



Autism Spectrum Disorders

People with Autism Spectrum Disorders are fascinating in many ways.

It is commonly known that there are three primary domains impaired in affected individuals: social and emotional communications, delays or oddities in speech development, and a restricted range of interests or repetitive behaviors (American Psychiatric Association [APA], 2000). These similar conditions – including Autistic Disorder, Pervasive Developmental Disorder not otherwise specified, and Asperger’s Syndrome – exist on a continuum, commonly referred to as the Autism Spectrum. Individuals later diagnosed with Autism Spectrum Disorders are often described as being in their own world or on a different wavelength from their peers. Children with these conditions have a number of characteristics that interfere with the full development of their lives and have an impact on the lives of those around them. Many challenges face children with ASD conditions, making learning and adaptation a slow and arduous process.

Not as commonly discussed are the strengths of people with Autism Spectrum Disorders. Identifying these strengths can help parents and professionals know how to best engage the affected child or teen (Kluth, 2010).

For example, they often like to be very organized. They like to know what is happening ahead of time so they can be prepared. They keep what is meaningful to them in an accessible and organized fashion, such as lining up their toys, shoes, or books. They often keep their prize possessions well cared for in these ways. Of course one doesn’t have to have an ASD condition to dote over prize possessions! Being organized is usually seen as a strength in the workaday world of adults.

People with an ASD condition often have unique interests and hobbies. They are many times very willing to share their passions with others. By doing so there is never a question as to what is the entree to a chat with them. Their fascinations with unique topics and activities can be informative and intriguing. One child I met was fascinated by his family's aquarium. He could tell me all sorts of interesting things about the tropical fish. Although he was a bit discouraged that he could never win a staring contest with the fish, he did not give up on his hobby and spent many hours quietly enjoying it!

People with ASD conditions often think outside the box. They have a unique ability to see things differently. Their different thoughts and perspectives might in some settings be poorly received, as they don't just go with the groupthink of their peers. They think their own thoughts. Many of their unique comments invite conversation about a range of topics many so-called neurotypical people don't know much about. Many affected individuals who are verbal will freely speak their minds. You don't have to play head games with them. They often let you know their thoughts and feelings without pretense. Relationships this direct and open are very predictable. You don't have to guess about where the person stands on an issue.

Many people with ASD conditions become specialists in their fields or topics of interest. While they may start these specializations very early, they are not unlike others who find great pleasure in researching their topics of interest. Many people have subjects or activities they love, and they spend a lot of time and energy learning about them: facts about basketball, baseball, computer games, movies, reading, research on weird topics, word search puzzles, mathematics, photography, unique wildlife, cars, bugs, crustaceans, celebrities, and on and on. While I would admit that being an entomologist by age 10 is unexpected for a child, would society really rather the child is interested in sex, drugs, and violence?

When taken to excess, certainly, these strengths can impair relationships and impede daily activities, but they do demonstrate that children and adolescents “on the Autism Spectrum” can do many important things. They can concentrate intensely on things once their interest is engaged. They can acquire great amounts of knowledge. They can become experts in difficult fields due to their tenacious focus. Once they are trained and have committed something to memory, they can be diligent workers. They can learn and adapt. Use of strengths such as these can help these individuals develop greater independence (Autism Spectrum Australia [Aspect], 2006).

Nonetheless, the degree or intensity to which an individual exhibits these strengths may be of concern. The excessive focus of these strengths in combination with the person’s relational deficits may be the culprit that causes them social or legal problems. Such an imbalance leads to emotional or behavioral dysregulation. Most neurotypical people can adjust to social response. People with ASD conditions are often inattentive to social response, which prevents them from being guided by spontaneous input from others, and, in turn, prevents learning and adaptation.

