IAS and that collected in the Neuro Developmental services is being progressed.

A core data set has been developed for use by each IAS this will give clear information of diagnostic assessments - number of positive diagnoses, waiting times etc. In addition, each IAS will have detailed information of impact with regard to support and training. The data development will align with WCCIS with 2 areas becoming pilots for a recording system that has IAS specific fields on the WCCIS system. Each IAS will utilise the outcome star to measure distance travelled for each person accessing the service for individual support. This is an exciting development as the impact will be measured on a national basis using a highly regarded planning and assessment tool.

This development offers a unique opportunity to record not only diagnostic data but other qualitative and quantitative data. This in turn can be used regionally to inform planning and commissioning decisions across a range of organisations

Examples of good practice across Wales were collected for the National ASD Development Team 2017/18 Annual Report, these range from general intervention in support of autistic people and parents and carers, to case studies specific to the IAS's. Included below are some summarised examples but please take the opportunity to review them in more detail on our web-site www.ASDinfoWales.co.uk/national-asd-development-team

Cardiff and the Vale:

Contact was made by the HR department of a national pub / restaurant chain. They had an autistic employee in the region who was on the brink of being dismissed from his role. They were seeking some specialist input and support for the manager in the premises with a view to the employee keeping his job. 2 short meetings took place, one with the manager only and the second with the manager and staff member. The employee had not completed a mandatory online training module that was a requirement for continuing work. The meeting highlighted some areas of information around awareness that the manager and his staff needed to take on board. The ASDInfoWales site was recommended and accessed by the manager for further reading. The meeting further highlighted a difficulty in communication. The manager was being kind and alluding to the consequences of non-compliance. What was needed was speaking plainly and informing the employee that if he failed to complete he would be dismissed by Friday.

Employment is one of the things that makes a huge difference to people. Having a stable job and income is so important. People often only seek help right at the very end, so time is often of the essence. In this case, it was essential that help was provided in a very short time frame. Doing this simple thing and doing it quickly meant that in this case the employee kept his job.

Gwent IAS:

One individual (SO) self-identified difficulties in managing inter-personal relationships as well as traumatic experiences related to sex. The IAS responded to this demand by jointly delivering support sessions with a third sector partner. The SAFE (Sexual Awareness for Everyone) Project delivers peer led sessions that support disabled young women to understand friendships, relationships and keeping safe online.

SO attended three out of the four delivered sessions and responded positively to the peer led approach. SO said that she would like to share what she had learned with other young women. The SAFE project offered SO a volunteering position and SO will help to deliver an upcoming group in the Summer of 2018.

Powys IAS

A client received a piece of joint work with the aims of increasing independence and to break the cycle of returns to the crisis team and admittance to the ward. Mental health services continued to support the MH needs of the client whilst the support worker's role was to increase the confidence of the young person in accessing public transport to attend the social group without travel assistance.

He went from quiet and reserved, unsure, with head slightly bowed at all times to visibly walking taller, definitely more sure of himself and rightly proud of his achievement. The young man is looking forward to college in September and being able to attend the Social and Leisure group as and when he feels like without having to rely on others to get there.

This shows the beauty of collaborative working when each service plays to its strengths and simultaneously wraps itself around the person to provide the support they require. Having faith between services is as important as having faith between practitioners and clients.

Education, Swansea Council, Western Bay

An Outreach Service is provided to mainstream schools' staff and pupils who need support, or are at risk of exclusion due to being insufficiently resourced, trained or equipped to meet the needs of pupils with a diagnosis of autism. The service has successfully upskilled staff in these settings so that they are able to meet the needs of the pupils which have currently been referred across the authority within the last two terms (2017/18). A range of training, resources and 'job swapping'

opportunities and observations have meant that staff have a better understanding of autism and the strategies and approaches that are effective in supporting the pupils and ensuring they are part of the class and whole school. The service has been provided by a range of highly qualified and experienced staff who alongside the autism specialist for the local authority have gone into schools and opened their doors to staff to visit a setup, well-resourced and active provision at Ysgol Pen-Y-Bryn. Pupils are identified through the Additional Learning Needs panels and forwarded to the team who immediately start supporting and intervening with a fantastic success rate.

The feedback from schools, head teachers, parents, staff and the local authority has been incredibly positive and each case has been successful. There has been feedback from schools which has not only thanked the staff personally for their input which has changed pupils experiences in school and relationships with parents. It has also changed the mind-sets of staff who are now able, with the knowledge they have gained, to adapt their approaches, teaching and provision to meet the needs of pupils as they so deserve.

