



Managing, While On The Behaviour Support Waiting List

The following advice is written for use by Needs Assessment and Service Coordination agencies working with people with autism spectrum disorder.

Unfortunately need for behaviour support services (BSS) often out weighs capacity, and waiting lists can be long. Asking for behaviour support is often a 'last resort', occurring when the person with ASD, their parents or family, or support service feel under extreme stress, and near 'breaking point'. Being referred, but put on a lengthy waiting list, can be devastating.

However there are things that people can do while they are on the waiting list which give relief, address stress, and speed up interventions when the person finally comes to the head of the queue¹. In a few situations, 'waiting list strategies' take away the need for behaviour support at all.

Re-empowering People, and Attend to Basic Needs

Often people with ASD, and their parents, families/whanau and support services have been managing on a day to day basis. Sometimes, for years. Being referred for behaviour support does not take away the ability to manage. NASC staff need to support people to continue implementing positive strategies that have been working for them already.

Also helpful is encouraging people to consider their needs and support holistically, rather than as behavioural issues. Look for ways to relieve pressure, even if not directly related to the referral

issue. Consider natural supports, like wider family and the local community (i.e. Are there relatives who can take on some of the day to day responsibilities? Could the person go to after school activities, have a buddy, or join a club?). Identify practical and tangible help (e.g. nappy services, home help, or section maintenance) which could free people up so that they have more energy/ability to manage with problem behaviours.

“things that people can do while they are on the waiting list”

Sometimes people benefit from problem-solving ways to eat healthily, exercise, get sufficient sleep, have opportunities to relax, and have time for themselves. Find creative and previously unrecognised support which could assist (e.g. whilst a parent may have to support their child with ASD, a friend or relative could take other children to sports practice).

Support Services: Generic, Disability and ASD-Specific

Talking through problems helps. Many generic services offer practical advice and a sympathetic ear. Consider referring people to Citizens Advice, Plunket, Presbyterian Support Services, etc.

Meeting people with shared experiences is invaluable. Encourage contact with disability and ASD-specific organisations, like: Parent to Parent, CCS, Autism New Zealand, Altogether Autism, Cloud 9 Children's Foundation, and networks of adults with Asperger syndrome (contact Altogether Autism for further information).

¹ **Important note:** the information above does not apply to seriously challenging behaviour that threatens safety and well-being. In these extreme cases, professionals (doctors, psychiatrists, psychologists) should be consulted *with urgency*.

By contacting Altogether Autism people can request information on ASD-related topics, such as behavioural and emotional problems commonly experienced by people with ASD. Altogether Autism will discuss the problem with the caller, and put together an information pack which addresses their specific needs and is at a level of sophistication that is appropriate to them. NASCs can also use this service.

Learning About ASD and Applying Knowledge to the Person Concerned

One of the key ways to help people with ASD and their families and wider supporters is to assist them to understand ASD as it affects the individual concerned. Using the 'triad of impairments' in ASD (problems in communication, social/emotional understanding, and fixed interests/routines) is a good guide. More information on ASD signs and symptoms can be found on www.asdguideline.com.

It can be helpful to write a 'manual' or 'users guide' on the person with ASD, and (if the person with ASD is old enough) on the non-ASD people that they interact with. This helps people:

1. Recognise when behaviour is specifically ASD-related, which can take blame and anger out of situations. (There is a big difference between deliberate naughtiness and an ASD-related anxious reaction).
2. Prevent or avoid situations likely to trigger unwanted behaviour.
3. Plan ahead, to minimise the impact of unavoidable triggers.
4. Identify helpful strategies in advance, so that people know what to do, and how to react, and their response is consistent every time.

Prepare for Behaviour Support

Sometimes 'problem behaviour' is an expression of other issues, like pain. This is particularly so when communication skills are poorly developed. Before attempting behaviour support, exclude medical reasons. Arrange for the person concerned to be seen by their GP, paediatrician, other medical specialist, and dentist. Check for hearing loss, seizures, pain, discomfort, and constipation.

The frequent 1st step of BSS is to collect information on the problem behaviour. Having information easily available will save time when the referral comes to the top of the list. This should speed up intervention. Relevant information includes:

1. Developmental milestones (e.g. birth details, information on when the person crawled, walked, said 1st words, said sentences, any diagnoses)
2. Key events in the person's life across time (e.g. illnesses, residential moves, starting or moving schools, bereavements or losses).
3. Describe problem behaviour clearly, noting strategies (helpful and unhelpful).
4. Video problem behaviour.
5. Record how often the problem behaviours occur (e.g. mark occurrences on the calendar).
6. Names and contact details of key staff and professionals involved (or recently involved).
7. Historical reports and letters from the pre-school, school, GP, other doctors, psychologists, and other allied health or educational staff.

... for information on ASD signs and symptoms see www.asdguideline.com

Parent Implemented Behaviour Management

Parents (and support workers) can implement basic behavioural strategies, as outlined below.

1. Make written descriptions of the problem behaviours that you want help with, in enough detail that anyone reading the description would be able to picture it happening.
2. Carefully consider possible reasons for the behaviour (consider changes in routine, new people, access to desired items or opportunities, avoidance). It may help to talk this through with other involved people.
3. Record occurrences of the problem behaviour, noting down the setting it occurred in, potential triggers, action taken, and responses of the person and others.
4. If patterns are found, make changes to the setting, triggers, action and responses. Consider using:
 - a. Exercise (e.g. walking, running, trampoline), to let off energy.
 - b. Visuals and clear instruction to ensure that communication is understood.
 - c. Social stories to explain situations and suggest more appropriate behaviour.
 - d. Simple relaxation strategies (e.g. listening to music, having a relaxing bath, going for a walk, relaxing breathing).
 - e. Simple rewards for desired behaviours.
5. Avoid using punishments, which rarely makes things better and often makes things worse.
6. Whatever you do, be consistent, and try out the strategy for a reasonable time.

For more detailed information on:

parent-implemented behaviour management

contact Altogether Autism for an information pack, and (if possible) specify what the problem behaviour is.

