

SOME INSIGHTS IN UNDERSTANDING THE SUPPORT REQUIREMENTS OF PERSONS LIVING WITH AUTISM SPECTRUM DISORDER

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In the 1950s, two pioneers in psychology, B.F. Skinner and Carl Rogers, held a famous debate on which of two developmental models is most effective in understanding and dealing with psychological problems. Skinner argued for “scientific best practice” based on principles that have evolved into what we now know as “applied behavioural analysis.” Rogers argued that we need to have “unconditional positive regard” for people that we are trying to support. He felt that, as humans, we are innately programmed to meet our potential and have the drive to do so, given a sufficiently supportive and nurturing environment. For many years, and up to the present day, these models have been regarded by many professionals to be in opposition to each other. These days, one hears echoes of this debate in the developmental services by proponents of what have come to be referred to as “Applied Behavioural Analysis” and “Gentle Teaching.”

Our experience has shown us that these philosophical orientations can be complementary, and in fact, both can contribute to providing an effective, holistic support to individuals with ASD. It is important to use best practices based on Applied Behavioural Analysis to understand what function(s) challenging behaviour may be having for the individual, and for developing strategies for dealing with this behaviour. Unconditional positive regard and mutual trust are critical in establishing an environment in which progress can be made.

Why this document was started

This paper is meant to capture some of the lessons that we have learned through supporting individuals with Autism Spectrum Disorder (ASD) and their families over the years. Much of what is discussed here may sound like common sense or motherhood and apple pie, and to a certain degree this is true. However, simple changes in mindset can result in significant changes in environment and support approaches that allow individuals to succeed. We have had failures along with our successes, and have learned from each.

The individuals we support have been very helpful and patient with us in helping us to learn some key principles in supporting people with ASD. Often these individuals had previously been identified as “hard to serve”. For some time now we have had the intention of honoring the contributions these individuals have made to our understanding by documenting these principles.

Therefore, we want to extend our sincere appreciation to the individuals we serve and their families. Without the patience and perseverance of these individuals, this learning would not have been possible. Time and time again, they have persevered in communicating to us, in a variety of ways (verbal and nonverbal), what they need and how to support them better. The perseverance and hope that these people have shown in many situations over

lengths of time, cannot help but to create a sense of humility and an incredible sense of respect for those living with ASD.

OVERVIEW OF KEY PRINCIPLES IN UNDERSTANDING AND SUPPORTING INDIVIDUALS WITH ASD

To assist in describing some of the experiences we have gained from those we support, we have categorized these experiences into Three Key Principles of Understanding and Supporting Individuals with ASD:

- a) Understanding the Person
- b) Building on the Strengths of the Person
- c) Gaining Common Understandings

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 a fundamental axiom to overcoming barriers to effective communication. Therefore, in supporting individuals with ASD, regardless of the situation, this is a non-negotiable first step

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 is sometimes successful in getting them 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.

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

1. Ask the individual: It is important to never underestimate the ability of the individuals to tell us (verbally or nonverbally) how to help them better. Even those with the most severe levels of autism and multiple disabilities have been able to help us gain increased understanding if we listen closely enough. **Active listening** not only involves our auditory sense but must also include watching, following, and interacting. Active listening leads to formulating understanding from a variety of perspectives.
2. Listen to those who know the individual including family, friends, and previous service providers.
3. Conduct functional analysis of behaviour to determine the function that a particular behaviour has in getting something the person wants, or avoiding something that they don't like or want.

4. Watch the individual and following 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. We have to be careful to not assume that the persons 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. Oftentimes, 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

The second key principle that we have learned 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.

In the past when individuals have communicated a particular distress that they are experiencing in their environments through a challenging behaviour, we have tended to consult with "behavioural experts" to develop plans to suppress these unwanted behaviours. These behavioural experts generally begin by observing the individual "in situ" to develop a report identifying when, where, and under what circumstances the problematic behaviour(s) occurs, along with an ABC (antecedent, behaviour, consequence) strategy for managing the behaviour.

Inducing the individual to modify his or her behaviour in this way can be effective under some circumstances, and in fact underlies the specific applied behavioural analysis strategy known in Ontario as Intensive Behavioural Intervention (IBI).

The research literature indicates that IBI is most effective for young children, generally in the pre-school range, who have good expressive communication skills and relatively strong intellectual skills. Thus, the likelihood of benefiting from this intervention varies greatly from child to child. One child at the age of eight will benefit more than another at the age of six. It is certainly true, that by the immediate pre-teen years, IBI has diminishing returns. The same techniques may be considered intrusive and even abusive if carried on as intensively after the early formative years or started later in life.

Many parents see IBI as a cure. It is not. What it is however, is an effective method for teaching a variety of skills that can be very useful for the individual. Younger children benefit more because their brains are more amenable to this kind of learning. The benefits need to be put in better perspective. Some families spend so much time and effort on IBI and other supposed "cures" for their child, that they neglect balance in their own lives, their

marriages and the lives of their other children. Even when children benefit greatly, they are left with sensory, social and other challenges. The support that they may need from a strong supportive integrative family can be jeopardized if parents are divorced and siblings become disaffected. Respite, sibling support groups, information workshops, and other forms of community outreach are required in addition to IBI.