Children and adolescents with ASD conditions have been observed to show little or no interest in other people. This lack of interest may look like the child is purposely ignoring others or is indifferent to others (Ozbayrak, undated). It is more likely that ASD-affected children and adolescents have difficulty recognizing and interpreting social information conveyed by and to neurotypical peers through facial expressions. Facial expressions are the most important mechanism of nonverbal communication (Batty & Taylor, 2006). In neurotypical children, the ability to correctly interpret facial expressions begins in early childhood and improves with age. By age 15 these abilities are said to be more like those of adults, although the process continues into adulthood. This is often not so for those with an ASD condition.

From another perspective, social interaction problems are not limited to those who have ASD conditions. Children with Fetal Alcohol Syndrome are noted to have social interaction problems, but a significant difference is the issue of the quality of the interaction for FAS-affected children rather than the quantity as for ASD-affected children (Bishop, Gahagan, & Lord, 2007). Motivation to engage socially is an aspect of interaction that is missing for most children with an ASD condition. Many of them feel ambivalent about social interaction, producing a social anxiety that is difficult to contend with. They may avoid interaction as a mechanism to avoid this anxiety (Ozbyrak, undated). While this avoidance may send the message that they are not interested in others, they simply don't have a strategy for communicating about the anxiety that is its source.

For many children and adolescents with an ASD condition it is more difficult to engage with their peers than it is to engage with people younger or older than they are. This preference or ease may be due to the impression of greater acceptance or tolerance by adults. Younger children may be less threatening and less judgmental (Ozbyrak, undated). Discomfort with their peer group may be an important factor in potential sexual misconduct, a subject we will return to in later chapters. It clearly impairs their ability to develop age-typical social skills.

Some adolescents with ASD conditions described as having High Functioning Autism or Asperger's Syndrome often seek out peer interaction. Newport & Newport (2002) describe a non-conventional version of friendships practiced by many with ASD conditions. Rather than seeking a deep, emotional friendship or avoiding relationships altogether, an intermediate level of relationship may be sought. Having associates is safer and less demanding. Pragmatic associates share specific interests. Beyond those interests there may be no other attraction or reason to affiliate.

For those on the Autism Spectrum, these associate relationships may be as good as it gets. These safe and emotionally non-demanding relationships are functional and satisfy needs in the child's life. Two children can exchange collector cards. Two teens can play video games together even if they have no conversation. An associate relationship may form between a child and teacher or a child and bus driver. A therapist can also become an associate. These associate relationships don't require reciprocity as they are task-oriented rather than personal.

Such pragmatic associate relationships are typically lacking in emotional connection. Friendships are usually thought to require an exchange of emotion and caring. Those aspects of relationship are uncomfortable and anxiety-provoking for ASD-affected youth. Social reticence too often overcomes the desire to be connected. Many people on the Autism Spectrum are quite content being alone, but feel pressured by their families to develop relationships (Newport & Newport, 2002). They don't know how to interact or are too socially clumsy to do so in their teen years. Starting with pragmatic associate relationships, nonetheless, is the beginning of relationship skills that carry the teen into adulthood. For some this relational style allows them to eventually meet a person with whom they feel safe and can then form a more intimate version of association.

Social and emotional communication and connection are not the only challenges faced by a person affected by an ASD condition. There are also delays and/or oddities of speech development, and a restricted range of interests and repetitive behaviors that impair or supersede daily life. Many of these children have sensory sensitivities as well, such as aversion or abreaction to certain sounds, textures, or other items. Children and adolescents with ASD conditions often have other behavioral issues as well, including severe attention, affective, language, and motivational deficits (Sherer, et al., 2001). These deficits may carry a cost of undermining social confidence.

Early Indicators

Although many children with ASD develop verbal skills, others do not. Some children learn to use a keyboard and type notes to communicate. Many children who are eventually diagnosed with Autistic Disorder are, in hindsight, noted to have failed to meet predictable social milestones by age six months. Early signs include lack of social smiles or reciprocity when smiled at, or not turning towards a parent who is talking to the child. The absence of these social cues may indicate the absence of other social capacities (Baker & Rain, undated). Similarly, babbling is expected in the first year with use of simple words by sixteen to eighteen months. The absence of efforts at verbalization in this period is an indicator of delay. Children are expected to speak single, non-echoed words by age two. If the child is not using short phrase speech by age three years the child may well meet the ASD diagnostic criteria (APA, 2000).

