

Pembrokeshire County Council
Cyngor Sir Penfro

Inclusion Service
Gwasanaeth Cynhwysiant



ASD Strategy

2017–20

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Introduction

- 1.1 The Strategic Action Plan has been developed in response to what people with autism, their families and carers have said is important to them. We have also worked with a wide range of stakeholders to identify some key priority themes and actions that will make a real difference to the lives of children and adults with autism.
- 1.2 The aim of the Strategic Action Plan is for:
'Children, young people and adults with autism and their family and carers to have their needs understood, to be supported to achieve their own wellbeing outcomes and to lead fulfilling lives.'
- 1.3 The Social Services and Well-being (Wales) Act includes a number of specific requirements for local authorities to establish information, advice and assistance services. The Regional Partnership Board is also responsible for ensuring there are services, care and support in place to meet the needs of people in Pembrokeshire.
- 1.4 A key development is the establishment of the new National Integrated Autism Service.
- 1.5 This Strategic Action Plan sets out in detail the specific actions that will be taken, including how they will be measured and monitored. We want to see a real difference in the services, care and support available to people with autism and therefore close monitoring of progress and delivery will be essential.

Definition of Autism

- 1.6 We will continue to use the World Health Organisation's¹ definition of autism:

"The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by restricted, stereotyped, repetitive repertoire of interests and activities".

The autism spectrum is very broad and can affect people with all levels of ability. Although there is no cure for ASD, appropriate support and

intervention can help people to reach their potential. The Strategic Action Plan is for people on all parts of the spectrum and includes individuals who may also have a co-existing learning disability, as well as those diagnosed with Asperger Syndrome. It is difficult to estimate how many people are affected by ASD as studies vary. Current evidence suggests prevalence rates of around 1% of the total population or above. Therefore, based on 2011 Welsh Census data the number of people with autism in Wales is estimated to be approximately 31,000, although many of these may not have a diagnosis and will not necessarily be known to services. The term Autistic Spectrum Disorder (ASD) is interchangeable with the term Autistic Spectrum Condition (ASC). Pembrokeshire recognises both terms but for the purposes of this strategy has adopted 'ASD' in line with the NICE guidelines.

- 1.7 Many people with autism will have a co-existing learning disability. Others may have mental and physical health conditions. Research indicates the most prevalent issues are sleep difficulties, gastro-intestinal problems, glue ear, epilepsy, anxiety, depression, dyspraxia, dyslexia, obsessive compulsive disorder, attention deficits and hyperactivity. The presence of autism in addition to another condition can lead to complex difficulties which may not respond to traditional approaches. It is therefore important that practitioners identify both autism and the co-existing condition and plan the care and support accordingly to best meet their needs.
- 1.8 We acknowledge the importance of National Institute of Health and Clinical Excellence (NICE) guidance on autism. NICE is a widely recognised body providing authoritative advice and information on a range of health issues. In recent years NICE has produced several guidelines on the diagnosis and management of autism in children. The purpose of the NICE guidance is to drive and measure quality improvements and describe what a good service should look like. Health boards should take the guidance into account when planning autism services as they are the accepted benchmark of what good services should aim to provide. More information on NICE autism guidelines can be found on the website www.ASDinfoWales.co.uk or directly at NICE at <http://pathways.nice.org.uk/pathways/autism>. In addition to technical advice documents NICE⁴ has also produced information for family and carers of children and young people to accompany this clinical guidance.

2 Developments that have taken place in Pembrokeshire.

Since developing the Autistic Spectrum Disorder Strategic Action Plan in 2008, within Pembrokeshire we have made significant progress in delivering improvements to the lives of children, young people and adults. These include:

2.1 Health *(Dr M. Simmonds)*

Assessments now include a number of components such as multidisciplinary discussions, assessment clinics where both detailed history from parents or guardians and a structured face to face exercise is undertaken with the child or young person.

