

# Into the Silence: Working with Autism

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## Clinical Points

- Autism Spectrum Disorder (ASD) is a group of neurodevelopmental disorders characterised by a triad of distinct features:
  - (i) impaired development of social interaction skills;
  - (ii) limited ability in speech and non-verbal communication;
  - (iii) presence of typical, restricted, repetitive and stereotyped patterns of behaviour.
- Individuals with autism experience the world differently; approach with understanding and respect.
- Autistic individuals report the following problems:
  - (i) altered sensitivity to stimuli;
  - (ii) limited ability to concentrate on more than one sensation at a time;
  - (iii) emotional distress;
  - (iv) poor communication skills;
  - (v) less socially-orientated priorities
- When interacting with autistic individuals, remember:
  - (i) their right as a person to demand equal, mutual respect
  - (ii) their thinking processes usually differ from others
  - (iii) their limited capacity in filtering and interpreting external stimuli; as well as limited ability to pay attention to more than one stimulus at a time
  - (iv) they may seem to have varying degrees of empathy
- Remember to consider the needs of the parents and caretakers; provide extra support for them.

## INTRODUCTION

*"I can remember when I tuned out, I would just sit and rock and let sand go through my hands. I was able to shut the world out... You have got to keep autistic children engaged with the world. You cannot let them tune out."*

Dr. Temple Grandin was diagnosed with autism when she was 3 years old, and has since fought to prove that being labelled 'autistic' is not a 'death sentence to achievement or productivity in life'<sup>1</sup>. Presently an Associate Professor at Colorado State University and a renowned professional designer of humane livestock facilities, she is arguably the best living proof that the reclusive characteristics of autism can be modified and reshaped. The outcome of Autism Spectrum Disorder (ASD) is dependent on both early detection and intervention, with about one third of autistic persons being able to attain some degree of independent living<sup>2</sup>. Having the crucial guidance of a mentor who can recognize abilities and encourage interests can make a world of difference to autistic children. However, before anyone can tap into their inner potential, there is a wall of communication and understanding difficulties which has to be breached.

ASD is a group of neurodevelopmental disorders which are usually diagnosed in children before the age of 3. ASD classically presents with a triad of features: a deficit in the general development of social skills (withdrawal, lack of interest in peers); limitations in the use of interactive language (speech as well as nonverbal communication);

the presence of typical, restricted, repetitive and stereotyped patterns of behaviour (preoccupation with rituals, repetitive motor mannerisms)<sup>3, 4, 5</sup>.

In 1943, Kanner identified a syndrome he labeled "autism"<sup>6</sup>. Since then, no single cause has been identified for the development of this disorder. A genetic basis has been suggested by studies on twins. It has been shown that there exists a higher incidence of recurrence among siblings<sup>7</sup>. In addition, some reports have suggested a possible association with genetic conditions such as fragile X syndrome<sup>8</sup>, tuberous sclerosis<sup>9</sup> and Down syndrome<sup>10</sup>. Neurotransmitters, such as serotonin, have been implicated in the development and expression of autism<sup>11</sup>. Other possible contributing factors in autism development include infections<sup>12</sup>, defects in protein processing<sup>13</sup>, errors in metabolism, immunological dysfunction, lead poisoning, and fetal alcohol syndrome<sup>14</sup>.

Many intervention strategies are available for children with autism. Pharmacological management is currently used only to control and help reduce behaviour problems<sup>2</sup>. The main focus of early interventions were psychological and behavioural. Interventions include sensory integration, touch pressure intervention, auditory integration training, behavioural interventions, comprehensive interventions or relative-based intervention<sup>15</sup>.

The incidence of ASD has gradually increased over the past few decades. This is due in part to changes in the diagnostic criteria, the development of the concept of a

wide autistic spectrum, and growing awareness among parents and professional workers. Other factors include the development of specialist services, as well as the possibility of a true increase in ASD incidence<sup>16</sup>. Between 1,200 and 2,000 children and young adults are affected by ASD in Ireland; increasing by nearly 100 new cases per year<sup>17</sup>. Recent studies in Ireland have found an incidence rate of 15 per 10,000 births<sup>17</sup>.