Children with ASD conditions are said to have a higher frequency of visits to a pediatrician early on. About one-third to one-half of affected children are appropriately identified before entering kindergarten (Costello, 2005). Early signs include inconsistent symptoms, such as hearing environmental noises but not responding to one's own name, poor eye contact, seeming to be in one's own world, and not seeming to notice if mother enters or leaves the room. Typical babies and toddlers will follow a caregiver's gaze and his or her pointing to or showing objects. This impaired joint attention is a hallmark indicator for ASD conditions which should raise significant concern if not present between six and fourteen months of age (Costello, 2005; Mastergeorge, 2005). Imaginative play and the beginning of reciprocal interaction are also typical developmental milestones for children by age eighteen months. The absence of these behaviors should lead to a screening for an ASD condition. Some professionals have advocated for universal screenings of all toddlers to rule out autism even before parental concerns

rise to the surface (California Department of Developmental Services [CDDS], 2002; Costello, 2005).

Children who do not have language delays but meet the other criteria are often diagnosed with Asperger's Syndrome. There may still be oddities of speech. The fluid nature of speech, tone, inflections, and redundancy are often identified as problem areas for children with Asperger's Syndrome.

The onset of autism is typically gradual. There are often less evident symptoms before the formal diagnosis is made (Courchesne, 2005; Miles & McCathren, 2003). A loss of communication or social skills occurs in about a third of ASD-diagnosed children, leading parents to seek professional help by which the condition is diagnosed. Such children appear to be developing within normal timelines only to regress. This loss of acquired skills and onset of autistic symptoms may be gradual, or it may be abrupt (Miles & McCathren, 2003; Ozonoff & Heung, 2005), and often an overwhelming shock to parents.

Related Developmental Conditions

More than half of people with autism are also diagnosed as having mental retardation, although many of these children's IQs improve with intervention (Ozonoff & Rogers, 2003). Most children with Asperger's Syndrome do not have such low intellectual functioning, but some may (APA, 2000).

Seizures are another challenge for children with ASD conditions (Miles & McCathren, 2003; Tharp, 2005). About one in four children with an ASD condition also have seizures. There appears to be no correlation between seizures and a regressive onset of autism (Tharp, 2005). Factors that are related include motor skill abnormalities, dysmorphic features and/or microcephally, auditory verbal agnosia, and a family history of seizures.

Let's Get Technical

By age two, the brain of a child with autism is larger than that of a neurotypical (NT) child, although the NT children do catch up. Of concern, however, is the pace of growth – or overgrowth – that occurs in those first two years. The overgrowth appears to come in a surge then slows to below the typical pace, before symptomatic behaviors bring the child to clinical attention. The frontal lobes have the greatest degree of growth in these first two years, which appear to undermine normal development and may be the genesis of the core features in ASD (Courchesne, 2005; Courchesne & Pierce, 2005). The overgrowth in the frontal cortex is also associated with a smaller cerebellum with less gray matter but overgrowth of white matter in the brain. The corpus collosum and amygdala are also said to be smaller in those with autism while the basal ganglia, parietal, temporal, and occipital lobes are larger (Rivera, 2005). Considering these findings, clearly early intervention is needed and appropriate.

That the frontal cortex is vital in higher-order cognitive processes, executive functions, language and social skills acquisition, inhibition, and emotional functioning is well accepted (Corbett & Constantine, 2005). Overgrowth in one area of the brain and undergrowth in another area of the brain, in simple language, will cause internal communication problems within the brain itself. It is hypothesized that the frontal lobes are thus over-connected within themselves and under-connected to other portions of the brain, leading to frontal lobe over-stimulation and under-stimulation in and under-interaction with other portions of the brain (Courchesne & Pierce, 2005). These challenges leave the child with autism struggling to make sense of a verbal, emotional, and social world.

