COMMUNICATING A DIAGNOSIS TO YOUR CHILD

by Kelly Moroz, R. Psych.

One of the most difficult decisions a parent with a special needs child must make surrounds how, when, and with whom to share diagnostic information. For several reasons, the child with the disability is often the last to find out this information. Parents often report that they are unclear as to what information they should share with their child, how this information might impact the child, and whether or not this knowledge could be misused. Parents frequently note that they are concerned that their child and his/her teachers might experience challenges seeing the child beyond the disorder: “their label.” Although children dealing with Learning Disabilities, Obsessive-Compulsive Disorder, and mood dysregulation issues must work hard to cope with and work through their challenges to gain a better quality of life, a discussion with children regarding a diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (ASD) is often met with greater hesitation. Children meeting the DSM-IV-TR criteria for ADHD and ASD are more likely to require lifelong coping mechanisms, whereas children with other forms of pathologies more often fall within the perception that with proper intervention, these disabilities can be “cured” or better managed. Whatever the unique circumstances in each family, telling a child about his/her condition is a confusing process.

In his book, The Complete Guide to Asperger’s Syndrome, Tony Atwood indicates that children with Asperger’s Syndrome inevitably hit a stage in life where they realize they are “different” from their peer group. I too have had several clients confide in me that they once believed that others behaved in odd and confusing ways. These initial thoughts concerning how other children seem to misread the world and behave nonsensically reliably shift; they realize that it is their own thoughts, perceptions, and ways of interacting with others that are indeed different. Though it is almost impossible to know when a child will reach this transition stage, Atwood indicates that one of the hallmark indicators will be the development of a variety of coping mechanisms; unfortunately, these mechanisms may further ostracize these children. It is at this stage of realization where many children and teens really begin to suffer and feel most alone. This is the time when it will likely be harmful for the individual to lack awareness of their condition. Luke Jackson, in his book Freaks, Geeks & Asperger Syndrome, feels that the earlier that an individual finds out about their condition, the better. This 13-year-old recalled how life was absolute torture for him until he was assessed and told of his Asperger’s Syndrome diagnosis. Up until that point in time, this young man felt that others behaved unfriendly to him because in some way, shape, or form, he was a “freak” and a “geek.” Recently Dr. Chang, of the Foothills Hospital, presented an interesting meta-analysis which revealed how women who did not learn of their ADHD diagnosis until their mid to late 20’s were dramatically more likely to suffer (e.g., experience severe depression) and experience a much lower quality of life than women who learned of this condition when they were children. It was hard not to be taken aback by such convincing statistics.

As stated earlier, it is often the situation where the child or teen with a particular condition is the last to know about it. At the time when their child reaches the age of formal schooling, many parents experience an upswing in negative comments or concerns from teachers and even parents of other children in the same classroom. This situation evokes a range of feelings in parents from denial, to anger and sadness. This is also the time when the child often recognizes that he/she is different. At this juncture, parents are often referred to a psychologist who specializes in psychoeducational assessment. Assessment findings will often help to explain why the child behaves the way he/she does; parents and teachers often report that they are less likely to feel like the child
is intentionally instigating negative situations and interactions. There will be many who point out that labels can have a negative bearing on children (e.g., lowered expectations); however, informing parents and teachers tends to bring about greater understanding and a more positive view of the child.

At our office, many parents request that a psychologist be present to help facilitate a discussion regarding a diagnosis with their child. To begin, we believe that obvious sensitivity with a strong emphasis on the child’s positive qualities must start the discussion, and be referred to frequently throughout the dialogue. When discussing how the child presents differently from his/her peers, I believe that a few of the core principals must be touched upon, with care taken to not overwhelm the child. The child needs to learn how the world might be different through the eyes of his/her peers. For children diagnosed with ADHD, for example, I might discuss how other children might find monotonous tasks less boring, how they seem able to hold lists in their mind as if they can see them at all times, and how working harder for a larger reward seems more thrilling to them than more immediately gratifying rewards. For children presenting within the Autism spectrum, I would likely touch on how many other children seem equipped at birth to understand body language and how they are able to communicate with far less of a reliance on actual words. Next, these discussions emphasize how others might be misinterpreting their behaviours (e.g., that by lacking eye contact, others might think they are disinterested). At this point, children seem ready to “put a name” to their differences; a diagnosis is viewed more as an abbreviated method of describing their unique way of viewing the world. Interestingly, in my experiences, children tend to feel less alone when they learn that there are many others going through a similar experience. This is where books written by those with the same diagnosis are quite helpful. Finally, these discussions end by highlighting that there are several coping mechanisms that can be learned to decrease feelings of helplessness. This part of the discussion revolves around the fact that these children will be able to pick up and learn many of these skills intellectually, as opposed to the more intuitive ways that their peers pick up these skills.

Although I might outline a couple of ideas and strategies, the purpose of this initial discussion is more of an outline for future discussions, with far less direct intervention.

Explaining a diagnosis to a child or teen will be a process that requires significant planning and brainstorming, but it must be important to never view this dialogue as a one shot deal; the discussion will obviously be on-going in nature, and will change as the child ages. The confidence to initiate these discussions should stem from the basic love and acceptance of the child. I am of the opinion that these open-ended discussions will function to empower the child, helping them feel supported as they navigate through life.

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