Children with ASD frequently pose a great challenge to caregivers and health professionals alike. Breaching the communication and comprehension barrier can be undeniably frustrating. This essay intends to explore this barrier from the point of view of both the individuals affected by autism and the people they interact with, namely the care workers and members of staff involved in their daily lives. Recommendations for creating more positive approaches and practices are also submitted. In addition, the provision of outside support for carers and parents are considered, as their level of tolerance and stress may have a compelling effect on the efficacy of communication and, ultimately, the overall progress and prognosis of the child.

### Breaching the communication and comprehension barrier

#### The First-Hand View of Autism

To understand the autistic experience one must begin to understand what it is like to have ASD. Many theories of autism have emerged though none accurately conveys the first-hand experience of this condition. Patients' histories, and indeed autobiographies, can impart details essential in establishing an 'insider's' perspective of ASD. A study by Olney was conducted using this method<sup>18</sup>. Three autobiographies<sup>19,20,21</sup> were selected as core texts to identify key themes from among 13 chosen to be analyzed. The themes were then compared and contrasted with the remaining books, identifying common points and disagreements

The study succeeded in pinpointing several key themes, concerning difficulties and experiences with sensation, attention, affect, communication, and social interaction. People with ASD experience the world differently and should be approached with openness and respect<sup>18</sup>. In order to understand ASD, strengths must be considered as well as deficits<sup>22,23</sup>. The findings are listed in Table 1.

Children with ASD experience frustration at being unable to communicate. Dr. Grandin once admitted that as a child, she "screamed because it was the only way (she) could communicate"<sup>24</sup>. She firmly believes "in lots of early intervention with little kids". The following excerpt from her book outlines the intervention she recommends; "get them talking if possible and get them interacting with people... It is important to look at the functioning level of the child, because what's appropriate for nonverbal

patients is totally different from what's appropriate for very mild Asperger's patients... they do need to learn social skills, but there's so much emphasis on social skills, there's no emphasis on career development...I get social interaction through shared interests at work, like talking about how to build something or solve a problem in animal behavior. Now that's really interesting to me; social chit-chat's not"<sup>25</sup>.

**Table 1 - Key themes identified by persons with autism regarding their condition<sup>18</sup>.**

Key Themes	Findings
1. Sensation	Persons with ASD can experience altered sensitivity to stimuli. Sensation may be fragmented, variable, increased, or decreased. This can result in what Williams <sup>25</sup> has termed "shut down". Sellin <sup>26</sup> described it as an acute panic attack brought about by sensory and emotional overload.
2. Attention	Those with ASD seemed to have limited capacity to give attention to more than one sensation at a time <sup>27,28</sup> . Both a dissociation between auditory and visual attention, and an inability to rapidly shift attention have been observed <sup>23,28</sup> . This can lead to either social and cognitive delays <sup>28</sup> ; or proficiency and the development extraordinary talents <sup>19,21,29</sup> .
3. Emotion	Not being able to easily interpret events and filter stimuli often result in distress and anxiety <sup>20,22</sup> . However, many also reported experiencing acute, intense pleasure while engaging in a particular activity which interests them <sup>19,21,25,27,30</sup> .
4. Communication	Individuals with ASD may face difficulty interpreting situational nuances, fail to consider context, and have trouble sifting the essential from the trivial <sup>31,32</sup> . Other dilemmas include initiating conversations, and specific problems with receptive and/or expressive communication <sup>19,22,33,34,35</sup> .
5. Social Interaction	Several authors disclosed that they did not feel the need for a mutual relationship in the same way that non-autistic individuals do, however, they sometimes desired companionship <sup>23,36</sup> . This is made complicated by the difficulties in understanding and producing the subtleties of both spoken and physical language, such as facial expressions and tone of voice.

