



Tîm Awtistiaeth Cenedlaethol
National Autism Team

www.ASDinfoWales.co.uk

Supplementary Annual Report 2019/20: Case Studies

The National Autism Team continues to collect more case studies from the Integrated Autism Services and local Autism Leads than ever before. The case studies range from testimonials of individual lives being changed for the better, to evidence of fantastic cross-service joint working which has the needs of the individual at its core.

We hope you enjoy reading through some of the case studies from as much as we did. We are grateful to the Autism Leads in Local Authorities and the Integrated Autism Service teams across Wales for gathering such rich examples of the impact of their work.

Please note there will be more to follow which will be published on the AutismWales.org website throughout the course of the year. The case studies vary from short compliments, to “spotlight” short paragraphs, to full case studies.

Cardiff & Vale IAS – socialisation and friendship building

The Cardiff and Vale IAS hold 2-hour forums in Cardiff Central Library on the first Monday of every month. The forum aims to provide a place for autistic adults to meet and share experiences, whilst also learn about local services and receive information which might be relevant to them through guest speakers. Some examples of the speakers we have had include, Four Winds (a mental health charity), MIND, Library Services, Innovate (gardening project), Community Care & Wellbeing Service, and Valley & Vale Arts.

Over the past couple of months, the numbers for the Cardiff forum have been increasing and the IAS are currently having approximately 20 people attend each session. Due to the increase in attendees, the IAS reviewed the structure of the forum and decided to make the second hour less formal, thus increasing the opportunity for socialising. The IAS were hopeful that this would increase the numbers of people who felt able to socialise and boost their confidence of socialising in smaller groups of people.

This new format was trialled in March 2020. In the second hour of the forum, the room was split into smaller groups of people. Everyone socialised throughout the entire hour and nobody chose to leave. With slight encouragement from staff, everyone in the room spoke to one another.

Outcomes

Since November 2019, a small number of people (3-4) had been meeting in Costa following the forum (although the offer had been for everyone from a confident attendee). After the March forum, the offer was extended again and over 10 people agreed to go to Costa, including an autistic adult who had very rarely spoken in the forum and never without prompting from staff.

Feedback

The facilitating staff spoke to a number of attendees in the forum, all of which provided positive feedback about the change of the structure and agreed that it was more relaxed and provided a better opportunity for socialising.

Lessons Learnt

The IAS have learned that they need to adapt to the needs of the clients and the increased numbers of attendees in the forums. Although the increase is a positive thing for the service, this may have increased the anxiety levels of those who were not confident enough to speak in front of others in a large group setting. Friendships can be formed if the structure is changed to help facilitate and encourage this.

The IAS will review the structure again after 3 sessions and respond to the feedback gained from speaking to the service users.

Cardiff & Vale IAS – mental health

The Cardiff and Vale IASs Assistant Psychologist completed a piece of work with a 23 year old white autistic female, who was referred to the service by the Primary Mental Health Support Service (PMHSS) for agoraphobia; JH did not meet criteria for secondary mental health support and PMHSS did not feel that they could meet her needs. The Assistant Psychologist met with JH for 7 sessions, after which JH decided to end the sessions and prepare for University. Using cognitive behavioural therapy methods, under the supervision of Dr Rona Aldridge, Clinical Psychologist, the IAS were able to provide JH with the foundations needed to begin leaving the house independently – something she has been unable to do for over 2 years.

Outcomes

JH is now studying for her degree and regularly leaves her flat alone for periods of a time and is continuing to work towards leaving the house more often. JH will be attending for a follow up review appointment and she is also on the waiting list for the IASs Socialeyes course.

Feedback

JH said that she found working with mental health professionals difficult in the past as they did not understand her and was able to build a good rapport with the IASs Assistant Psychologist, which facilitated the intervention.

Lessons Learnt

The IAS learned that using CBT for an autistic person delivered by a specialist team in a short-term piece of work contributes to intervention facilitation.

Cardiff & Vale IAS – parents/ carers support

A recently retired married couple self-referred to the IAS about 18 months ago at a point of crisis with their son. He is 40 years old and has a diagnosis of autism but also some delusional ideas and paranoid thinking, which can be quite overwhelming for him and his parents.

The Clinical Psychologist (CP) and a Community Worker (CW) met them for an initial appointment, and it was clear that both him and his parents needed some support. It was agreed that some carer support around understanding autism and how to support their son, including putting some boundaries in place, would be provided by the CP, and the CW would engage the autistic adult to try and increase his activity and connections and improve his quality of life.

Outcomes

The CW was able to develop a trusting and positive relationship (something that has not been easy for other services) and through the CW introducing him to other services, he has now been able to engage with other services including Take Charge and now the Peer Mentoring service. He also regularly attends the Cardiff forum.

The Assistant Psychologist supported him to an ESA assessment due to his significant anxiety. Due to past experiences, he will not seek any support from mental health services. His parents came to the carer workshop and also meet with the Clinical Psychologist every few months, but also know they can call the IAS for telephone support and advice when they need it. The parents are now keen to support the set-up of a regular support group for carers of autistic adults.

Feedback

The parents are very grateful to the support from the whole IAS and regularly comment on the team-based approach to support.

Cardiff & Vale IAS – food and nutrition

Kevin Jones, IAS Dietitian, is providing training for local third sector services who are working with autistic people and are interested in increasing their food and nutrition knowledge to support these clients.