Fragile X Syndrome (FXS) is a known cause of mental retardation. Fragile X Syndrome affects about 8 percent of children with ASD conditions (Hansen & Hagerman, 2003). It is genetically transmitted due to damage on the X chromosome and is highly correlated with males born to the same parents. Fathers can carry the condition without being affected themselves. Those with FXS have

many symptoms similar to ASD, including poor eye contact, tactile or sensory difficulties, social deficits and speech perseverations. Interestingly, children with Fragile X Syndrome – but without an ASD condition – do have interest in social interaction (Dykens, Hodapp, & Finucane, 2000; Hansen & Hagerman, 2003). Fragile X is known to cause a number of functional and behavioral problems, including hypertonia in infancy, sensory hyperarousal, sleeping problems, short attention spans, and tantrums (Hansen & Hagerman, 2003).

Another health condition correlated with ASD conditions is tuberous sclerosis (TS). TS is a rare genetic disease that causes benign tumors to grow in the brain and other organs (National Institute on Neurological Disorders and Stroke [NINDS], 2010). It affects the central nervous system and causes seizures, mental retardation, behavior problems, and skin abnormalities. TS is a lifelong condition with no known cure.

TS is associated with cognitive impairments including emotional and behavioral problems. Learning disabilities are common, as are anxiety, hyperactivity, aggression, communication problems, and sleep difficulties. These impairments are also common symptoms of those with ASD conditions. Approximately 4 percent of those with ASD conditions have TS. Some researchers hypothesize that TS contributes to brain abnormalities due to disruption of normal brain cell migration, changing the architecture of the brain itself (Hansen & Hagerman, 2003; Tharp, 2005; see also Courchesne & Pierce, 2005). Serotonin reuptake abnormalities have been identified in conjunction with TS as well (Hansen & Hagerman, 2003).

Many mental health problems co-occur with ASD conditions. These include attention-deficit hyperactivity disorder, anxiety and mood disorders, and schizophrenia (Ozonoff & Rogers, 2003). These conditions compound the challenges of having an ASD condition. One study identified that approximately 65 percent

of the individuals with ASD were also diagnosed with an additional psychiatric disorder (Hendren, 2003). Sometimes family members have traits of an ASD condition even though they do not meet the diagnostic threshold. This is not a surprise given the genetic nature of ASD conditions.

The developmental course of an ASD condition is different for each child. About a fourth of those diagnosed at age two or three eventually learn to speak and communicate. By ages six or seven many of these children blend into mainstream classrooms, to varying degrees. The other three-fourths of those diagnosed with Autistic Disorder continue to have a lifelong disability requiring ongoing and sometimes intensive support from family, school, and social agencies (Miles & McCathren, 2003). The prognosis is better for those with Asperger's Syndrome, those with normal cognitive capacities, and those who have verbal skills.

Family, Too

Autism Spectrum Disorders don't affect just individuals. Autism affects families. It is vital that parents, siblings, and care providers be involved in the assessment and treatment planning processes (CDDS, 2002; Gutstein & Sheely, 2002; Lockshin, Gillis, & Romanczyk, 2004). Families experiencing ASD have a high level of stress. Some parents experience stress related to caregiving, while others may feel more financial pressures. Having a child or sibling with an ASD condition creates pressures to reorganize family structure, expectations, leisure, routines, and priorities (Hanson & Lynch, 2004). Since ASD conditions affect families, strategies must be family centered and not focus solely on the individual who has the ASD condition (Fox, Benito, & Dunlap, 2002). Interventions should be focused on improving functioning in the lives of all family members (Koegel, Bimbela, & Schreibman, 1996). Everyone in the family is experiencing the ASD condition. Intervention should address everyone's needs.