#### The Carer and Staff Member's Point of View

The staff involved in caring for children with ASD play a significant role in their lives. Not only do they affect the child's future success and outcome, they are looked upon to deal with any challenging behaviours which could arise in the present. At times, individuals may become violent and harmful, not only to others but to themselves as well. They might appear to be resistant to all forms of treatment. Staff members are held responsible to handle and deal with such situations professionally, with most managing via both practical and factual knowledge<sup>37</sup>.

Emotional responses to challenging behaviours can affect the staffs' reaction to those behaviours and also play a fundamental role in maintaining their psychological well-being. A study by Jahoda and Wanless<sup>38</sup> found that when faced with these situations, the majority of staff members had a significantly intense emotional response. Nearly one half of the staff believed that the individual's aggression was directed at them personally<sup>38</sup>. The majority of staff

members described patients in negative terms, and mentioned that their first impulse had been to confront them<sup>38</sup>. A qualitative study by Hastings and Brown<sup>39</sup> on the possible predictors of staff member's emotional reactions revealed several factors which may influence their vulnerability to experiencing negative emotions in reaction to challenging behaviours. These factors include their beliefs about the cause of the behaviour, lower level of competence and poor prior behavioural knowledge. Surprisingly, staff with formal qualifications also reported more negative emotional reactions when compared with those without<sup>41</sup>.

Staff behaviour can sometimes be unsupportive and discouraging. The enormous workload burdened upon staff members may cause them to spend less time interacting with those under their care; and make the quality of these interactions poor<sup>40</sup>. Self-report studies reveal that most of the staffs' responses to challenging behaviour were that of the nature which reinforces such adverse behaviours<sup>40</sup>. Occasionally they may act in a paternal manner, dominating over the individual's rights to decide over his own body and liberty, claiming that 'doctor knows best'. The paternalistic "typecast" notion that people with ASD do not have the capacity to exercise their right to self-autonomy can be seen as discrimination of the disabled, and even a breach of human rights.

This ethical issue has been brought forth to the European Court of Human Rights in 2004 by HL, a man with autism who was held for 5 months in a psychiatric hospital without his consent<sup>41</sup>. Because of his autism, he was deemed to lack the capacity to exercise autonomy, and so, despite the existence of the Mental Health Act, he was detained. The Court ordered the British Government to pay £20,000 compensation to HL for breach of his human rights. This ruling could potentially affect thousands of people with learning disabilities and dementia, who cannot consent to or refuse treatment. The Government should allow patients without the capacity to consent to be protected by the same safeguards set up to defend the rest of society against wrongful, forced admissions to hospitals.

### **Recommendations for creating more positive approaches and practices**

Anyone who works with individuals with ASD must be able to grasp the concept that every human is unique. Personal interaction style differs from person to person. However, experienced staff members and carers have several distinct qualities which create positive interpersonal communication. General approaches and strategies can be used but they must, however, be tailored according to individual needs<sup>42</sup>.

Before engaging with persons affected by ASD, one must carefully consider their strengths and weaknesses. One must also always remember that underneath the layers of skin and sinew lives a person who has equal rights and demands equal respect just like any other. Several basic

points on interaction to bear in mind when one is working with children and adults with ASD include:

#### **1. The right of a person with ASD to demand equal respect.**

People with ASD should be treated with the same respect shown to others<sup>41</sup>. Conventional etiquettes still apply; mutual respect is still regarded as the seed from which a fulfilling relationship will grow and flourish.

Be sensitive when you are talking to or speaking about those with ASD<sup>42</sup>. Don't refer to them as "an autistic". They are affected by autism; they are not autism *per se*. People with gastric ulcer or Parkinson's disease are not referred to as, "he is a gastric ulcer" or, "she is Parkinson's", and autism is no different.

