

1

What Asperger's Means for the Child

As you'll soon read is the heart of this book and approach, what matters most is what children with Asperger's think, feel, say, do, and experience. Their experiences and engagement power their therapies and growth. To grasp and appreciate these subjective and personal aspects of Asperger's, we need to agree on the more objective—what we all can see in and about these children. By necessity, this chapter reads somewhat more abstract and theoretical than the more clinical chapters to come.

We begin by revisiting two early, familiar, and well-articulated descriptions of Asperger's made more than half a century ago by the American child psychiatrist Leo Kanner (1943) and the Austrian pediatrician Hans Asperger (1944/1991). It is indeed a "strange coincidence" that Kanner and Asperger never met, yet they both came from Austria, spoke German, described the same type of children with similar words, and wrote their papers in 1943 (Lyons & Fitzgerald, 2007, pp. 2022–2023). As Hans Asperger's original paper was in German, I, as did many others, first learned of his work from Lorna Wing's 1981 clinical account of Asperger's syndrome. Only later, to my and the field's great satisfaction, did Uta Frith translate the original into English (1991).

Both Asperger and Kanner believed they saw and described a particular type of child whose traits were recognizable and that defined a disorder.

Both researchers spotlighted a “poverty of social interaction and the failure of communication; stereotypic behavior, isolated special interests, outstanding skills and resistance to change” (Frith, 1991, p. 10). Kanner agreed totally with Asperger that the “autistic personality is highly distinctive despite wide individual differences” (1943, p. 67). In other words, while the children’s traits varied dramatically, both men felt confident that they could readily identify such a child. Though neither used the term, they implicitly agreed that these children shared a collection of symptoms, odd and ranging, that added up to a *syndrome* exhibiting consistency and constancy.

Both men noticed extraordinarily atypical language. Some of Kanner’s children were mute, speaking little or no language. He wrote of children who echoed and parroted phrases as if words were without meaning and who referred to themselves in the second or third person. Asperger’s children used words in clever if idiosyncratic ways, coining new words (neologisms) and reshaping words into uncommon forms. These children, he wrote, talked more like adults and stuck out nonverbally, lacking typical eye contact, facial expressions, humor, and, in general, a spontaneity of body and voice.

While the chronicles of both men are exemplary even by today’s standards, there are deeper aspects of Asperger’s paper that justify mention. While to their credit, both men saw Asperger’s as biologically determined, Kanner felt compelled to write in the next-to-last paragraph of his lengthy article that in his sample, “there [were] very few really warmhearted fathers and mothers” (1943, p. 250)—a seemingly innocent aside that tragically didn’t go forgotten by Bruno Bettelheim some 25 years later (1967).

Not only did Asperger make explicit his belief that parents don’t cause autism, but he further saw that some parents shared Asperger-like qualities with their children. Many of the parents in Asperger’s group were obsessive, highly intelligent, eccentric, and accomplished men and women in advanced fields. From his sample of children and families, Asperger inferred that the disorder is genetic, more heavily carried by the male chromosome, and more frequently seen in boys than girls. To Asperger, the fact that the children he met tended to come from one-child families said more about the parents genetically (their being people satisfied with one child). He did not want others to misinterpret this preponderance of one-child families as suggesting that living in a one-child, adult-centered home causes Asperger’s in a child who with siblings would have developed free of autism.

Asperger's view toward the parents was modern, enlightened, and sympathetic. In his case studies, he told of one mother who "knew her son through and through and understood his difficulties very well" (p. 41), a second who "fought desperately against [her son's] transfer into a special school for retarded children" (p. 60), and a third who found her mercilessly bullied son a protected situation where he could be educated more safely. Asperger tactfully described how exhausting, frustrating, and ineffective parenting such a child can feel, even for loving parents who understand what's happening. Without blaming, he described how the nature of the condition precludes the child's offering the kinds of closeness, affection, feelings, and empathy to the parents "that normally make life with a small child so richly rewarding" (pp. 80–81). Elsewhere, Asperger underscored the toll that the child's constitutional contrariness—disliking flattery, not wishing to please, oppositional, and neither wanting nor needing human attention—can take on parents and a family, however involved and caring.

In his efforts to know these children, Asperger had their intelligence tested, revealing consistently erratic performances involving average to strong intellects, extreme unevenness in skills, and difficulty concentrating and organizing. The children tended to do well on tasks measuring puzzle solving and factual knowledge but poorly on tasks that involved social understanding and sequential narrative. In reporting the varying IQs of his children, Asperger "anticipated a spectrum" of autism (Wing, 2000). That Asperger so richly and aptly laid out the intellectual profile of the children testifies to a study informed by a modern-day synthesis of clinical assessment, parent reports, teacher observations, and (for its time) sophisticated psychoeducational evaluation that hints at the field of neuropsychological testing to come.

Historically, any sort of autistic disorder was originally diagnosable in the *DSM-I* as *Schizophrenic reaction, childhood type* (APA, 1952) and in the *DSM-II* as *Schizophrenia, childhood type* (APA, 1968). The diagnosis of *Infantile Autism* was added to the *DSM-III* (APA, 1980), with much expanded and detailed criteria in the *DSM-III-R* (APA, 1987). *Asperger's Disorder*, as its own diagnostic entity, wasn't established until the *DSM-IV* (APA, 1994).

