

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.