One should also limit and avoid using psychiatric terminology as much as possible, unless it is for psychiatric or medical analysis. Terms such as obsessive, compulsive, ritualistic, or delusional can be quite inaccurate and judgmental, and should be replaced with less incriminating terms like "highly liked activity, or intensely focused interests"<sup>42</sup>. Where terms may be misunderstood, observed descriptions of the behaviour could be used.

Some people prefer to discuss cases while the patients themselves are not present. This is because no one truly knows the extent to which patients with ASD understand or their emotional reaction to what is being discussed, they simply may or may not be able to express themselves quite as well as other people<sup>42</sup>. If it is unavoidable, and the patient is within hearing range, one must remember to include them in the discussion even if they might not contribute anything to it.

#### **2. ASD implies different thinking processes.**

People with ASD usually have comparatively different cognitive processes. They are more inclined to think in a channeled, serialized manner ("monotropism") and are also less likely to be able to think in general terms ("closed thinking")<sup>43</sup>. Children, in particular, tend to think in literal terms<sup>43</sup>. They often fail to interpret subtle expressions used in everyday life. One must therefore be patient and understanding when talking to them as it may take them some time to digest and formulate a response to what one is saying to them.

Individuals with ASD may have difficulty understanding or complying with requests<sup>18</sup>. One should avoid *asking* a series of questions and should instead *tell* the patient what to do directly using concise, concrete language. For instance, rather than saying, "Where are you supposed to be right now? What do you see the other people doing? What is it time to do?", one could say, "Lucy, it's time for painting. Come to the table."<sup>42</sup>.

Furthermore, people with ASD may not readily differentiate a question from a statement. Use a different tone of voice and communication cues when conveying a message and when asking a question<sup>42</sup>. For instance, if a question has been asked, patiently wait for an answer and try to look like one is anticipating the answer. One must not be too quick to add more verbal information and non-verbal cues when individuals with ASD seem to be taking a long time in processing what one has said to them. Extra information may just confuse and serve as a distraction to their train of thought<sup>42,43</sup>.

### **3. People with ASD may have limited capacity to filter external stimuli as well as limited ability to concentrate on more than one stimulus at a time.**

Individuals with ASD may be hindered from social interaction by their limited capacity to filter sound, touch, visual input, and movement. They may not be able to concentrate on more than one stimulus at a time. Too much stimuli may lead to frustration and agitation<sup>18</sup>.

When working with another staff or family member, it is important that the patient is not put in a situation in which he/she needs to divide his/her attention<sup>42</sup>. Try not to talk simultaneously or repeat each other verbally. Rather, try using appropriate cues such as gestures, physical prompts, written or visual signs to reinforce the statement said by the other person. One must also try not to interrupt active interaction.

### **4. People with ASD have varying degrees of empathy.**

Although empirical evidence show that individuals affected by ASD are lacking or have diminished empathy<sup>44,45,46</sup>, one must understand that this is only from a psychological and psychiatric point of view. It would be inaccurate to assume that individuals with autism do not have feelings for others. They may just be unable to express the right body language or they may not fully comprehend the need for the expression<sup>18,47</sup>.

#### **Provision of extra support for carers and parents**

Parents and carers of children with autism face unique challenges everyday. Sometimes these challenges may get to be too much for them to handle. Anxiety and frustration arising from carrying the burden day in and day out could potentially lead to more serious psychopathology. A little understanding and support may alleviate some of the stress.

Possessing a more positive sense of one's own efficacy ("self-efficacy") and belief in one's own competence ("self-competence") has long been linked with better psychological well-being and less psychological distress<sup>48</sup>. This optimistic view of oneself has also been

known to hold great influence on parenting behaviors and reduced parenting stress<sup>48</sup>. Adopting coping strategies which have a positive impact on self-efficacy increases the likelihood of more positive and adaptive outcomes<sup>50</sup>. Examples of such coping strategies include actively seeking social support and reframing experiences to make them more positive. It is important to turn parents away from using escape and avoidance as coping mechanism as it has been shown to be associated with higher levels of stress in the family<sup>51</sup>.