Consider the criteria for 299.80 *Asperger's Disorder* according to the revised *DSM-IV-TR* (APA, 2000), which we'll then compare to Gillberg's diagnostic criteria as revised in 1991. I, like Attwood (2007) and others, much prefer Gillberg's criteria. I recognize and fear that diagnostic lists, no less two in a row, can cause clinicians' and readers' eyes to glaze over. I think you'll find our closer attention worthwhile.

DSM-IV-TR Criteria

- (A) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) Impaired nonverbal behavior, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) Failure to develop peer relationships appropriate to developmental level
 - (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
 - (4) Lack of social or emotional reciprocity
- (B) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least two of the following:
 - (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in either intensity or focus
 - (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, complex whole-body movements)
 - (4) Persistent preoccupation with parts of objects
- (C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- (D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases by 3 years).
- (E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

Gillberg's 1991 Criteria

- (A) Severe impairment in reciprocal social interaction (at least two of the following):
 - (1) Inability to interact with peers
 - (2) Lack of desire to interact with peers
 - (3) Lack of appreciation of social cues
 - (4) Socially and emotionally inappropriate behavior

- (B) All-absorbing narrow interest (at least one of the following):
 - (1) Exclusion of other activities
 - (2) Repetitive adherence
 - (3) More rote than meaning
- (C) Imposition of routines and interests (at least one of the following):
 - (1) On self, in aspects of life
 - (2) On others
- (D) Speech and language problems (at least three of the following):
 - (1) Delayed development
 - (2) Superficially perfect expressive language
 - (3) Formal, pedantic language
 - (4) Odd prosody, peculiar voice characteristics
 - (5) Impairment of comprehension including misinterpretations of literal/implied meanings
- (E) Nonverbal communication problems (at least one of the following):
 - (1) Limited use of gestures
 - (2) Clumsy/gauche body language
 - (3) Limited facial expression
 - (4) Inappropriate expression
 - (5) Peculiar, stiff gaze
- (F) Motor Clumsiness
 - (1) Poor performance on neurodevelopmental examination

There is much about Gillberg's system (1991) that adds to its appeal and usefulness. Contrasted with the stilted precision of the *DSM-IV-TR* (APA, 2000), Gillberg's list uses plain language that we understand and relate to. But the attraction goes farther. Gillberg's criteria, as he states them, add meaningful and necessary context to what without such grounding can appear to be a sterile listing of symptoms. Consider some of the differences.

The *DSM-IV-TR* defines "impaired nonverbal behavior," whereas Gillberg defines "nonverbal communication problems," describing such behaviors in clear language that we can't mistake. By couching nonverbal behaviors within a "communication problem," Gillberg suggests why it matters and what it implies for the child's functioning and personal experience. Similarly, the *DSM-IV-TR* states a "failure to develop peer relationships"; Gillberg instead qualifies the child's social impairments as "difficulties interacting

with peers,” offering a more humane and realistic view that is less absolute, allows for degrees of relating, and again speaks to the child’s perspective of having a hard time with social relations. Gillberg’s addition of “indifference to peer contacts” further hints to the child’s experience. Rather than an “encompassing preoccupation” that is “restricted” and “abnormal” (*DSM-IV-TR*), Gillberg writes of a “narrow interest” involving the “exclusion of other activities.” Gillberg also categorizes the “speech and language peculiarities” that Asperger and Kanner both noticed, a characteristic that the *DSM-IV-TR* doesn’t mention at all.

Though a chapter could be spent parsing out the differences, we can readily see that Gillberg’s criteria are more comprehensive, descriptive, child-centered, and plainly stated. I for one could read and read the *DSM-IV-TR* diagnosis and still not recall what I’d read. Reading Gillberg’s criteria, which is basically just a list, begins to leave me with a sense of who these children are, an image that I can recall and from which I can start to think about the real children that I’ve met. Lastly—and perhaps I see too much in this—Gillberg’s list leaves me less discouraged.

ASPERGER’S FROM THE CHILD’S EXPERIENCE

You know that feeling of the sun in your eyes or when someone beside you on a plane hasn’t showered? Multiply it by a thousand and run it 24 hours a day. You now are beginning to appreciate what sensory sensitivities are like for children with Asperger’s. These children seem not to have the sensory equilibrium and censoring that protect and maintain the rest of us. The world literally pounds on their doors and ears, in their eyes, on their skin, and through their noses. Nails on blackboards and jackhammers next door—that’s what ordinary sensations can be like to children with Asperger’s. Then, to complicate it more, atop those supersensitivities, these children can be less perceptive of pain or perhaps know sensory synesthesias by which they smell sounds or hear numbers. Besides the obvious sensory onus of having to sense these noxious stimuli, the child’s sensory susceptibilities get in the way of life. How, for example, does it affect bonding if the child, through no ill or free will, dislikes the smell of his parents?

