



Making Assumptions vs. Building Relationships

Lessons from a participatory action research project to identify effective practices for learners with autism spectrum disorder

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ABSTRACT

This article describes a participatory action research (PAR) project conducted in a large urban, co-educational secondary school. The project focused on two senior pupils with autism spectrum disorder (ASD) who, seemingly as a result of feeling stressed or anxious, displayed behaviours that inhibited communication. Using questionnaires, observations and teaching activities, factors that both caused and reduced stress for these students were identified. Interventions were introduced that successfully helped the students to recognise and manage their stress appropriately. These were principally the use of a variety of visual strategies and Social Stories™. As a result of the PAR project, school staff learnt to question assumptions made about students and to give priority to getting to know them and developing positive relationships on which teaching programmes could be built.

Keywords

Action research, autism spectrum disorder, effective practices, interpersonal communication, participatory action research, secondary school students, stress, teacher student relationship, teaching strategies.

INTRODUCTION

One of the key characteristics of autism spectrum disorder (ASD) is a severe difficulty in social communication. Many children who have ASD have major difficulties in forming relationships and interacting with others. However, educational programmes for these children often do not set a high priority on building student-teacher or student-student relationships but rather focus on developing a range of academic and functional living skills. This is despite the belief that it is only by understanding the particular challenges faced by students at school that teachers are able to make changes and use strategies that reduce stress and

increase success (Ministry of Education, 2006). This article reports on findings of a participatory action research (PAR) project, which suggest that, contrary to common practice, placing emphasis on initial relationship building may be the key to successful programmes for learners with ASD.

The PAR project was one of a number of small research studies investigating effective practices for students with ASD funded by New Zealand's Ministry of Education. It focused on Aroha and Maurice¹, two senior secondary school students who received part of their education in regular classes and part in the school's learning support facility. Both students were involved in transition to work experiences in order to prepare them for life beyond school. Frequently and seemingly as a result of feeling stressed or anxious, these students displayed behaviours that inhibited communication with work experience personnel, their teachers, teachers' aides and parents. Therefore the PAR project was developed to discover: What factors appeared to cause stress for Aroha and Maurice; what strategies were effective for them when they felt stressed; how they could be taught to recognise and understand their own stress levels and to use this knowledge to manage stress independently; how knowledge of what caused stress could be used to maintain effective two-way communication; and what constituted a supportive environment when Aroha and Maurice became stressed.

Stress is something that is commonly associated with ASD, however, despite 30 years of ongoing research, there are relatively few published reports in this area (Grodén, Diller, Bausman, Velicer, Norman & Cautela, 2001). One such report (Mullins & Christian, 2001) noted the worth and success of interventions around coping strategies to reduce anxiety in people with autism.

¹ Not their real names

In their consideration of stress and autism, Groden et al. (2001) hypothesised that 'persons with autism may be even more vulnerable to the effects of stress because they may lack a repertoire of appropriate coping mechanisms' (p. 207). They added that many of the "autism" behaviours may, in fact, be related to an individual's lack of coping skills rather than to their autism per se. The present study was motivated by these hypotheses, by the potential of interventions to reduce anxiety in people with autism and by a firm belief in the importance of this field of research.

WHO WAS INVOLVED?

PAR involves a collaborative approach where people work together to investigate and improve their own practice. It aims to use critical reflection and analysis to drive changes within and beyond the immediate environment (Mills, 2003). Weiskopf and Laske (1996) consider that PAR recognises a role for the researcher as a 'facilitator, guide, formulator, and summariser of knowledge, and raiser of issues' (pp.132-3). These issues include the possible consequences of actions and the awareness of structural conditions. Within an educational context it can be argued that teachers are more likely to change their behaviours and attitudes if they have been engaged in collaborative research, such as PAR. Their involvement and ownership of the research problem helps them to see the need for change and also to realise that it can be done (Cohen, Manion & Morrison, 2000; Oja & Smulyan, 1989).