12 places were offered to a number of third sector services. There were challenges in sharing the information across a wide range of third sector services, which might have contributed to the initial poor uptake of the course. It was recognised that timing might have also contributed to the poor uptake. Therefore, the IAS changed the day and time for the course, and the numbers have now increased to 11 attendees. The staff attending the course include the National Autistic Society, Glenwood Church, Cardiff and Vale Learning Disability Physio Technician, IAS Community Worker, Barnados, and a foster carer. Staff from Autistic Spectrum Connections Cymru were also due to attend. The 10-week course is held in Glenwood Church. Completion of the course will achieve a Level 2 Accreditation with Agored Cymru using adapted Nutrition skills for life TM resources.

The aim of the course is to inform one-to-one interventions with the people that the staff support. The hope is that staff will have increased confidence when carrying out work such as skills for life, basic healthy eating, meal planning, shopping budgeting and dispelling food and nutrition myths.

Outcomes

Specific work that has been planned following completion of the course includes:

- The Physiotherapy Technician working in Learning Disability services is going to pilot a nutrition and physical activity group.
- Glenwood Church are going to run a cooking group specifically for autistic people. They have been offered support from the IAS Dietitian, who can offer consultation, resources and recommendations. The IAS will signpost clients to this new resource.

Feedback

The feedback from the staff attending the course has been very positive, with formal evaluation data available.

Lessons Learnt

It is important to consider what time of day such courses take place to ensure staff availability. This will continue to be taken into account when planning future training. Ways of sharing information across a wider third sector network is currently being reviewed by the IAS Team.

Cwm Taf IAS – mental health

The IAS Team Leader supported a client to attend an appointment with the CRISIS team in Prince Charles Hospital (PCH). The client was unable to travel independently to access the CRISIS service, they had no family support nor means of transport, and it was an emergency, so this required 1:1 support.

The client had reported issues of mental health, suicidal thoughts, self-neglect and “binging” on diazepam to a member of the IAS’ community support staff during a welfare call that morning. The client was desperately requesting to access CRISIS services in order to speak to someone about his extreme distress and anxiety.

The community support worker contacted the Team Lead for advice and support. The Team Lead contacted the CRISIS team and arranged for the client to be seen later that morning. The client had been known to the Team Lead since the end of last year. There were no known previous incidents of harm or risk towards self or staff. All risks in relation to harm to the client, harm to staff, and risks relating to COVID-19 were measured and assessed via the Cwm Taf IAS risk assessment & risk pathway as a matter of urgency. Due to COVID-19 and Health Board guidance, full PPE was worn by the staff and also provided for the client to wear, such as face masks, gloves, and aprons. Hand sanitiser and anti-bacterial wipes were also used.

Whilst waiting for the Team Lead to arrive at the client’s home to assist with transport to PCH, the community support worker continued messaging the client to keep him updated of what was happening and to check his safety.

The client was seen by the CRISIS team alongside the Team Lead, and during the two-hour assessment consultation he was provided with advice, reassurance and a card from the CRISIS team staff with the telephone numbers and out-of-hours contact number should they be needed again.

The Team Lead then supported the client to return home, offering and reiterating advice and reassurance along the way.

Outcomes

Since this incident, staff continue to stay in touch with the client via conducting welfare calls at least once a week. Face to face meetings have also been arranged on a fortnightly basis between the client, Team Lead, and his tenancy support worker. All present at such meetings must wear the required PPE and keep a strict 2m distance.

The client now has contact with a telephone Primary Care Mental Health service, which will hopefully return to its regular face-to-face service once lockdown restrictions begin to ease. This would benefit the client as the main issue he reported causing his mood to be so incredibly low at this time was the feeling of isolation and not having any face-to-face contact with someone one he can discuss his feelings with.

Feedback

The client has told IAS staff and his tenancy support worker that he is very grateful that the staff at the IAS were able to listen to him and provide the help and support he needed.

The client is also very pleased that the Team Lead is now providing face-to-face appointments on a fortnightly basis, as he feels it is more beneficial than phone calls, due to the fact he feels more able to talk and reflect on his feelings this way.

The client acknowledges that he is in a much better place mentally since starting the intervention and the fact he knows he will be having regular face-to-face contact with the IAS is reassuring for him.

The client is also looking forward to having 1:1 support to help access his local community once the lockdown restrictions are eased.

Lessons Learnt

The recognition that some autistic people find it extremely difficult to ask for help and to know how, when, and where to access support, especially if they are in crisis.

The team have plans in place for all new staff to access 'blue light' or 'assist' training as soon as training opportunities are in place. This will give staff more confidence, preparation, and guidance on what procedures to follow if they receive a call such as the one from this client.

To ensure risk assessment processes are in place to support staff and clients when needed.

Cwm Taf IAS – pregnancy and perinatal mental health

The IAS' Occupational Therapist (OT) was asked to carry out joint work with the Perinatal mental health OT to support a client who had recently received an autism diagnosis and was 17 weeks pregnant. The 20-week scan was due, and the client was getting anxious because the 12-week scan had been a bad experience due to her sensory and communication difficulties.