Parents advocating for IBI have been very effective, and must be congratulated for the progress they have made in leveraging access to an important intervention. However, there needs to be stronger advocacy, informing the public and putting the benefits of IBI in context, while promoting a broader range of more balanced supports across all ages.

Since IBI does not “cure” the neurological condition(s) underlying ASD, the individual will likely continue to live with social and sensory challenges even if they develop good coping skills in other areas. In fact, some professionals are beginning to report that some individuals with a diagnosis of Aspergers Syndrome, having significant support needs, are being refused access to developmental services funding which they would have received with their previous diagnosis of classic Autism (that they have been able to overcome with the “benefits” of IBI.)

Development of Common Understandings Across All Parties Involved

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. This development of common understandings across all parties requires a great deal of work and discussion. However, these common understandings can be critical to implementing effective environmental and support approaches. 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 OT/SLP/ Psychology, funding agencies, and medical professionals.

The Biopsychosocial Approach allows the individual, his or her family members, staff and professionals to work together to understand how best to support the individual.

The following diagram represents the “Biopsychosocial Approach that has been used by KPAS.



Until the advent of Person Centred Planning and other “individualized approaches,” as children and adults entered service systems (whether institutions or group homes), families were often not encouraged to be actively involved in the planning and supporting of their family member. Sadly, this distancing was often recommended and encouraged by professionals of the service system. This occurred despite what was most often wanted by the individual and family, this being, assistance and continued close involvement. As a result, the service system wrongly and inadvertently imparted the message to families that their knowledge and input was not needed. We need to remember this and be patient with families whose loved one has been in the “Service System” for a long time as we now ask for their involvement and input.

Trust and teamwork between families/support circles and agency members 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. That is, the provision of optimal support for the individual in need.

Differences in understandings and how to best support someone with ASD is often the result of communication difficulties. When communication breaks down and common understandings are lost, a situation can lead to extreme polarization of viewpoints.

Communications difficulties can arise from lack of shared understandings around such issues as:

- The use of prescribed medications in response to medical conditions and / or behaviour.
- Use of homeopathic remedies in place of conventional treatment
- Cultural differences: Experience has taught us the value of bridging cultural divides. For families and individuals, cultural communities provide sources of social and spiritual support. For individuals, their culture may define their dress, diet, personal care, influence their social behaviour and understandings of the etiology of mental health concerns.
- Individual’s abilities, whether day to day decisions such as diet and personal spending, or in regards to more risk assessment decisions such as ability to travel in the community alone.
- Individual’s choice of friends or housemates
- Choice of direct support providers / employees

In difficult situations, the use of Protocols or Memorandums of Understandings may be helpful to provide increased clarity of joint understandings and agreements. *Protocols* are a pro-active approach to establishing supportive roles and responsibilities and can be used to guide: our response to behaviour in risk situations, the administration of medication, the frequency and flow of information sharing between members, the amount and type of family involvement and dispute resolution. *Memorandums of Understanding* between all members define negotiable and non-negotiable items in the support plan. Memorandums of

Understanding and Protocols are only effective when developed with the participation of all members, and then, consistently applied.

Both ASD and Intellectual Disabilities are, by definition, developmental disabilities. Persons having a diagnosis falling under each, or both, can also have a psychiatric condition, and therefore a dual diagnosis. A person with ASD may also have an intellectual disability, but this is not necessarily the case.

It can take quite different understandings and skills to successfully support a person with ASD versus one with an intellectual disability. In part, this is because of the special social and sensory issues involved in the former, which are not as likely in the latter. The requirements to support a person successfully with a psychiatric condition are generally quite different again. The requirements to successfully support someone with various combinations of conditions (Intellectual Disability, ASD, and Psychiatric Illness) render the situation even more complicated because these separate conditions tend to interact in their impact on a person's well-being/behaviour. Specific interventions may be required to deal with these separate interactions.

Investigating the reasons for challenging behaviours, and tailoring the environment to the needs of the individual, generally leads to a reduction in the behaviour and subsequently improvements in the individual's quality of life. It is unrealistic to expect the individual's complex behavioural issues to change quickly. In fact, it is not possible to generate a list of formulas, or "to do's that can be applied blindly," to all persons with ASD. If we have learned anything over the years, it is that each person with ASD is unique. The reaction of each individual with ASD to his or her environment is unique

It is important to note here that extra considerations need to be taken when individuals are moving from one environment to another. This is particularly true if the initial environment is one where the individual has lived for a number of years in a congregate care situation. Institutional living can be static and restrictive, and we find that many individuals experience considerable growth in the years after leaving an institution. In spite of the evidence that institutional living does not offer the best possible quality of life to individuals, family members are often apprehensive when people leave institutions and move into community settings. Parental concern for the health and safety of their children can lead to a desire for the creation of the "ideal" living situation, one from which their child will not have to move again. Family support must be built into transitions between institutions and agency/community. Ultimately, the family will also be in transition. As such, they may need extra support in working through this transition.

We have learned not to assume that it is possible to find the one "best" living situation, or support option for an individual. Over time, and as individuals realize their potential, their aspirations, wants and needs evolve. Their support environments must evolve along with them. Like all of us, as our interests, strengths, and needs change over time, there is a need for us to be flexible in our support for persons with ASD. The question of whether a particular support option is suitable needs to be considered very carefully and only after time is taken in which to learn to understand the person.