The collaborative team for this PAR project consisted of teachers, teachers' aides, parents, family members and three mentors appointed by the Ministry of Education. The mentors had expertise in special education and research and played a supportive, advisory role in the project. The team also drew on the expertise of a speech-language therapist and a music therapist.

WHAT WAS DONE?

The nature of PAR is that it is cyclical: information is collected, analysed and, as a result, interventions are devised and introduced. In turn, these are evaluated and consequent refinements and changes made. This process of ongoing and evolving improvement was followed in the PAR project.

Data gathering

This project began with a concerted data gathering exercise. More information was needed on when, where, and why Aroha and Maurice became stressed; how their stress was exhibited or avoided; what happened before and after stress-related incidents; and the intervention and diversion strategies that parents, teachers and teachers' aides found to be either helpful or unhelpful. A variety of data-gathering techniques were used to answer these and other relevant questions. The techniques included:

- observations employing anecdotal and event-recording techniques to gain information on the nature and frequency of stress-related behaviours

- a questionnaire to teachers' aides, focusing on stress factors, the students' likes and dislikes and modes of communication (this questionnaire was developed from ideas in Watson, Holton & Andrews, 1997 and is included as Appendix 1)
- a questionnaire to parents asking about their child's ability to recognise their own feelings and the parents' interpretation of these feelings (this questionnaire was developed from ideas in Baron-Cohen, Howlin & Hadwin, 1999 and is included as Appendix 2)
- student worksheets probing their ability to interpret situations and associated feelings (developed from Baron-Cohen, Howlin & Hadwin, 1999)
- reflective journals used by the two lead teachers to record student observations and issues related to the PAR process
- specialists' evaluations – relevant data was gleaned from speech-language and music therapists' reports.

Professional development

Data gathering was complemented and informed by a substantial, ongoing professional development component. Initially one of the mentors conducted a literature review of research relevant to the PAR questions. This review provided some insight into how similar problems had been addressed elsewhere and highlighted issues that had arisen in previous research. In addition to this, the two lead teachers and two mentors attended a two-day PAR workshop at which they developed the proposal for this project.

Staff at the school's learning support facility participated in a full-day session run by a New Zealand consultant on autism and a shorter session conducted by an international expert. Also offered to all staff were: a three-hour compressed version of SPELL Training²; a two-hour workshop on PAR; and a half-day session on effective strategies for working with students with ASD run by one of the mentors.

The two lead teachers spent a day with a consulting psychologist who has acknowledged expertise in the ASD field. This consultation included in- and out-of-school observation of the students, and related discussion. These lead teachers were released from their teaching every Friday afternoon to work on PAR-related tasks. These included: professional development activities; reflection on and analysis of data; intervention planning; and monthly meetings with the mentors. At the fortnightly learning support staff meetings both general ASD information and specific project-related data and issues were shared and discussed.

Finally, the lead teachers, a mentor, a parent/teacher's aide and two sisters of one student attended the National ASD Conference in Christchurch³. The parents of Aroha and Maurice also attended two local workshops run by an expert on ASD. These workshops were partially funded from project money.

² SPELL is a framework for intervention when working with people with ASD. SPELL training is offered in New Zealand through Autism New Zealand. SPELL stands for Structure, Positive Expectations and Approaches, Empathy, Low Arousal, Links.

³ The conference entitled *Autism: Unlocking the Potential Within* was hosted by Autism New Zealand in 2004.

In addition to the organised professional development programme, money from research funding was used to purchase a wide range of books and videos recommended by the various ASD experts. These were housed in the staff library and were freely available for staff and parent use. Computer software for students' use was also purchased. (See Appendix 3 for a list of recommended resources purchased from research funds.)