The Peri-natal OT and IAS OT met with the client and together they worked out what adaptations could be made to help the client feel more comfortable at the 20-week scan e.g. having her partner there, writing questions down before attending, waiting in the car and being called in only when they were ready to see her, adjusting the lighting etc. These were communicated with the ultrasound department and they had no problems putting these adjustments in place for the client.

Alongside this, the IAS OT carried out a sensory assessment, fed this back and put in some strategies to help with the main difficulties of touch, sound and visual processing. The IAS OT also created a one-page profile with the client which she could take with her to the scan and also use at other hospital/midwife appointments outlining her main difficulties and how she could be supported.

The IAS OT also met with the client and her husband and carried out some autism awareness work with the client's husband who was very keen to learn more about autism and how he could support his wife. Work is now underway to look at how they can communicate more effectively in their relationship, especially when the client is anxious or distressed as this is an area that they felt was most difficult for them.

Outcomes

The client has been positive about the input she has had from both services. Although she is still anxious about scans, being pregnant, and giving birth she now has a better understanding of her sensory difficulties and how she can manage these. The client also knows that adaptations are in place for when she attends future scans and hospital appointments. She is also aware that the Peri-natal and IAS OT's will work with her until the birth of her baby and beyond, in order to support her with the changes that she is going through.

Lessons Learnt

It has been a positive experience working alongside the Perinatal OT – a service the IAS had not yet had the opportunity to collaborate with. The IAS OT had never worked closely with an autistic pregnant client before either, so it is an exciting challenge to think about pregnancy and how some of the difficulties experienced by the client may impact on this and vice versa.

The IAS OT has had to think in new ways about the sensory challenges that women experience during pregnancy i.e. morning sickness, aches and pains, and feeling the baby moving.

Gwent IAS - employment

G met with the Gwent Integrated Autism Service at one of the service's drops in sessions in October 2018, after he had been signposted to the team by the jobcentre. G required support with accessing and sustaining employment, anxiety, depression, and a better understanding of his autism.

- Completed an Adult Profiler to help G explain why he found something difficult and what someone might do to support him.
- Completed a star outcome; G found this difficult at the time, however when we did the review at the end, he was surprised to see how far he'd come.
- Planner was used to help G to see what he needed to do, and how prioritise it without him overloading; helping him function and for him to be able to reflect how much he had completed and how long did it take him to do it.
- He attended a Post Diagnosis Course to learn more about his autism and what it means to him. He found being able to talk to other autistic people that were
- experiencing the same or similar difficulties enlightening and empowering.
- Looked at the five-point scale for him to learn how to regulate/ what intervention is the most effect to the way he is feeling at any time to try to identify a possible overload.
- Completed a sensory checklist and plan which was aimed at identifying, alerting, calming, and regulating strategies to build into a daily planner.
- Developed a routine and strategies to cope with shopping.
- Problem solving tools to identify what barriers were stopping G from completing goals and setting realistic timescales.

Outcomes

G is now actively engaging with Remploy to find opportunities in the workplace. He is also more confident, and his motivation levels increased so much so that he has been in contact with some old friends and arranging to go and meet them.

Gwent IAS - wellbeing, self-esteem and communication

JT is a 19 year old female who was diagnosed with Autism Spectrum Disorder (ASD) at the age of 18, and was referred for support by one of the Gwent IAS team's clinicians following her diagnosis. JT identified two main areas of support which would be most beneficial to her:

- Developing her wellbeing and self-esteem
- Improving her expressive and receptive communication skills

Wellbeing and self-esteem

JT was supported with the following interventions:

- A visual schedule to enable JT to balance her time effectively between her interests, completing university work, and doing household chores. I supported JT to set up the visual schedule on her mobile phone, sync it to her tablet, and set alarms to prompt her when to start tasks and ADLs.
- Encouragement and positive affirmations for JT to continue her interests in playing roller hockey and watching her favourite football team play.
- Information about the points to consider before disclosing her diagnosis and ways in which JT could go about this in the future.
- Developing a list of strategies to minimize anxiety so that JT could engage in activities that relax her, distract her, or ways of avoiding triggers that cause her to feel overwhelmed.

Communication

The strategies that JT and I co-produced were aimed at equipping her with ways to keep on top of her studies at university, deliver presentations, and strategies to give to her university lecturers regarding reasonable adjustments. JT was supported with the following interventions:

- Developing scripts to ask for help at university if she didn't understand how to complete aspects of her work.
- Using checklists to ensure that she has completed tasks.
- Using the "checking questions/ phrases" list, developed by the IAS, to ensure JT's understanding of what is expected of her.
- Recommending that JT apply for the relevant support at university to assist her with her studies; following this recommendation she sought and obtained dictation software and study skills support.
- Recommending that JT ask for things to be rephrased if she didn't understand what lecturers were saying or what was expected of her.

- For JT to keep in regular contact with her lecturers to ensure that she has understood the project briefs and that she is able to discuss any concerns that she may have.
- Giving JT information and guidance on the correct speed to deliver presentations as due to her anxiety she delivers too quickly. I gave her some 'rules' to follow when delivering her work which relies on the use of punctuation to slow her delivery down.
- Delivering role playing excerpts of a presentation several times; JT's pace had noticeably slowed down, and she felt more confident in her ongoing presentations.

Gwent IAS - employment and confidence

C was diagnosed by the Gwent Integrated Autism Service in 2018. At the time he felt he needed time to process his diagnosis and made further contact with the service in 2019. C self-referred to undertake the Post Diagnostic Course (PDC) with the service, which he completed in October 2019.