In some cases, it is necessary to undertake school observations or more extensive assessments such as the Autism Diagnostic Observation Schedule (ADOS).

Feedback from the multidisciplinary team's assessment and discussion is given to each family with sign posting to additional services and/or recommendations as indicated.

The All Wales DVD and Handbook for Parents and Guardians when a child or young person receives a diagnosis of an autistic spectrum condition is provided.

If a diagnosis is made of an ASC a profile for the child or young person is offered. This can be an online updateable profile which is an option within the ASDinfoales website.

At the completion of the assessment proves the child or young person is discharged back to the referrer.

The provision of some family support in the post diagnostic period is under development.

2.2 National/Regional Services *(Francis Rees)*

Learning with Autism programme's

Following the success of the Learning with Autism, Primary school programme, the Early Years has been launched in Pembrokeshire, with train the trainer sessions continuing to promote the programme. The Learning with Autism– Early years is available for all mainstream schools, early years' education providers, maintained and non– maintained early years' settings to use.

We have also launched a resource for secondary schools which includes a lesson that shows peers some of the challenges faced by young people

with an ASD during a normal school day. The lesson is designed to stimulate discussions and increase understanding.

Raising awareness about autism has the power to change lives, it encourages understanding, tolerance and respect, so that together we can all reach our full potential. All resources are available at no cost from the ASD Development team, funded by the Welsh Government and developed by the Welsh Local Government Association details can be found on our website www.ASDInfoWales.co.uk/professionals

Working with Autism

We have delivered Autism Awareness training to Workways Pembrokeshire and also representatives from Norman Industries. We have a range of resources online for employers to assist in supporting autistic people into employment and supporting them during employment. For autistic people seeking employment we have a range of tools to support in the search for employment including a Master skills dictionary, Personal Skills builder, CV builder, searching for work tool and Working with Autism App. For more information, visit our website www.ASDInfoWales.co.uk/employment

Supporting Children and Adults to Access Sports and Leisure Activities

Working with Pembrokeshire's Sports Disability Officer we have delivered train the trainer to increase awareness for those supporting children and adults to access sports and leisure activities in Pembrokeshire. For more information, visit our website www.ASDInfoWales.co.uk/leisure-staff

Can You See Me

We have launched a National Campaign to raise awareness of Autism in towns and communities across Wales. Our aim is again to increase understanding, tolerance and acceptance of autistic people.

Working in collaboration with the neighbourhood policing team, Milford Haven has achieved a Rainbow award with a range of shops, restaurants, cafe's, hairdressers, etc. The Torch Theatre and Phoenix Bowl receiving our resources in addition to the distribution of our Can You See Me scheme. We are now working on the Bronze award and also moving to Haverfordwest to commence the scheme with Pembrokeshire People's first. More information can be found on our website www.ASDInfoWales.co.uk/can-you-see-me

IAS Integrated Autism Service

The IAS for HDUHB is underdevelopment and will launch in late summer/ early autumn 2018. The service will provide diagnostic assessment for autistic adults (sometimes jointly with other services), support and advice

for children, adults and those who support them. The IAS will support parents and carers by providing advice and support, signposting to other services and delivering programmes for young people. This will include support and advice to help manage difficulties such as:

- sleep problems
- issues with eating
- challenging behaviour
- anxiety
- developing Social Skills

For adults, you will be able to get support from the service without needing to be referred by someone else. Staff in the service will be able to provide you with support and advice in relation to:

anxiety

social skills accessing leisure and recreational activities

developing your daily living skills

accessing other services such as healthcare or employment support or other difficulties that you may be experiencing

For adults that think they may have autism but do not have diagnosis, the IAS will be able to offer an assessment for autism if the autistic person wishes to seek this.

For those with more complex needs (where other services such as mental health support is needed), staff from the IAS will work with other professionals to ensure they are able to provide “autism friendly” support.

