

LESSONS LEARNED IN SUPPORTING INDIVIDUALS WITH AUTISM SPECTRUM DISORDER (ASD)

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I have been in this movement for more than 35 years as a parent, volunteer, staff member, and professional. You'd think that this would mean that my family and I would really have it together in knowing how to support my daughter with a diagnosis on the autism spectrum, wouldn't you? Well, I have a confession to make. My wife and I are not totally consistent in the way we have applied professional "best practices" in supporting our daughter.

As a professional who may only see individuals and their families irregularly, it is relatively easy to be prescriptive on what parents should be doing. Staff may be a bit more sympathetic with the difficulties of follow-through since they support the individual for whole shifts at a time. Parents of children living at home may face significant challenges 24 hours a day seven days a week. Follow-through and consistency, while necessary, can be very hard indeed. This does not lessen the requirement to keep on trying to do our best; it is just an acknowledgement that we can't all be perfect all the time.

Separating Fad, Fact and Fiction

Another confession has to do with adopting fads which have been put forward as "cures" or at least "effective treatments" on the basis of anecdotal evidence. As parents, we have been known to try new "treatments" or "cures" that seem to have helped others—megavitamins with magnesium, gluten or casein-free diets—even, I am a bit hesitant to admit, facilitated communication.

With the possibility of multiple origins for autism, it might well be that some interventions help some individuals greatly, but not others. Therefore, I see nothing wrong with families trying new things, so long as this is done with a reasonable amount of caution.

In fact, I freely admit that we have tried things as a family that I would not support as a professional, or would not authorize for funding as head of a government sponsored "transfer payment agency." While it is the prerogative of parents to want to ensure that their child has every advantage to the best quality of life, I firmly believe that this must be tempered with caution that can only come from well-researched evidence, especially when there is potential risk to the individual or others.

In my practice as a psychologist, and as the Chief Executive Officer of a large organization specializing in supporting individuals with ASD, I have seen great harm done to individuals whose families have too wholeheartedly adopted one fad or another in the hopes of a cure. This includes families who have insisted that psychiatric medication be stopped to implement a naturopathic or other such approach.

Psychotropic Medication

At Kerry's Place Autism Services (KPAS), we believe that one should continually strive for the least and most appropriate psychotropic medication for the best quality of life. The fact is, medication prescribed by a psychiatrist has generally been well-researched and is administered under controlled conditions with known side effects. The same is not generally true of naturopathic approaches. It is also not true, of course, for medication that some medical doctors prescribe that has not been well-researched for the specific purpose for which the prescription is written. This is not to say that such "off-label" prescription, naturopathic or herbal approaches do not work for some people, however; just that the likely outcome(s) or potential side-effects are not as well determined.

Behavioural Modification – Whose Behaviour?

For many years my wife and I tried to modify our daughter's behaviour to be what we wanted it to be, that is, to appear more normal. Being a psychologist and my wife a special needs teacher, we tried most "state of the art" behaviour management techniques of the time. As our daughter got older she was less willing or less able to conform to our

expectations. She began to communicate her dissatisfaction through aggression, self-abuse and property damage. This in turn led to the vicious circle familiar to many individuals with ASD and their families in which various psychotropic medications were used to help our daughter and us deal with the many challenges that we were experiencing with each other. It was only when we began to back off, and let her be what she was prepared or able to be that these challenging behaviours diminished.

In recent years we have gone through a similar evolution in Kerry's Place Autism Services in which we are much more cautious about intrusive behaviour modification techniques, including medication. We now spend more time analyzing what function the person's behaviour has for him or her, then: tailoring environmental circumstances to the needs of the individual, and helping him or her develop alternate means of communicating what he or she wants or needs and providing the means for him or her to achieve these wants or needs.

One of the key things that we have learned over recent years is that it is critical to gain common understandings when planning for and supporting individuals. These common understandings must be shared by the individual with ASD, their family (both immediate and extended), friends, and direct service providers, professionals such as occupational therapists, speech and language therapists, psychologists, psychiatrists, other medical professionals and funding agencies. This is best done in the context of what has come to be referred to as the biopsychosocial approach in which the individual, his or her support circle, staff and professionals share information and work together to understand and deal with medical, environmental, and behavioural challenges facing the individual.

Understanding the person

The first and most essential principle in supporting people in challenging situations is to listen, and to work hard at understanding the individual with ASD. This is fundamental to overcoming barriers to effective communication.

If difficulties have existed in the individual's life for a long time, he or she may have become increasingly frustrated and learned that aggression and self-injurious behaviour are sometimes successful in getting what they want. Obsessive compulsive disorder and other types of behaviour may have been adopted as ways of temporarily reducing stress, or of satisfying particular sensory needs. Without truly understanding the person, the response from support providers is often inconsistent, delayed and unrelated to the wants or needs of the person with ASD. The individual may be ignored, punished or rewarded for the same behaviour at different times, by different people sending mixed messages. The resulting confusion, fear and anxiety are felt most acutely by the individual and may pervade the support environment. Chronic stress and anxiety can lead to depression and other psychiatric conditions especially if there is a genetic predisposition for these conditions.

Some of the ways we've learned to understand the person:

1. Ask the individual. It is important never to underestimate the ability of the individuals to tell us (verbally or non-verbally) how to help them better. Active listening not only involves our auditory sense but must also include watching, following and interacting. Active listening leads to formulating an understanding from a variety of perspectives (i.e., Just because I can't talk doesn't mean I don't have something to say).
2. Listen to those who know the individual including family, friends, and present and previous service providers.
3. Have qualified personnel conduct functional analysis of behaviour to determine the function that a particular behaviour has in getting something the person wants, or avoiding something that he or she don't like or want.
4. Watch the individual and follow his or her lead with patience and tolerance. Too often we assume we know better than the person and try to redirect him or her rather than following to see what they will tell or show us.
5. Provide the individual with an increased and wide range of opportunities for new experiences. Be careful to not assume that the person with ASD cannot handle new experiences, although they may have to do it on their terms and at their pace. Many individuals we support have had very limited positive opportunities and experiences for personal growth and enhancement of self-esteem. Often as we provide opportunities for new places and experiences, we learn a great deal about the individual's skills and interests of which we were unaware.

Building on strengths of the person: focus on changing the environment and support approaches rather than trying to change the person

Another key principle is to build upon the strengths of the person. People with ASD have taught us that we often misidentify the underlying reasons for their behaviour. Through experience we have learned that it is generally more effective to identify and treat complex needs, modify environments and attempt to change difficult circumstances, rather than to try and modify the individual's behaviour in the absence of these other considerations.

Development of common understandings across all parties involved

Trust and teamwork between families/support circles, agency members and professionals can, at times, be difficult to foster and maintain, particularly if there is a history of difficulties and mistrust between family and service providers. A sound basis for developing trusting, working relationships between members is the declaration and acceptance by all that they share a common goal—to support the individual with ASD to have the best possible life.