Following the PDC, C felt that he may need some support around his confidence, in particular in relation to having some issues at work that he felt he could not challenge.

In December 2019, I made a visit to C to explore these issues further. I advised C to make a note of his priorities that needed to be addressed, and making consideration to what he had learned from the PDC in relation to addressing his sensory needs. C's employer initially told him he would have a lengthy wait for a full needs assessment but when C provided his list of issues and solutions to his employer, he was assessed within a few days.

Outcomes

C has since had a height adjustable desk, a chair with lumbar support, a change to lighting, agreed use of headphones if needed, and access to a breakout area in times of stress. All of this has meant C now looks forward to going to work.

C also reported that since doing the PDC on which he made friends, he has a life outside of his immediate family, which has given him a greater sense of purpose and wellbeing.

Further to this, C reported an improvement in his relationship with his son (who is also autistic), as he feels he can "see where he is coming from." This has helped C to address his son's issues in school too, and he feels that the school take him more seriously now that he has disclosed his own diagnosis.

Heads of the Valleys Tang Soo Do, Monmouthshire – martial arts school for autistic children

AR runs a martial arts school, Heads of the Valleys Tang Soo Do, and he recently left his job to run the school full time. This has allowed AR to hold more 1:1 lessons with pupils, which is especially popular with autistic children who tend to prefer 1:1 lessons than a group session. Thus far, AR has had four autistic students attend his martial arts school, and all of the autistic pupils are seen to be making tremendous progress both in and out of the sessions. AR has taught two of the autistic children for more than 6 months, and they have now joined the group class.

Outcomes

The students learn how to logically solve problems and improve skills by listening and focusing on what they are learning. From overcoming these obstacles, they grow in confidence and learn behaviour to overcome other stimulus which might distress them, such as sounds and large groups.

Here is one example of the students showing how they have progressed and improved in their mental and physical attitude towards the sessions.

Feedback

Parents/carers have left the following reviews:

- “Fantastic club – AR is so patient with my son, totally understands his autism. Seeing him smile when in these sessions is worth a million pounds!!”
- “My son has additional needs and struggles with class settings and following instructions which have more than one thing for him to do at one time. His attention is very poor, and he is easily distracted. I found out that this club does 1:1 lessons, which have been amazing. My son has come on so much and even got his yellow tag on his 3rd session. AR, who runs these sessions, has been amazing. He has so much patience and understanding and has really helped my son learn a new skill. I highly recommend this class and the 1:1 session in particular.”

One Life Autism Support Group, Monmouthshire – grandparents support

One Life Autism Support Group is an independent registered charity serving Blaenau Gwent and beyond.

Grandparents were caring for an autistic child, GF, because GF's mother has severe medical issues precluding her from caring for him. The private tenancy of the grandparents' housing was coming to an end as the landlord was selling and the local Housing Association was not providing accommodation in the area, only a bed and breakfast. The grandparents took the issue to court, but because of their limited understanding of court procedures and difficulties in articulation, one of the One Life Autism volunteers accompanied the family to court and took the role of advocate for the family. The outcome of the case was that the family were rehoused into suitable accommodation. Further One Life Autism volunteers assisted them in the move.

Feedback

The grandparents were very happy with the work of One Life Autism.

Lessons Learnt

Many of our families are either unwilling or unable to represent themselves in court in the absence of Legal Aid, so the onus often falls to local volunteers to support them as advocates. Furthermore, courts may need future educating to become autism aware.

North Wales IAS – a young female being supported to move from a mainstream sixth form to a special needs college

HJ completed a referral form to the North Wales IAS. At the time, she was attending a mainstream school in the sixth form department. Unfortunately, this wasn't suitable for HJ due to bullying and the stress of the curriculum. HJ and her parents met with me at the "IAS Hub" and we discussed with the Careers Wales regional link worker a possible move to the Priory College, which is a special needs college.

Outcomes

After a few meetings and a report which indicated the support that I put in place and a written report to assist her application to the Priory, HJ's application was successful and she was to start in January 2020. It is very difficult to obtain a place in the Priory College as the applicant requires substantial evidence to achieve a place, and this is then decided by the Welsh Government as they fund the college. HJ was very fortunate and is enjoying her time at the Priory.

Feedback

HJ's parent commented: "Thanks for all your help and support with pointing us in the right direction, and thanks for all your help over the year."

Lessons Learnt

By taking the time, patience and assisting with written reports, great results will be achieved.

North Wales IAS – managing anxiety and accessing employment

The North Wales IAS was involved in assessing SK, and then offering post diagnostic support to help with managing anxiety and accessing employment. The support included creating communication aids, working on strategies to managing anxiety, as well as supporting the individual's partner to help implement the strategies provided.

Outcomes

Both the individual and their partner are now in employment. SK is using a structured timetable and is also managing their anxiety using the strategies provided. Communication aids and social skill strategies are also put in place to support SK within the workplace. SK is now working as a receptionist, which is a real accomplishment given that communication was one of the targeted support areas.

Feedback

“Thank you so much and thank you for the support you’ve given! I wouldn’t even be in this place if it wasn’t for you first”.