Interventions

As a result of the analysis of initial information, a number of interventions were introduced. Ongoing data gathering throughout the cycles of PAR led to the dropping or modification of unsuccessful approaches, the extension of successful interventions and the development and trialing of new strategies. For example, the first intervention to be trialed was Tony Attwood's *Exploring Feelings* programme (Attwood, 2004a & b). A teacher in the project used this programme individually with each student. However, very early on, observations and work samples revealed that Aroha and Maurice did not have the conceptual understanding needed to benefit from the programme. Consequently, this intervention was discontinued.

On the other hand, the previously mentioned questionnaires and focused observations identified both factors that caused stress for Aroha and Maurice and also situations and activities that helped them avoid or lessen stress. Teachers successfully incorporated this new-found knowledge into developing interventions around the use of Social Stories™ and visual strategies^{4,5}, which had proven to be effective teaching approaches in the past. These were developed specifically to address the students' stress-related communication difficulties.

Social Stories™ were used to help Aroha and Maurice prepare for and cope with situations and events that were identified as being stressful. These were particularly successful with Aroha who helped write and illustrate her own Social Stories™. Examples included stories to help her: cope with her fear of balloons; make good food choices when away from home visiting relatives; stay calm when being re-directed; identify situations and times when it was appropriate to write letters to people; and cope with the transition from secondary school into the community. While Social Stories™ were usually initiated by adults, a breakthrough came when Aroha, recognising that a visit to her mother who had shifted to a new city would be stressful for her, asked her step-mother to write a Social Story™ about the upcoming visit. Together they prepared a story that focused on areas Aroha identified as stressful. The Social Story™ included what food to avoid, how to behave towards her siblings and what to do when she felt stressed.

Neither Aroha nor Maurice coped well with change so daily visual timetables were introduced and used for stress prevention, and as reminders of what should be happening. For example, if either of the students became stressed, they were shown their visual timetables that outlined the programme for the day.

Visual prompts were prepared for Aroha with photos of things she liked to do. These included dancing, listening to music and time on the mini-trampoline at school, and tennis, basketball and trampoline at home. When Aroha showed initial signs of stress in either location, she was shown a card with photos of the appropriate calming activities. On the back of each card were directions for the adult to read: 'Aroha, I think you are feeling stressed. You need to do one of these activities to make you feel better. Which one do you choose?'

Observations also revealed that on some occasions Aroha and Maurice became stressed because the information that was given to them by adults was not properly understood or they were not given sufficient time to process the information. As a consequence, staff members developed their ability to give clear, specific and easily understood information. They also gave advance warnings and allowed the students more time to process and communicate.

HOW EFFECTIVE WAS THE PAR PROJECT AND WHAT WERE SOME OF ITS POSITIVE OUTCOMES?

The effectiveness of the PAR project can be determined from two different perspectives. Firstly, it can be judged by how well Aroha and Maurice learned to recognise, understand, communicate and manage their stress in an appropriate manner. A second measure of effectiveness is how well the adults involved in this project learned to identify stressful situations and behaviours; maintain communication; assist their students to cope with stress; and provide a supportive environment for them. A further measure of success for school staff relates to how well they learnt to use the skills of PAR to improve their own practice.

Anecdotal observations throughout the project showed that Aroha and Maurice made slow but steady progress. Given the nature of their disabilities dramatic changes were not expected. However, a decrease in incidents of stressed behaviour and an increase in the students' abilities to recognise and deal with stressful situations indicate that the interventions introduced were beneficial for both students. As previously reported, Aroha began taking the initiative and participated in writing her own Social Stories™ to help her handle situations she recognised as stressful for her. School staff considered this an important step for a student whom the initial observation data identified as unable to recognise stress or to use her own volition to avoid or reduce stressful situations.

Similarly, initial data showed Maurice's usual mode of handling stressful situations was to: 'throw himself on the ground and become vocal and agitated or repeat actions/verbalisations over and over again' (teacher's observation journal).