For more information, visit our website–

www.ASDinfoWales.co.uk/integrated-autism-service

2.3 **Education** *(Claire Bullock)*

The early identification toolkit for children with Autistic Spectrum Disorder is now well embedded. Results of the EY nursery communication screen (Hands on Communication) for N1 and N2 pupils are now recorded by schools on G2 as an early years intervention mark book. Over the past academic year, Early Identification and Intervention network meetings have been established for clusters of schools. The meetings take place after each half term following completion of each screening phase. This is an opportunity for Early Years Practitioners to discuss individual pupils and seek advice from specialist teachers and Speech and language

therapists. Additional resources and activity ideas are provided and good practice is shared.

Training for Hands on Communication and Hands on Literacy continues to be offered each term for practitioners new to early years.

Non-maintained nurseries now have resources for parents to borrow which support the activities recommended in the parent pack. The EYPDG grant was used to purchase toys and books. Colour coded prompt cards were made to link to each communication strategy.

Evaluation of progress data from these interventions indicates that, at nursery, following the Hands on the Communication intervention, over 50% of the children moved up one whole screening level or into the “no concern” level.

The establishment of an Educational Psychology Consultation – led delivery model (The Team Around the Pupil Parent and School) provides each school with a termly meeting to discuss early intervention around emerging needs and to identify specialist support for pupils with more complex needs. The meetings are attended by the specialist services advisory team and speech and language therapists and use solution focused approaches to joint problem solve across all agencies.

For those children identified at TAPPAS as requiring support for their social and communication needs, a communication forum is now in place made up of health and educational professionals to allocate support and provision.

The development of a school outreach support team, now includes 2 Advisory teachers and 2 outreach support workers, in the process of integrating with a wider group of advisory teachers, providing an early help offer for communication and specific learning difficulties team. This will include:

three Speech and Language Therapy Assistants (SALTAS), the appointment of an occupational therapist to provide support and advice to schools and families in relation to sensory needs

The successful pilot programme to support children in Y6 moving to Pembroke School, is being replicated with the Milford Haven family of schools

80% of schools are now trained in the Primary school Learning with Autism training programme. A version for Early Years settings and secondary schools is also being delivered to school staff this Spring. The increase of 8 additional placements at Portfield Special School.

The opening of Johnston LRC has created 24 placements for children with ASD. The service is working towards creating a support base for children with ALN and ASD in Milford Haven Secondary school.

A tool box of interventions for schools and Learning Resource Centres has been developed and is being piloted in the Bro Gwaun and Preseli family of schools.

A lending library of books and more costly resources are being trialled in the Bro Gwaun and Preseli cluster.

Implementation of a professional development programme for Learning Support Assistants, of which one module is supporting children with ASD. bespoke training to schools on request to meet individual needs and to help build capacity across a variety of settings.

Development of a website to provide information about autism and support strategies is taking place being launched at the end of the summer term.

Following a successful pilot, a Music Therapist is funded to work with to children at Milford Haven school to support engagement, anxiety and attendance.

The Inclusion Service are working closely with Pembrokeshire College to ensure that effective transition arrangements are in place for all pupils attending College. Key information about each pupil's additional learning needs (IDP) are fully shared with the College.

2.4 **Parent Support Services (Education)** *(Leonie Rayner)*

Parent Partnership– Parent/ carers can self–refer for advice and support through the duty desk 5 days a week, or via email. The service offers local, up to date and relevant information to parent/ carers about rights and responsibilities in a variety of ways, including face to face, information leaflets, phone, social media and partnership working with other agencies. The 'In House' Parent Partnership service allows officers to work closely with educational professionals to achieve timely outcomes for families.

Parent workshops– The service offers various workshops for parent/ carers to attend, including ‘Moving Forward After a Diagnosis’, ‘ALN Reform–updates’. We also facilitate workshops from health care professionals such as ‘Understanding language demands’ and ‘Surviving the school holidays’. These are held across different areas in the county. Parent Networking Groups– these are informal coffee meetings for parent / carers facilitated by an Inclusion Support Officer. The meetings aim to provide an opportunity to Network with other parents/carers of children with additional needs including ASC, and share experiences over a coffee. Parent carers can also gain further advice and information from the Inclusion Support Officers who facilitate. These parent network meetings are held in 8 areas across the county.