SK has said that they are happy and have a lot less financial stress due to them both accessing employment. This is the individual’s first job, and the support has also positively impacted on the relationship with their partner.

Lessons Learnt

Supporting individuals with the development of key skills can help reduce difficulties when in employment and other social settings. This case shows the potential individuals have once support has been provided, and they are given the chance to achieve their goals.

North Wales IAS – work experience and employment

A recent self-referral to the North Wales IAS has resulted with an individual, Y, in a successful work placement. Following an initial triage with the North Wales IAS, a support worker called the individual in to the IAS advice hub and began working on Y’s outcomes. The support worker referred Y to a gaming course led by North Wales Training (NWT) – a qualification in information technology that enables the individual to set up web pages and create games – as the individual wanted employment within the gaming industry. The IAS support worker took Y to the first few courses and encouraged Y to travel by bus independently to the NWT. Y couldn’t see the relevance of the course with regards to employment, and so following discussions with NWT, a work experience placement was arranged for Y with Poundstretcher in Mold.

Outcomes

The training course with NWT engaged Y and empowered him to attain an outcome of finding work and becoming independent. Y previously was very introverted and would not leave his home. Y’s life has fundamentally changed through these interventions.

Feedback

This is what the work-based learning provider had to say:

“Y almost bounced through the door and he couldn’t take the smile of his face all the way through our interview. He is loving his time at Poundstretcher, the manager and staff are very helpful and are making it enjoyable for Y. He is more hopeful of finding employment at the end of the work experience (04/12/2019). I haven’t seen Y this positive since he has been on my caseload, with continued support and Y’s willingness to engage I am confident Y will find a position to suit him.”

North Wales IAS – Post Diagnostic Group

Feedback from parent over young autistic adult and benefits of attending the North Wales IAS Post Diagnostic Group:

“It’s been absolutely invaluable to her [...] and I’m so grateful she’s had the opportunity to attend. She has learnt so much from it and it’s therefore made her so much happier, so thank you very much for arranging it for her.”

North Wales IAS – the IAS making a difference in lives where clients are ‘stuck’ and at a loss how to move forward

People’s Collection Wales is a website dedicated to discovering the story of Wales and its people. They made the following post on their Facebook page (@pplscollection):

This is what we like to see – a full set of hearts on our How Do You Feel Today feedback form!

Most of the Bailey Hill Project volunteers at our Oral History session yesterday in Mold left feeling enthusiastic and ready for some exciting work. Over the next months, OO, the Project Officer, and her team of volunteers will be unearthing some of Bailey Hill’s history, rediscovering and reimagining this mediaeval motte and reclaiming this fantastic location for the people of Mold and beyond. 2020 will see a new visitor centre with improved accessibility to the site for everyone to enjoy.

LL, a volunteer for the Bailey Hill project, came along to our oral history session in Mold yesterday with RR, a link worker from Flintshire County Council’s Integrated Autism Service. LL loves to research – “Being a part of a project like this one is a great opportunity to learn and to meet people. It helps with depression and loneliness, and I suppose it helps to give you a positive sense of wellness”.

The North Wales IAS had been working with LL for about five months. He had been assessed in July 2019 for autism and this was validated by MDT. LL was very introverted and would not leave the house. But the IAS staff worked hard at encouraging LL to go outside and to join up with several projects which were in line with his interests.

Outcomes

The Facebook post is testament to the work which has been done and now LL is starting to mix with his peers and starting to fulfil his potential and increase personal confidence. This exemplifies the purpose of the IAS – which is to make a difference to people’s lives where clients are ‘stuck’ and at a loss how to move forward.

North Wales IAS – a series of compliments to the service during the year

- Compliment for the North Wales IAS Psychologist: “Thank you for [...] your kindness, patience, and time. It was a real pleasure meeting you. XD enjoyed it too, which is remarkable because he is generally very reticent with new people.”
- The following compliment was received after a link worker at the North Wales IAS worked with a client offering parent/ carer support and assisted the client with contacting services via the IRT pathway with WCBC: “Without your input I would have been lost and my daughter would have continued missing school due to anxiety and stress.” The link worker’s involvement enabled the client’s daughter to get the correct and relevant support in school. Furthermore, the family have since been assigned a social worker thanks to the IAS, who will continue working with the local authority to ensure that the family’s needs are maintained.
- The following compliment was received in an email to the North Wales IAS team after two staff members conducted training for perinatal staff: “On behalf of the team I would like to thank you so much for the training you provided for our team yesterday. It was excellent and so informative, from a personal point of view I was coming from a very low level of knowledge of autism and I now feel more confident in my practice and I have downloaded the recommended reading ‘Neuro tribes’. In relation to the ICan campaign and the ‘Power of 5’, I have shared with 2 of my family and I have added 3 people to this email, but it won’t stop there, I know Kelly has already ‘Tweeted’ what a positive event. Thank you again an excellent session.”
- Compliment for the North Wales IAS from a carer perspective: “I just wanted to thank you again for your time on Friday. Since XX's diagnosis in November last year, you are the only person/ organisation that's sat down talked to me about autism and provided so many different learning resources, and other points of contact. Because XX is not on any medication we sort of feel, you get the diagnosis and that's it... just get on with it. But you have provided us with an element of reassurance. You also put a positive spin on things which I really like – thinking positive is the key to this, I think. Many thanks again - please pass this feedback on to your managers too.”
- Compliment for the North Wales IAS received via social media: “I would like to say how wonderful these drop ins are. I cannot thank OL enough for the support and advice she had given to me. She has helped us make transformational changes in our family.”
- Compliment to the North Wales IAS following training delivered to Clwyd Alyn: “Big thanks for the session yesterday, the staff I spoke with afterwards said it was one of the best training sessions they’ve ever had, so that’s fantastic.”