⁴ For information on writing and using Social Stories™ and visual strategies refer to: Gray, C. (2000). *The new social story book: Illustrated edition*. Arlington TX: Future Horizons. Hedeon, D.L., Ayres, B.J., & Tate, A. (2000). Getting better, happy day, problems again! The ups and downs of supporting a student with autism in her home school. In M. Grenot-Scheyer, M. Fisher & D. Staub. (Eds.), *At the end of the day: Stories of ordinary lives and youth in inclusive schools and communities*. Baltimore: Paul H. Brookes. Hodgdon, L. (1995). *Visual strategies for improving communication*. Michigan: Quirk Roberts.

⁵ See also the article *Learning from Each Other* in this issue for a description and example of a Social Story™.

However, towards the end of the PAR project, observed incidents of such behaviour were minimal. Instead, Maurice would remove himself to a place of “sanctuary” (the equipment room or foyer). Additionally, the parents of both students reported improvements in stress-related behaviours in the home environment. They noted that Aroha and Maurice generally appeared more happy and content. Furthermore, parents reported that they felt better equipped to meet their children’s needs.

Aroha and Maurice’s progress also reflects how effective the PAR project was for the adults involved. In depth, focused observations, questionnaires and activities enabled the identification of a wide range of stressful situations and behaviours and resulted in the compilation of a dossier on the students’ likes, dislikes, ability levels in various areas, communication strategies, behaviour patterns, environmental supports, learning preferences and so forth. (See Appendix 4 for an approach to compiling an information leaflet about a student with ASD.) Ongoing data collection, analysis, reflection, and sharing of information and ideas, combined with an increased knowledge of ASD and appropriate teaching and behaviour management strategies gained from professional development activities, all contributed to the development of successful interventions.

However, arguably the most valuable lesson that was learned from the data-gathering process was the extent to which adults made assumptions about the students’ ability level in various areas. For example, because Aroha was verbal and Maurice was non-verbal it was assumed that Aroha’s understanding of emotions and feelings exceeded Maurice’s. When a mood barometer was introduced as part of Attwood’s *Exploring Feelings* programme it was discovered that in fact Aroha’s understanding of emotions and feelings was more limited than Maurice’s. Staff realised that the programme activities she was being asked to do were actually adding to Aroha’s stress levels rather than decreasing them.

On the contrary, Maurice’s understanding of feelings and emotions exceeded people’s expectations. He was able to recognise stress, anger, unhappiness and relaxation both in himself and others. He could also recognise happiness and hurt in others but not in himself. Being non-verbal, Maurice used an Ultimate 8 talking machine to communicate. Messages relating to his emotional state and his likes and dislikes were recorded onto this machine. For example:

I am feeling grumpy. I want to be left alone.

I would like to type on the computer.

While Maurice regularly used the talking machine to request favourite activities, he did not progress to using the messages that communicated his feelings. However, he did learn to use visual cards to express a limited range of emotions and enjoyed and responded well to music therapy sessions.

Through the PAR process, staff learnt about the danger of basing teaching activities on assumptions of what students could or could not do and the value of taking time to build trusting relationships, of getting to know the students well and of developing programmes based on this knowledge and trust. Staff members now place emphasis on initial

student-teacher relationship building before they launch into their teaching programmes. It is reported that this has taken pressure off staff and students and has led to more relaxed working relationships and more effective teaching activities. This appears to be verified by parents of newly enrolled ASD students who, since the introduction of the PAR project, have reported very positively on their child’s entry into secondary school.

Staff learned to use their increased knowledge of Aroha and Maurice to make adaptations and introduce teaching activities based on Aroha’s and Maurice’s individual needs and strengths, likes and dislikes. However, it was acknowledged that getting to know their students and building effective relationships with them was a time consuming and ongoing process. A supportive environment was considered to be one that allowed time for this to happen – both time within the school day and time over the student’s lifespan.