Whole school training in raising awareness of ASD and approaches and strategies to support these pupils needs to continue to be a focus across all schools, so that staff are sufficiently equipped to provide the best education for each and every pupil.

Autistic male, North Wales Region

"My experience of initially seeking help wasn't great; my GP didn't seem to recognise what are pretty clear traits, though masked as many adults do. When learning that it could be a queue of years, I decided to seek a private diagnosis. My diagnosis, though important, just confirmed what I already knew after intensive reading, but it has been key in seeking out reasonable adjustments at work. However, this increased self-awareness, through absorbing the plethora of useful information, lifestyle changes and self-acceptance, has resulted in considerable improvements in my health and wellbeing. I am now a volunteer with the IAS Team in North Wales and I hope to help others through my experiences.

It really concerns me that access to diagnosis is so slow for the vast majority, but thankfully there is now positive action in hand to help address this. However, diagnosis is only one part of the work that is needed. Working with what we have, by pulling together and supporting dedicated and hard working professionals is key to helping those on the Spectrum, who may otherwise fall between the cracks and end up in crisis. Diagnosis, pre/post diagnostic support, awareness raising, signposting, training, providing information (e.g. the excellent resource that is the ASDInfoWales website) and so on are all vitally important in my view and can't come soon enough."

Website and Resources

The IAS will have a pivotal role in supporting this. However, community provision and wider society will need to be aware of the needs of autistic people and how to support them for this to happen in the context of a social care model of disability. Parents, carers and families of autistic children and adults need advice and guidance to support them and increase society's understanding of the condition.

The National ASD Development Team continues to raise awareness of autism and develop and deliver training, awareness raising materials and supportive autism resources that can be utilised by the IAS, wider services, autistic people and all those who support them, including professionals. The National ASD Development team also support the co-ordination and delivery of training in line with the National Training Framework for Wales. The "Can You See Me?" scheme promotes awareness and acceptance in communities to improve access to community provision for autistic people. Specific training is available on the national website for sports and leisure providers and housing providers

(www.ASDinfoWales.co.uk/leisure-staff and www.ASDinfoWales.co.uk/housing-provider-scheme).

The team manage the National ASD website www.ASDinfoWales.co.uk, which provides support and advice for all professionals with an interest and role in autism and to ensure that the needs of autistic people are communicated to key stakeholders. Some of our resources are listed below.

Growing with Autism

Our Growing with Autism resources are aimed at parents and carers of children and younger adolescents. In this section of our website you will find a range of resources including a guide following diagnosis, advice sheets, 5 short films which provide an overview of autism and advice on other common issues including communication planning, coping with changes and visiting health professionals.

We have also developed resources to support peers and siblings in understanding autism. Teifi and Friends is an animation, voiced by the cast of Stella, which shows young children how to be kind and accepting to those with additional needs. Autism Superheroes is available as a story book and adventure comic strip story designed to develop understanding of autism for children of primary school age.

Learning with Autism

We have a series of resources aimed at educational settings from early years to secondary school and with a further education and work based learning programme currently in development. The Learning with Autism programmes are designed to help staff develop their knowledge and skills to support those with autism. Children and pupils are also encouraged to undertake learning with the Teifi and Friends, Autism Superheroes and Sgilti resources. Once all staff and pupils have undertaken the appropriate training schools can apply to become an Autism Aware setting.

Living with Autism

The Living with Autism resources include a supportive guide containing tips and advice to those that have received a diagnosis of autism. People are also able to create and download a personal profile to highlight their strengths and difficulties and ways in which others can support them.

Working with Autism

This section of the website has resources for those supporting autistic people into employment and for managers and co-workers for those working in HR. To support people into employment, we have developed the Living with Autism film, e-learning training, CV builder, searching for work tool and a skillset builder. For co-workers and managers there is the Positive about Working with Autism scheme which includes a charter to sign, advice and a training scheme for those working in HR.

This briefing note is a snapshot of the considerable number of resources available, funded by the Welsh Government and co-produced in a collaborative way with partners and stakeholders across Wales, including Autistic people, their families and carers. The National ASD Development team is also facilitating an adult diagnosis Community of Practice,

bringing together health and social care professionals in order to develop consistent assessment, diagnostic and support pathways across Wales. The team further facilitates a network of local authority ASD leads and IAS leads across Wales. These fora are critical to sharing good practice, exchanging knowledge and maintaining a key focus on the needs of autistic people, parent, carers and families.



ASDinfoWales_Resources leaflet_ENG.pdf