Powys IAS – individual support to access the GP

The Powys IAS Team supported LK, who is autistic and has a stutter, to access her doctor's surgery. LK had previously experienced great difficulties arranging to meet with her GP as the system that the surgery uses involves a telephone call to arrange the appointment. Each time LK rang the surgery, she was unable to speak and the person at the other end of the phone would say "sorry I can't hear you" and hang up. A support worker at the Powys IAS rang the surgery and explained what was happening. They asked to put a note on LK's file to explain that she has a stutter and has difficulties interacting over the phone. The support worker also arranged for a doctor to call LK directly, so that she could discuss what was wrong. The doctor suggested that LK nominate her sister as a contact so that she can assist LK in the future when calling the surgery.

Feedback

LK commented – "I am really pleased that my support worker sorted the doctors out for me. I had not successfully accessed the doctors for over six months. My sister still needs to fill the form out so that she can ring on my behalf, but hopefully if i need to ring them they will wait until i start speaking before they hang up."

Lessons Learnt

Sometimes individuals will look on the outside as if they do not require support or help, but it is important to ensure that the right support and intervention is given to help our clients to be able to live as independently as possible and for other agencies to make small adjustments to allow this. Joint working is paramount to be able to achieve this.

West Wales IAS – individual support to overcome isolation

KR came to the West Wales Integrated Autism Service for support following diagnosis. KR would not leave the house and therefore his diagnostic assessment was done at home as he would not attend appointments.

KR's goal was to attend a family meal in a restaurant on New Year's Day. The team started working with KR in October and started doing some graded exposure e.g. walking to the car and returning to the house. The team worked with KR to complete an anxiety diary for each time he left the house. On the next visit, they walked to the end of the drive, and continued doing different things with each visit. They sat in front of the restaurant that KR wanted to go to on New Year's Day, and the following visit they went in for a coffee and sat on the table where he would be sitting.

Outcomes

KR attended his family meal on New Year's Day and stayed in the restaurant for an hour, before returning home. In the New Year he has given himself new goals, such as losing weight and walking 5 miles a day with his mother. KR is also engaging with the Engage to Change project to look at employment options. He has since applied for a job at Folly Farm.

Feedback

KR commented: "Thank you for all your help over the last few months, it may of only been 20 mins a week but it's really helped me get in a better place. I really appreciate everything that you done for me and I will miss you. Take care and thank you again."

Lessons Learnt

So much can be achieved when working directly with an individual. Short interventions on a consistent basis was important for this gentleman. Using direct language with limited options also made a significant difference. Having achieved so much in such a short period of time has been very rewarding for KR, and he continues to develop and push his own boundaries on a daily basis.

West Wales IAS – individual support to overcome isolation

Apple is a 25-year-old man who has a diagnosis of autism. He currently lives at home with his parents in Carmarthen. Before Apple was referred to the service for support, he was increasingly isolating himself in his home and would only leave his house on very rare occasions. He had been in this situation for years and his family and he were at breaking point. Apple had been accessing other services but due to a lack of engagement was typically discharged.

When I met Apple in the first appointment, he was very reserved, he was visually anxious and struggled to engage in conversation. We carried out a “Spectrum Star” together – an outcome measuring tool used to highlight an individual’s strengths and areas of difficulties where support would be needed. The first priority area highlighted was to attempt to try and increase Apple’s time in the community. The second area of support highlighted was to support Apple with his social skills.

After a couple of weeks of interventions, Apple began to visually relax in my company and began accepting strategies to trial. Within a few weeks, he was going out with his mum in the car to supermarkets and on the rare occasions was even going into the store to purchase groceries. Providing coping strategies for Apple has empowered him to access venues that he would never have accessed before.

Apple then had the opportunity to attend the IAS Post Diagnostic Workshop. During the 4-week session he did not engage in conversation to begin with but expressed the validation he felt that other autistic individuals faced the same difficulties that he has. During session 3 and 4, he began initiating conversation with his peers and expressed sadness that the workshop had come to an end. In Apple’s words, “I really miss the PDW workshop, I looked forward to it every week.”

Outcomes

Apple now attends the Autism Forum in Carmarthen where he is a valued member of the group. He now makes his own arrangements to attend and engages with the other attendees – something he would never have done before. Whilst attending this forum, it was discovered that Apple had similar interests to a few of the other attendees who were a similar age to him, mainly football.

Since this was highlighted, Apple and two other young men created their own social group with support from myself and a fellow worker. They now meet up in the bowling alley once a month where they play pool and have a game of bowling. The conversation between all three participants flows and Apple is visually more comfortable. Not only does Apple attend the forum, a social group, and has attended the PDW, he now attends the gym once a week where he is working on building his self-esteem and self-identity.

Apple’s outlook on life has completely changed. He can now see that he has a future and is being given the appropriate support and “tools” needed so that he can successfully lead a fulfilled life. He feels more confident in himself and feedback from his parents have been amazing.