A further change the project brought about was in teachers’ aides’ attitudes and approaches to teaching students with ASD in general. Previously there had been a focus on changing the student to fit the environment. With the new-found knowledge gained from professional development, emphasis is now placed on understanding the student’s behaviour, by asking, “What is happening for the student in this situation? Why are they behaving in a particular way? How are they feeling? What are they trying to communicate? And what changes can be made to our practices and the environment to reduce stress and to support our students?” As one teacher’s aide explained in her evaluation of the project:

The project has changed the way I relate to Aroha and Maurice and other students with ASD in so many ways! I feel I can communicate at a much better level than before. Using visuals has helped me no end, i.e., stories, rules, signs etc. I have more confidence in my own ability and I have a much better understanding of autism. I now speak to Aroha and Maurice not at them. I try and think ahead of ways to make up-coming tasks and events as easy as possible for them to accept, i.e., Social Stories™, simple instructions etc. I also see their behaviours as a way of their communicating to us that things aren’t going right instead of naughty behaviour. I’m not scared of Aroha and Maurice any more! I can “push” harder and end up getting much better results. (Teacher’s aide evaluation.)

As a result of this project, staff have introduced two new resources. The first is a portfolio for Aroha and Maurice to take with them when they leave school. This includes information on their respective signs and causes of stress and on strategies that future teachers or employers can use to reduce stress for them. The second resource is a booklet that outlines effective practices when working with students with ASD. This resource is a useful starting point for new staff who have not previously worked with students with ASD.

Meyer, Park, Grenot-Sheyer, Schwartz and Harry (1998) note that PAR is a process which involves narrowing the gap between research and practice and allows for innovative

interventions validated by research to be adopted into everyday educational practice. This was evidenced in this particular PAR project. In addition to the positive attitudinal and teaching changes that were made, staff are now able to use their newly acquired PAR skills to inform their future teaching. Not only do they have increased confidence and competence in meeting the needs of students with ASD but also in meeting the needs of students in general.

CONCLUSION

When staff were asked what they would recommend to other teachers who work with students with ASD or who were considering becoming involved in PAR they emphasised the following five points:

- In respect to PAR, active support from school leaders is a vital ingredient. PAR involves a time commitment over and above a teacher's busy work life. There needs to be financial support from school leaders to release classroom teachers from some of their normal commitments. School leaders also need to provide support that demonstrates the importance of such projects.
- Collaboration is critical. Staff members and parents need to work together as a team and keep each other fully informed of the student's behaviours, programme and progress. This collaboration allows for the information sharing needed when interventions are implemented across settings. It also allows for the sharing of expertise and experience that occurs when parents, teachers and other professionals work together.
- School staff must be given time to reflect upon their practice and to share their thoughts and observations with others. The teachers in this study reported their weekly meeting and reflection times as one of the most important benefits of the research. They believed that this time helped them to shape their understanding of autism in general and the needs of Aroha and Maurice in particular. Funding support and careful scheduling may be required to ensure this reflection and sharing time happens on a regular basis.
- In respect to working with students with ASD, the importance of staff taking time to get to know students and to build relationships with them cannot be over-emphasised. Before teachers focus on academic tasks, social skills programmes or the like, a supportive, mutual relationship should be developed. Teaching plans and strategies are best built on a positive student-teacher relationship and an accurate knowledge and understanding of each individual. This may require teachers and other professionals to be less hasty to establish intervention programmes and instead give priority to the development of meaningful relationships.
- Ongoing professional development is essential to developing effective practice for students with ASD. Professional development should include not only teachers and teachers' aides but also parents and other interested family members.

This PAR project showed that no single strategy could provide a panacea in the education of learners with ASD. Rather, it is the combination of a collaborative, informed approach, positive student-teacher relationships and teaching strategies based on the interests and abilities of students that underpins effective practice for learners with ASD.

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APPENDIX 1

Questionnaire for teachers' aides (developed from Watson, Holton & Andrews, 1997).

(This is a compilation of the questionnaires used for Aroha and Maurice.)

GETTING TO KNOW AROHA

Date:

People who contributed information:

Likes

What activities or places appear to relax Aroha?

What are Aroha's favourite things and special interests?

What are Aroha's favourite places?