TAPPAS 3 – The meetings are held termly in each area and provide a range of advice and support for families about additional learning needs. Each term the Inclusion Support Team will highlight key themes or developments that are taking place locally or nationally. Parent / carers are offered 1:1 sessions with professionals including Advisory Teachers, Paediatric Occupational Therapist, Educational Psychologist, and a Parent Partnership Officer.

Targeted Saturday clubs across the county for children aged 5–18 years with a diagnosis or on the waiting list for assessment is provided by the Trinity Club offering the opportunity for parents/ carers to drop off their child with additional needs for 2 hours.

The after school club for children aged 5–16 years (Tots 2 Teens) runs 3 days per week and is open to all children who might benefit from it. As well as offering child care to parents it gives children/ young people an opportunity to interact with their peers.

Holiday Play scheme – This is a targeted holiday scheme for children with additional needs including ASC, offering childcare provision at reasonable rates for parent/ carers.

Annual Parent Conference– each year parent/carers are invited to a conference, which includes a Key Note Speaker within a particular area of additional needs; parent workshops and an opportunity to meet professionals. This offers parents a chance to have their voice heard as well as receiving updates from services.

Communication tools. There is now a parent/ carer Newsletter twice yearly, with updates from services, as well as our own social media Facebook and Twitter sites, with regular updates and events. The newly

developed Website offers parents an overview of services as well as attached specific information sheets for common theme areas.

2.5 Pembrokeshire College

2.6 **Social Care** (*Jonathan Griffiths/Jason Bennett*) TBA – Chase Adult Services

2.7 **Pembrokeshire People First**

Since developing the ASD strategic action plan in 2008 within Pembrokeshire, we have made significant progress in delivering improvements in the lives of children young people and adults. These include:

Don't Leave Me Out – 2015/18

Specific advocacy provision for people who define as higher functioning autistic.

Peer advocacy; self-advocacy group; social / communication skills training; reducing social isolation inclusion in wider community via participation in art and well-being events across Pembrokeshire; filmmaking

This group has now come to an end, although there will be one final session where members will be afforded the opportunity to complete the scrapbooks they have been developing.

Training – from 2016

Autism awareness training delivered by adults with ASC to statutory services, support providers and other Third Sector organisations such as CAB.

ASC US – 2018 / 2021

The steering group has evolved from the Don't Leave Me Out Group and will assist in the delivery and development of Autism Awareness and Acceptance Training. Additionally there will be opportunities for the development of Peer Advocacy and unique social opportunities. A small group of consultants who are high functioning autistic adults, with a range of experiences and expertise, alongside a facilitator from Pembrokeshire People First have been actively building on the Advocacy Awareness short course; to deliver a longer training course that covers not just awareness but acceptance too. The design of the course has almost been completed and very much focusses on empowering individuals to take the lead in telling their stories and talking about their experiences of being autistic. It covers areas such as gender, education, work, employment and some useful and practical tools and advice for practitioners and

participants in the course. In its final draft, the course now needs to be presented to the wider stakeholder group for additional material and information. We are actively receiving nominations for this course and will be planning to deliver over the next eight months. As we have been exploring the content of the course, we are already seeing opportunities to expand on certain areas and the possibility of developing further courses in the future.

All points included in the previous meeting continue to be a priority with some additional developments:

Training

Pembrokeshire People First regularly deliver learning disability awareness training, with ASC included as part of that day, this will continue.

Young Tudor Project – from 2016

Safe and enjoyable space for young people (13–18) with autism.
Self-advocacy group; social / communication skills training; film making; living skills.

Strategic

Pembrokeshire People First continue to play an important and active role in both local and national consultations, ensuring that the voice of ASC is included. Active engagement in the Autism Bill continues to be important piece of work.