Feedback

"I would like to take this opportunity to thank your team for the work that you do. I feel this is a service that is so necessary for people on the ASD spectrum. My son has learnt so much about himself in the short time that James has been involved with him. Even though it is early days I feel confident now that we are going in the right direction following many years of disappointments from other services whom did not 'quite' understand. The post diagnostic workshops were invaluable and Apple reports to 'miss going'. Big thank you to James and Anwen and the participants. Thanks to your service – we as a family are now looking forward to the future and to see Apple progressing further. Big thank you to James Etheridge for your effort, professionalism and personality."

Lessons Learnt

With the correct support, goals can be achieved, and the lives of individuals can be improved and turned around.

Early Help Team, Pembrokeshire – children and young people support

Three wellbeing groups have been piloted in three secondary schools in Pembrokeshire. The pupils who attended were:

- At risk of not attending school or currently not attending.
- Pupils with anxiety that is impacting on their ability to cope in school.
- Have autism and/or social communication difficulties.

The programme delivered twelve sessions which aimed to enhance self-esteem, teach some self-help anxiety reducing strategies, and practice social skills. The programme aims were:

- Identify individual's strengths, likes and dislikes – this will help to increase self-esteem. Pupils will be more likely to engage with enjoyable, productive activities. It will aid goal setting and motivation.
- Improve ability to identify, discuss and explore emotions and feelings related to anxiety – this will help pupils to self-regulate and respond to situations more positively. Pupils will be more able to identify their feelings.
- Relaxation techniques – pupils will have techniques to use to help them calm.
- Social Skills Practice – this will help pupils become more confident in their social interactions and more able to make and maintain friendships and social relationships.
- Develop ability to solve problems independently – this will help to increase self-esteem and self-efficacy. Pupils will feel more empowered to confront challenges and try out new experiences.

The Stirling Children's Wellbeing Scale was used as a measure.

Outcomes

There was an improvement in the wellbeing scores of all participants in one Group, but unfortunately lockdown interrupted two other groups.

One Group consisted of all high functioning girls, two of which made a friendship due to being in the group. All girls reported that they enjoyed being in the group and a level of trust was created amongst the girls. It was a 'safe space', where the girls felt listened to and able to express themselves. Two thirds of the group expressed an interest in further work with the group leader in the future, such as a possible mindfulness session. Training for group leader is currently being explored.

Feedback

Pupil A (boy, 15) – "I've really enjoyed the sessions. I try to relax more."

Pupil B (girl, 15) – "I look forward to the sessions every week."

School staff – "It has helped her. She's come out of her shell more and will talk about what is going on with her."

Lessons Learnt

The mix of pupils needs to be right. In one group the pupils were very low ability. The work needed to be tailored more specifically for the individual needs of each pupil and quite a few sessions were needed at the start as 'ice breakers' before moving on.

With the all-girl group, the sessions were fairly organic at the beginning, going off the set plans. This allowed for them to express themselves more freely and get to know each other better.

Western Bay IAS – PIP assessment

MR self-referred into the Western Bay Integrated Autism Service in April 2019 for a diagnostic assessment of autism. She told the service that she'd had "severe difficulties" since leaving university. MR explained that social situations are incredibly difficult for her and she is unable to attend appointments or meetings unaccompanied.

MR received a diagnosis of Autism Spectrum Disorder (ASD) in May 2019 and attended a Post Diagnostic Course in September 2019. Attending the course gave MR the opportunity to think about her autism and open up about her struggles. The IAS talked with MR about her rights as an employee and as an individual, and discovered that she'd had an upsetting experience with a PIP assessment, which she found traumatic and resulted in the loss of her payments. Due to her social and communication difficulties she was unable to effectively explain her struggles to an assessor. Without these payments, it was becoming likely that she would have to move back into her parents' house, as she would no longer be financially able to live independently.

As a team, the IAS were able to support her to challenge the way she was assessed and acquire a re-assessment. The IAS were also able to provide evidence of how MR's autism affects her day to day.

Outcomes

MR's PIP award was successful, and she is now able to continue to live independently.

Feedback

The IAS received the following email from MR's mother:

"I just wanted to say a huge thank you to you and your team for all the support you gave MR and her PIP claim. She was awarded the full amount, which means she is able to stay living independently and afford things that will make her life easier. Thank you so so much for your help and telephone calls to PIP ... just knowing your service is there to support us is a peace of mind and definitely has made a difference to our lives. We both cannot thank you enough for your support and guidance."

Lessons Learnt

On a practical level, the IAS have learnt more about the PIP system, how it works, how to challenge decisions, and how the service can support applications. This has been a good starting point on which to base future learning.

It took time to get to know this individual, she had lost trust in professionals and communication is a huge struggle for her. This successful outcome has proven that by using the team's knowledge and experience of autism, they can gain the trust of autistic individuals so that they feel comfortable to speak openly.

As a relatively new team, the IAS have learnt that they can work together effectively to share information and skills. This example involved good team coordination. MR was assessed by the Occupational Therapist and Speech & Language Therapist, and then went on to attend the Post Diagnostic Course, facilitated by the Specialist ASD Practitioner and Wellbeing Support Worker. Whilst the Wellbeing Support Worker challenged the PIP decision, the ASD Practitioner wrote a supporting letter which was confirmed and supported by the Speech and Language Therapist in her capacity as diagnostician. It was a real team effort, and the team are delighted with the successful outcome.