What are Aroha's favourite foods and drinks?

Dislikes

Are there any places where Aroha doesn't like to go?

Are there any activities in which Aroha doesn't like to participate?

Are there any objects which Aroha doesn't like or where she becomes agitated/frightened if they are around?

Unusual behaviours

In which situations does Aroha show unusual behaviours and what does Aroha do?

How does Aroha use her senses?

How does Aroha explore new objects and places?

Which sense does Aroha appear to rely on?

Does Aroha smell or sniff some objects?

Does Aroha appear to be looking at some things "out of the corner of her eye"?

How does Aroha react to certain sounds?

Which sounds are causing difficulty?

If Aroha is concentrating on something and you speak or there is a sudden noise, does Aroha respond?

Does Aroha touch or tap things as she moves around?

Does Aroha appear to be disconcerted if the surface on which she is walking changes? If yes, when?

Movement

Does Aroha sometimes have difficulty getting started on a task even though you are sure she knows what to do? If yes, when?

Does Aroha sometimes "freeze" halfway through doing something that you are pretty sure she knows how to do? If yes, when?

Does Aroha have difficulty doing different actions with each hand? If yes, when?

Does Aroha sometimes repeat an action over and over again? If yes, when?

How does Aroha communicate?

In what situations is Aroha able to use speech effectively?

How would Aroha let you know she wanted you to help?

How would Aroha let someone know that she wanted them to go away?

Does Aroha have any manual signs she uses? If yes, which signs?

Does Aroha use sounds to let people know she wants something? If yes, when?

What gestures or body movements does Aroha use to let people know what she wants?

Does Aroha repeat something someone has just said?

Is Aroha repeating part of a conversation which she may have heard some time ago?

What gestures or body movements does Aroha use to let other people know what she wants?

Does Aroha use facial expressions? Are they appropriate?

Does Aroha use eye-contact to communicate? If yes, when?

How would Aroha draw your attention to something interesting?

How does Aroha show emotions?

How does Aroha show pleasure?

How does Aroha show unhappiness?

How does Aroha show fear?

How does Aroha indicate ill health or pain?

How does Aroha show excitement?

How does Aroha show boredom?

How does Aroha show that she is tired?

How does Aroha show frustration?

How does Aroha show affection?

How does Aroha show sadness?

How does Aroha show other emotions?

Routines

What parts of the day go smoothly most of the time?

Which parts of the daily routine are most likely to cause upset?

What are the signs that Aroha is becoming upset?

Calming activities and places

What activities appear to calm Aroha down? (List as many as possible.)

Are there any actions which Aroha uses to calm herself?

Are there any places which Aroha seems to use as a refuge to get away from the world when she is overwhelmed?

Teaching strategies

What strategies have you used successfully to teach Aroha a new routine or skill?

Are there any ways which you have discovered to help prepare Aroha for a change of routine?

APPENDIX 2

Questionnaire for parents (developed from Baron-Cohen, Howlin & Hadwin, 1999).

Do you think Aroha recognises the following emotions in herself or others?

	Self	Others	Comments / How does she show it?
Happy	Y / N	Y / N	
Sad	Y / N	Y / N	
Relaxed	Y / N	Y / N	
Stressed	Y / N	Y / N	
Angry	Y / N	Y / N	
Hurt	Y / N	Y / N	
Afraid	Y / N	Y / N	
Confused	Y / N	Y / N	
Tired	Y / N	Y / N	
Bored	Y / N	Y / N	
Does Aroha recognise when she is stressed?	Y / N		Comments
Does Aroha use any actions to calm herself when stressed?	Y / N		What does she do?
Do you recognise when Aroha becomes stressed?	Y / N		If yes, how?

APPENDIX 3

Resources purchased with research funds

BOOKS

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VIDEOS

Attwood, T. (2004). *Anger management across the spectrum*. Video presented at the Autism: Unlocking the Potential Within Conference, Christchurch 2004.