Advocacy

Providing a specialist independent advocacy service, with an increase in referrals being received from Autistic people. Approximately 30% of our advocacy partners now define as autistic.

Community

Involvement in Can You See Me project
Development, with SpaceToCreate, of Take 5 film.

Other

All PPF activities are open to, and accessible to, people with ASC.

3. Local Action Plan (2018/20) Autistic Spectrum Disorder

This Strategic Action Plan includes 9 key priority areas for action. These have been based on what people have told us and build on what we have achieved to date.

3.1 Early Identification and Intervention – Children *(Pip Large/Claire Bullock)*

What do we want to achieved	What we will do	How will we know	Who is involved
Children with autism and/or autism traits are identified early	<p>Establish within all Early Year Settings the Hands on Communication Early Identification and Intervention tool.</p> <p>All settings are trained in using the tool and attend termly network meetings to share practice and children causing concern.</p> <p>Improve tracking of pupils identified through screening</p>	<ul style="list-style-type: none"> • Pupils identified through the screening tool make the appropriate progress; are monitored by the link SALT and follow up support and advice is put in place • A transition plan into school is established and followed through by the advising service for ASC. • Parent workshops provide support and training for families 	<p>Speech and Language Therapy team</p> <p>Specialist Teacher for ASC</p> <p>Parent Partnership Services</p> <p>ASC Third Sector Organisation</p>
Lead Officer	Claire Bullock		

3.2 Assessment and Diagnosis – children *(Dr Simmonds/Bethan Edwards)*

What do we want to achieved	What we will do	How will we know	Who is involved
Lead Officer	Dr Martin Simmonds		

3.3 Assessment and Diagnosis – adults *(Dr Helen Matthews/Sarah Dudley)*

What do we want to achieved	What we will do	How will we know	Who is involved
Timely assessment using evidence based approaches	Continue the specialist ASD Diagnostic service within the health board. Implement the IAS service within HDUHB	Individuals will not wait more than 26 weeks for assessment Audit of NICE Compliance, service stats, WG mandatory requirement Service user feedback	Adult metal health services (host arrangement for current diagnostic service and new IAS Service) IAS Strategy Board
Lead Officer	Sara Rees, Head of Service, Adult Mental Health		

3.4 Education *(Sue Evans/Claire Bullock)*

What do we want to achieved	What we will do	How will we know	Who is involved
<p>Children and young people will have their needs identified and met within a range of appropriate settings.</p>	<p>Early identification to be prioritised. A continuum of different kinds of provision, to be available to meet individual needs: –Bespoke 1:1 work by ASD support worker –Small Group interventions –Specialist school placements –Alternative curricula</p> <p>Ensure that a range of training linked to autism is available for all staff.</p> <p>Staff will have the opportunity to discuss concerns through multi-agency consultation group meetings such as the TAPPAS model.</p>	<p>Pupils will be identified and placed/supported appropriately.</p> <p>Progression will be monitored</p> <p>Regular review meetings to monitor progress and ensure current provision remains appropriate</p> <p>TAPPAS 1 and 3 meetings to indicate progress or otherwise</p> <p>Reports from other professionals/ASD outreach</p> <p>Monitor success of capacity building through referral rates for specialist services.</p>	<p>Communication Team (Specialist teacher and outreach workers)</p> <p>Speech and Language Therapist</p> <p>Parent Partnership</p> <p>School Staff</p>
<p>Lead Officer</p>	<p>Nichola Jones</p>		

3.5 Support Services for children and families (*Diane Beacroft*)

What do we want to achieved	What we will do	How will we know	Who is involved
Lead Officer	Nichola Jones		

3.6 Transition into adulthood (*Jason Bennett*)

What do we want to achieved	What we will do	How will we know	Who is involved
Lead Officer	Jason Bennett		