Western Bay IAS – mental health and anxiety

A Consultant Clinical Psychologist for Adult Mental Health services in Western Bay contacted Catherine Vaughan (the IAS Service Manager) via email regarding a 32 y/o male that he was working with who he believed needed to be referred for a Diagnostic Assessment. He was looking for advice from Catherine regarding referral routes through the IAS for this man who was presenting mild depression, and moderate/severe social anxiety, had lost his job due to bullying by management probably related to difficulties with social understanding and social interaction in workplace, and who had applied to employment tribunal. The man was living with his parents but had recently been “thrown out” due to arguments.

The Psychologist explained that the individual had “pretty poor eye contact & slightly odd interactions during assessment, even though he commented on finding the assessment context relatively easy because it was a well-defined / non-social interaction.” The Psychologist had put the individual on his waiting list for CBT for social anxiety, but he also saw a strong possibility of autism. Having discussed the pros and cons of having a diagnostic assessment with the individual, the Psychologist confirmed that the man would like to be referred.

To this email, Catherine responded that, from the information the Psychologist had provided, the male met the threshold on screening tools and that the history was strongly suggestive of autism. Given the male was not open to secondary mental health services, the Western Bay IAS were happy to accept a referral from either the Psychologist or the patient – and she attached the appropriate referral forms to the email. Catherine also offered that the LPMHSS clinician, who would be offering the male intervention whilst waiting for this assessment with the IAS, refer to the Western Bay IAS if they required professional consultation around tailoring to a more autism-specific approach.

This is a positive example of joint working between the IAS and Mental Health services in Western Bay, as the individual was offered psychological interventions in the interim of waiting for an assessment, as the Western Bay IAS waiting list was approaching 9 months at the time.

Western Bay IAS – mental health

A Consultant Clinical Psychologist for Adult Mental Health services in Western Bay contacted Catherine Vaughan (the IAS Service Manager) via email regarding a woman that he had seen for a screening assessment. She had received an autism diagnosis at age 6 and of semantic pragmatic language disorder a couple of years later. She was now aged 21. She had lots of rumination, for which she was keen to undertake rumination focussed CBT group with the Adult Mental Health service.

However, she also had difficulties in peer relationships, finding that she was good in relationships with people who were much older than her, or to children, but struggled with people of similar age. The Psychologist asked for Catherine's advice in the context of autism, and whether the Western Bay IAS could offer any intervention/ support.

To this email, Catherine responded that the woman could self-refer for support to the Western Bay IAS, or that the Psychologist could do so on her behalf. Catherine reiterated that the CBT focused group with the Adult Mental Health service should remain intact.

This is an example of positive joint working across services, where different services can offer different kinds of support for one individual.

Can You See Me Campaign, Neath Port Talbot – autism friendly restaurant

The following compliment was received via Facebook to The Castle Hotel Restaurant in Neath, after the Neath Port Talbot Autism Lead had completed the CYSM training with the restaurant:

“Went for lunch on the off chance there was room today with my husband and son. My son walked in earphones on, watching his iPad. The waitress asked quietly if he was autistic and the answer of course was yes. She asked us which seats would be best and kindly gave them to us without hesitation. I overheard her say to colleagues to rearrange seating in order to accommodate his needs. She didn't mean for me to hear, but I did, which made me smile. She understood, listened and was happy to help. The Sunday lunch came quickly and was delicious. 2 courses for £10.... amazing. Will I be back? YES, without hesitation. For all my fellow autistic parents out there, I'm happy to recommend the Castle as an autism friendly restaurant.”

Halo Leisure's Autism Friendly Swimming Lessons Programme, Bridgend – autistic children

With the initial support of the Bridgend Autism Lead, Bridgend Halo Leisure identified that they would like to offer an Autism Swim provision.

Autistic children are 160 times more likely to drown than their neurotypical peers. Therefore, it is even more important that children on the autism spectrum learn to swim. However, learning to swim can be a particularly stressful experience for many autistic children. Adjusting to the swimming environment, with its different sights, sounds, smells and feelings, can be overwhelming. As such, 91% of parents/ carers have left mainstream aquatic services due to those services not understanding their child's needs.

With the assistance of the Western Bay Integrated Autism Service, Autism Swim Research dedicated lessons was created and piloted, helping children to learn to swim in an enjoyable and relaxed way, avoiding the more noisy and boisterous nature of regular swimming lesson sessions. Specialist training, procedures, resources, and support was put in place for the autism-friendly swimming lessons.

Outcomes & Feedback

During the last session, parents/carers and staff were interviewed as part of a film that was taken during the swim session, which can be viewed [here](#).

The progress of the children from the first session to the last session was very clearly observed by the IAS, parents/ carers, and the staff. The IAS attended 3 sessions in order to provide information and advice to parents/ carers if needed.

Lessons Learnt

From the perspective of the Western Bay IAS, the established advice hub during the swimming lessons was valuable, but may not be required every time as parents/carers are keen to watch their children swim and learn. Information and advice provided via handouts and links to the ASDinfoWales website is better during the classes themselves.

Having other parties to support the hubs, for example the local National Autistic Society group, and the local Autism Lead would be of benefit.