Holliday-Willey, L. (2004). *Aspie Land as experienced by one of its citizens*. Video presented at the Autism: Unlocking the Potential Within Conference, Christchurch 2004.

COMPUTER SOFTWARE

Boardmaker, Mayer-Johnson.

Mind Reading Emotions Library, Jessica Kingsley Publishers.

Writing with Symbols, Mayer-Johnson.

APPENDIX 4

A guide for compiling a “Getting to know me” leaflet about a student with ASD.

FREQUENTLY ASKED QUESTIONS ABOUT THE “GETTING TO KNOW ME” LEAFLET

Who is this leaflet for?

This leaflet has been designed so that teams supporting individuals with differences on the autism spectrum can work together to share ideas and information to assist the individual in situations where they are not known.

Why should we compile a leaflet about a particular child?

Children with differences on the autism spectrum are often referred to as having a “hidden disability”. At first glance it may not be obvious that some adaptations are required to assist them. Some quick information and tips may assist both the child and adults through their day. This brief information would assist at transition points for the individual, relief teachers, student teachers, new staff, paraprofessionals and visitors (where appropriate).

When should we do this?

At any time that works for the individual’s team. Perhaps times when known periods of change are expected.

Who should do this?

Compiling this leaflet is a team venture. The team will include different people depending on the individual’s situation. However, we suggest that a “key” school person and parents would be the minimum team. The individual being discussed should be aware of the leaflet and we would strongly recommend that you include something from the individual themselves if at all possible. It should not be done by only a teacher OR only a parent.

How does this fit with individual plans (IPs) or individual education plans (IEPs)?

This leaflet should contain key information points about an individual and therefore serves a different purpose to individual planning. However, teams may review this document at IP/IEP meetings to keep it updated. There is a section in the leaflet in which IP/IEP goals could be shared.

What should the leaflet look like?

Essentially this is up to you. We have made the leaflet so it can be an A4 sheet folded in half, like a booklet, to give four sides of information. However, please change to suit your needs.

Do we write about an individual in third person or from the person’s perspective (first person)?

You decide this. It will depend on the individual situation.

GUIDE FOR PAGE 1 (FRONT COVER)

Photo

It is suggested that you take a photo of the child and include it on the front cover. This ensures new staff can quickly identify the child who this relates to.

Child’s name

Include the name of the child on the cover. You could choose to add “and I have Asperger syndrome/high functioning autism/some things you need to know”.

Optional headings for personal information:

A little bit about me...

Stuff I want you to know...

Important stuff...

Did you know?

Talk to the child to gain some information about what they want to share. Here is a script you can use to talk with the child about the leaflet and why it is being made.

We want to put together some information to help you at school. It will also help people to know you a little better.

I am going to ask you some questions. I will write down some of your answers and then put the information into the leaflet.

If there is anything you don't want written down that is okay.

You just need to tell me. We will read through your information and we will check it is correct.

Some questions that you could ask are included below. You will need to adapt these to the age and ability of the child.

Who are you?

What is your name?

How old are you?

Do you have a nickname or something people should call you?

Who is in your family?

Who is important to you?

What do you like?

What hobbies do you have?

What are your interests?

What makes for a good day?

What happens at school to make it a good day?

What subjects do you like?

Who are your friends?

What trips do you like?

What things do you dislike?

Are there any sensory things that do not feel good?

What are you good at?

What are your dreams?

What would you like to do as a job when you leave school?

What do you want to do when you leave school?

GUIDE FOR PAGES 2 AND 3 (MIDDLE OF LEAFLET)

Information about Asperger syndrome

Include some general information about Asperger syndrome using a description of your preferences. Utilise books and articles if required.

Specific attributes and strategies

With people who know the child well, use the headings in the table below as a guide for describing the child's specific attributes. For each attribute, write a strategy that will support the child in that area. The table below is an example only.