Provision of adequate social support to the family helps to reduce stress and depression<sup>52</sup>. Having a good social network aids in the family's adjustment and relieves fathers' psychological distress<sup>49</sup>. Support can be sought from either family, friends, support groups or counsellors. People who will be caring for the patients may be experiencing different dilemmas: parents may feel incompetent and guilty towards the child; siblings may feel embarrassed or jealous at the attention given to the child; close relatives may not know how to handle the child. In these cases the help of a professional counselor may be of great benefit<sup>53</sup>.

Respite care may provide a much needed break for overstressed families. Burke and Cigno cited that it 'removes temporary strain and crisis in the family unit...Once parents used respite facilities, they were unequivocal in their praise...feeling that they could not survive without them'<sup>54</sup>. Many may only consider respite care as a last resort. This may be because parents tend to initially feel guilty at wanting to place the child into institutional care and are afraid to cause the child distress. The use of respite care indicates a realistic acceptance that some parents could not continue to care for their child without any rest or pause<sup>34</sup>.

Some parents may be distressed or 'hurt' as a result of the aloof nature of autism. Spontaneous and impulsive physical 'displays of affections', such as cuddling, are usually rejected and even feared by the child. Touch Therapy Programme<sup>55</sup> or massage intervention<sup>56</sup> therapy have been shown to help. Children who have had these therapies are generally more relaxed, able to tolerate more physical contact, and even expresses the desire to initiate massages at home. Parents reported feeling both physically and emotionally 'closer' to their children<sup>56</sup>. These therapies open a communication channel between parent and child, thus working to strengthen the emotional bonds between them.

#### **CONCLUSION**

As the incidence of ASD in Ireland increases, there is a need to become more competent with its management. Many in our profession are ill-equipped when it comes to having the skills required to work with autistic individuals, including medical students. ASD presents a special kind of challenge. Children with ASD may experience difficulties

in sensation, attention, affect, communication, and social interaction on a wide continuum, some of which may be hard to comprehend. The barrier of silence, or indeed, chaotic tantrums could merely be a coping mechanism due to an inability to filter and comprehend verbal and non-verbal communication. To the child with ASD, the world is an alien place which may seem very confusing and hostile at times. It is a challenge then to coax them out of the comfort of their inner worlds and get them to be a part of the real world. Patience and understanding of their condition is the key to helping these children communicate and understand the world.

Patience, dedication and respect are cardinal attributes required in creating positive practice. Though the way one would approach these children differs from one person to the next, several key ideas have been identified which are generally practicable when interacting with people with ASD. One should treat them with as much courtesy and respect as one would any other person. Considering the way they think is simply different from others and that they have limited capacity in filtering and interpreting external stimuli, one should be more tolerant when interacting with individuals with ASD, and not be too quick to blame them if they seem to be taking too much time responding. Always remember that, although these individuals may seem to have varying degrees of empathy, they are not without emotions. They feel what everyone else can feel, but they may simply be unable to express it.

Frustration and stress in parents, carers and staff members may lead to counter-productive attitudes, which is why additional support may be warranted. The psychological well-being of Staff affects the care and therapeutic progress of the individuals. The social stigma and stereotyping of autism, as well as emotional factors, may affect the judgment of the professional staff and increase family stress. Being able to trust one's own competence and manage stress effectively can allay depression and psychological instability, as well as prevent burnout. Strong social support is of considerable importance, and this includes having supportive friend and family, and counseling if need be. Families will also benefit from the occasional respite care. Special therapy, such as the Touch Therapy, can increase the child's tolerance to physical contact, and thus enable the parents to be more physically affectionate with their children.

Dr. Grandin once said 'I would think in an ideal world, you don't want to have people who can't talk, but on the other hand, you definitely don't want to get rid of all of the autism genetics because if you did that, there'd be no scientists. After all, who do you think made the first stone spear back in the caves? It wasn't the really social people.'

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