Because they have a wish for connection with other people, though it may not look as apparent, vigorous, or invited as with a nonautistic child, children with Asperger’s can be alone a lot and experience various levels of

loneliness and exclusion, even as it might look utterly self-imposed. These young children are not good at playing with others, and so, by definition, they tend to play less with others. Lacking some of what it takes to read and respond to social cues and data, their best efforts for companionship and affiliation can go unrewarded, to put it gently, leaving them to walk away, give up, and continue to go it alone. While some of the child's being alone is comfortable and desired, it also represents an adaptation, or a solution, to a life problem that's gradually shaped over a childhood. How much social rejection and discouragement could you or I take? How long would we try and try to no avail?

Many times, the child is unaware of or cannot articulate this social estrangement and disconnect, the distress of which surfaces in aggressive or angry behaviors. As their awareness in therapy heightened, several older children and teenagers told me that they were quite lonely when younger but that they felt shame and hid it. They also revealed long-standing feelings of jealousy and envy for the other children who, so it looked, enjoyed and easily interacted with each other. One teen recalled going after and "seeing the enemy in" any child who dealt with life better than he did. And as we'll see, adolescence in itself, with or without treatment, can bring awareness of being different, along with self-consciousness, anger, and despair.

The child's difficulties with reading and expressing emotions create a comparable dilemma. What must it be like to feel all that happens to you in a vague, amorphous, overexciting and overstimulating way that threatens to overwhelm your body and mind? I am not exaggerating. Think of when you have had such moments of feelings that you thought it would drive you mad or cause you to jump out of yourself. Even good feelings can overcome the child's capacity to stay regulated and intact. Add the frustration of not being able to speak what you feel. As one teen looking back on his earlier years put it, "Hitting and biting and screaming were my only options." Unable to process their feelings and social experiences adequately, these children are hindered in their understanding, resolving, and putting it away, all which compromise the development of more coherent and cohesive senses of self.

Then, there is the extreme worry and apprehension, social anxiety and phobias, generalized anxiety and irritability, depression and maybe even suicidal thinking, attention deficits, moodiness, obsessive thinking, and compulsions that often distress if not plague the child. These symptoms, which can be caused by, consequent to, or wholly independent of the Asperger's,

are all much worse since the child has fewer internal resources to cope with and master them. That their social support network is probably neither supportive nor a network hardly helps.

Back in 1989 (Bromfield, p. 448), I wrote that “autism represents a syndrome or collection of symptoms originating primarily from a basic [...] neurological deficit [...] in information processing and emotional communication, secondly, from ‘psychological defenses against states experienced as a result of those deficits, and (thirdly from a) lack of crucial socializing experiences’” (Bemporad, Ratey, & O’Driscoll, 1987, p. 477). But that’s a lot of big words and jargon. What does that really mean for children with Asperger’s?

It means that they get hit with a triple whammy. First, they are born less equipped to understand and connect with others, themselves, their feelings, and so on. It’s kind of like being dropped in a foreign country with a bag full of U.S. dollars that no one will accept or exchange. After all, what are words, body language, and social cues if not the currency that the interpersonal economy of people and relationships deals in?

Second, inherent deficits shrink and shrink their social worlds. The ways that these children have to protect themselves to survive isolate them further. Because they’re biologically less equipped for connection, children with Asperger’s rely heavily on more comfortable ways of being to handle the angst and frustration that their social mishaps and predicament create.

Third, these children’s self-protective and eccentric ways tend to push people away, leaving them more alone and deprived of opportunities to use and grow their social skills. It resembles a job applicant who is never hired because he lacks work experience or a 90-pound weakling who is judged too puny for the gym. This catch-22 leads the children to get less practice time with others, even though they—the children with Asperger’s—are the ones who need social exposure and experience even more than their peers do.

I add to the list of three whammies a fourth and often neglected consequence of Asperger’s. Because they can be so hard to understand, children with Asperger’s get less understanding, empathy, admiring, and confirming—enormously less. Because they are less adept at the human things that tend to engage others and because what they say and do can be hard to relate to, these children are at great risk of being misunderstood, not just by peers but even by those who love them, whose job it is to parent and teach them. And this is serious, for empathy and understanding are the basics that

nourish and sustain human existence and connection, even for the child with Asperger's.

In his award-winning picture book *The Arrival*, Shaun Tan (2007) tells the moving story of a man who says goodbye to his wife and daughter and goes to a new land to find a better life for his family. Tan's illustrations vividly capture this new world that to the immigrant appears strange, different, frightening, and completely alien. Through Tan's subtle story and near overwhelmingly mysterious artwork, readers are halfway through the book before the meaning hits them: This is what one feels as a stranger in a strange land.

I'm not equating Asperger's to the immigrant experience, though I believe the comparison stands. Being misunderstood is part and parcel of a life with Asperger's, and that life includes a childhood. How can having their appeals and occasional efforts to share go unheard not discourage the child? We all know that the child with Asperger's is often an expert at exotic knowledge, but do we realize that the child is even more an expert on living in a constant state of not being understood?

This chapter offers just a glimpse of what it is like for a child to have Asperger's. In the next many chapters, the children themselves show us what it's like, how it feels, and what we can do to help.