Attributes for (insert name of child)	Strategies to support (insert name of child)
<p>Communication</p> <p>I may not make eye contact with you when you are talking to me.</p> <p>I usually understand your words but not your emotional tone, sarcasm, innuendo.</p>	<p>Communication</p> <p>Don't force eye contact from me. If I look at you, I cannot listen properly.</p> <p>Name your emotions for me. If you are mad with me and tell me off, you need to let me know before you do.</p>
<p>Sensory</p> <p>I will have difficulty hearing your voice over background noise.</p> <p>I do not like to be touched or crowded.</p>	<p>Sensory</p> <p>I sit in front of teacher's desk so background noise is lessened.</p> <p>When you talk to me do not get too close.</p>
<p>Mobility and fine motor</p> <p>I have real problems catching small balls.</p> <p>I will sometimes walk over people to get to my space on the mat.</p>	<p>Mobility and fine motor</p> <p>Ensure there are a few different sized balls available for use so I can choose a larger one.</p> <p>Leave a space in front of the white board – I know to walk along the front to my space.</p>
<p>Anxiety</p> <p>If I start to rock, you know my anxiety level is getting higher.</p> <p>I get highly anxious if there is a new teacher in the room.</p>	<p>Anxiety</p> <p>At this time, you need to say "You looked stressed, take your reading book to the quiet space"... I will do this.</p> <p>Give me 5 minutes to calm.</p> <p>Write the new teacher's name on the board so I can read it. Tell me you have read my leaflet and I will know you understand me better.</p>
<p>Unusual behaviours</p> <p>You may think my behaviour is unusual. For example: vocalisations, flapping, sucking my clothes. I may be concentrating or anxious.</p>	<p>Unusual behaviours</p> <p>You may simply ignore these behaviours. If they are disturbing others, please tell me what I am doing and how to make it right.</p>
<p>Personal care</p> <p>When I am highly anxious I will not eat lunch.</p>	<p>Personal care</p> <p>If I do not eat and you know I am anxious, please let me go when the other children are released. Ensure my parents know. If I do not eat, allow me to use my quiet place – to enable me to cope with the afternoon.</p>
<p>Safety issues</p> <p>I will talk to anyone!!! I do not have stranger danger awareness.</p>	<p>Safety issues</p> <p>When I wait for my parents outside, my assigned buddy waits with me. There is a list on the form room wall.</p>

Attributes for (insert name of child)	Strategies to support (insert name of child)
Organisation My desk is often messy.	Organisation You need to tell me what I need out and what goes away.
Special Interests I will talk to you forever about dinosaurs.	Special Interests I am only allowed to talk to you about dinosaurs before morning tea.
Social skills I am practising taking turns in conversation.	Social skills If I talk over you, say "stop, it's my turn to talk".
Curriculum I love maths. I have difficulty generalising learning. I often learn in isolation.	Curriculum As a special reward, give me extra maths – honestly! Give me lots of over learning opportunities. Give lots of examples to help me generalise.

GUIDE FOR PAGE 4 (BACK PAGE)

Current goals/targets and notes

Include some information about the child's current goals and targets. Consider the following when writing this section of the leaflet:

Who is going to fill in this section or will everyone contribute?

Do the goals match the IEP?

When will the goals be reviewed?

Are there sensitive goals that should not be in a public document?

Important people

People to include in this section may be from home, school, other agencies, or emergency contacts.

SOME FINAL THOUGHTS AND CONSIDERATIONS

Checking information is complete

It's a good idea to send a draft copy to all concerned parties to ensure the information is correct.

Reviewing the leaflet

In order to be effective, the leaflet will need up-dating and adapting over time. Therefore, set a review time for the leaflet. An IEP may provide a good opportunity to do this.

Ownership and distribution

The idea of ownership should be addressed when the leaflet is compiled. Who owns this information? When it is no longer needed what happens to the leaflet? This is a different issue to authorship of the leaflet.

This leaflet and guide was developed by the Manawatu High Functioning Autism/Asperger Syndrome working group.

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