3.7 Access to support and services for adults *(Jason Bennett)*

What do we want to achieved	What we will do	How will we know	Who is involved
Resources and strategic developments			
Lead Officer	Jason Bennett		

3.8 Support for parents and carers *(Leoni Rayner/Sam Stone/Nikki Williams)*

What do we want to achieved	What we will do	How will we know	Who is involved
Parents and carers of CYP with ASD to be offered information and support to inform and empower their parenting.	Provide and facilitate workshops, information sessions, and 1:1 consultations with specialists. Facilitate opportunities to develop peer to peer networks. Provide a duty telephone line for advice and support.	Through ongoing consultations with parents and carers. Through digital and non-digital evaluation processes. Reduced number of referrals to specialist services.	PPS. Advisory teachers. Educational Psychologists. Health professionals.
Facilitate opportunities for parent carers to meet to develop peer to peer	Parent network groups, termly cluster school meetings,	Evaluations and feedback methods. Measuring engagement figures.	PPS. Inclusion support officers. Families

<p>networks and support</p> <p>Parents and carers to have opportunities for breaks from caring responsibilities. Social interaction opportunities for children with ASD.</p> <p>Improve communication for families and multi agency professionals and schools.</p>	<p>Geographically placed Inclusion Support Officers.</p> <p>Offer a range of early help services, including Saturday clubs, After school care and Holiday schemes for children and young people with additional needs including ASD. No referrals needed– parents can access and book their own children in.</p> <p>Introducing social media platforms. Websites– in house and regional Annual parent conference. Bi annual newsletter. Regular digital and no digital updates for those subscribed to mailing lists.</p>	<p>Attendance. Feedback from parents through social media and consultation opportunities. Feedback from CYP.</p> <p>Data taken from social media platforms. Feedback from all those involved. Evaluation methods.</p>	<p>Early Help coordinator. PPS. Paid staff and volunteers. Parents</p> <p>PPS Families Communications project worker</p>
Lead Officer	Leonie Rayner/Social Care		

3.9 Awareness raising amongst services and professionals *(Francis Rees)*

What do we want to achieved	What we will do	How will we know	Who is involved
Promote understanding and acceptance through awareness raising amongst services and professionals including; Education,	Extend our resources and programmes throughout the county which are supplied with no additional costs as funded by WG	Extending the ‘Can you see me campaign’ to Haverfordwest. Milford Haven progressing to a Bronze award when Schools in the community	Regional Officer– National ASD Development Team Specialist Teacher for ASC Educational Psychology

Health and Social Care, Leisure providers and Employers	Provide Train the trainer for Early Years and Secondary schools throughout 2018	complete LWA award. Increase in completion of Whole school certification scheme for Primary schools. Annual data (documenting stats on all ASDinfoales programmes including working with Autism and Access to Leisure facilities) to be forwarded to ASD Lead in Pembrokeshire to monitor progress.	ND service (distribution of Can you see me packs at point of diagnosis) Milford Haven Neighbourhood Policing team Parent and carer Volunteers. Pembrokeshire People's first Sports Disability Officer Sports and Leisure centre teams Volunteer groups and third sector
Lead Officer	Regional Officer		

3. Governance

Role of the Pembrokeshire Autistic Spectrum Disorder Steering Group

Effective governance arrangements will be essential if the actions within this plan are to be achieved. Integral within these arrangements will be Pembrokeshire ASD Stakeholders Group. This group will take the lead role in supporting implementation of the objectives in the ASD Strategic Action Plan for Wales across the authority area. Therefore, it will be the body which will be accountable for improving ASD services across Pembrokeshire. It will, as a key action within this plan, establish and maintain a number of task-specific sub-groups that will lead on the development and implementation of projects and initiatives aimed at improving ASD services locally. Importantly, the group will promote and actively support an agreed cross-agency approach to strategic planning for, and commissioning of, services for people with ASD. As a key part of its role, it will report into the Children's and Young People's Partnership regarding progress in implementing this plan.