



The Symbiosis of Disability

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Received December 2008

Volume 15, Number 3 and 4, August 2009
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[1] Navigating the challenges along life's road is hard work for everyone. Nevertheless, a person with a physical disability may face additional obstacles that increase the difficulty of overcoming life's challenges. A person whose disability is not physical sometimes must navigate an especially demanding road because he or she must also overcome prejudice associated with the disability. She or he may even have to prove a cognitive disorder, for example, is a disability. Trying to convince people who have little or no direct experience with disabilities that caring for a child with a cognitive disorder can be as difficult as if you had the disability yourself is often an exercise in futility. You find yourself repeating often-heard criticisms as a way of motivating yourself: "well, I guess this is really not as hard as I think it is," or, "I'm just not trying hard enough," or "I need to manage my time better." However, one day you inevitably meet someone else whose situation is similar to your own. You trade war stories, exchange information, give each other tips, and have the realization that the challenges you have been facing are real, shared by others, and extremely demanding both emotionally and physically.

[2] Having and caring for a child with a disability affects one's life in many ways. I remember reading a story about the actress Jenny McCarthy whose husband abandoned her and his child after learning that the child had been diagnosed with autism. While I do not agree with his response, I can sympathize with the fear that must have driven him to his extreme decision. When I learned my oldest son had Asperger's syndrome, an autism spectrum disorder, I felt overcome by despair. A sudden turn had appeared in my life's road that I never anticipated, and I feared I would never find my way back to the path I had envisioned myself traveling. First, I felt as if I had failed as a parent. We all want our children to have better lives than our own, and I believed at the time that I had somehow sentenced him to an unnecessarily harsh life. I wondered if he would have any kind of a life at all. Would he ever be independent? How would other children treat him? Would he ever find someone to love? Once the fear subsides, you accept the challenge and try to do your best.

[3] For me, perhaps the greatest challenge was managing two mutually exclusive situations that require a lot of my time. The demands of a child that needed constant supervision to help him control and manage debilitating anxieties were always conflicting with the demands of teaching and research. Children with Asperger's syndrome also do not learn social cues and rules by observing social interaction. In other words, they do not learn how to manage social situations by participating in them, so a parent must act as a referee always accompanying the child to help him or her navigate and learn social interactions. For example, I would constantly have to remind my son to look at the eyes of the person to whom he is talking, or teach him how to interpret facial

expressions and take the proper action, or how to listen for cues in a conversation to know when it is proper to respond.

[4] Essentially, I had to form a symbiotic relationship with him to find ways to help him learn what other people unconsciously learn. I found I had to form theories about things, such as humor and behavior, as way of helping him internalize and understand why one response is inappropriate in one situation but perfectly fine in another. I found that many Asperger's children first understand things intellectually, and theorizing about situations helps them eventually understand those situations on an emotional level as well. This is backwards from the way most people learn about these types of things. Nevertheless, just because it is backwards does not mean it is necessarily defective. It goes against the established social structure of transmitting certain types of knowledge; it often makes my son seem socially odd; and it makes interactions with him harder for other people. However, these children often see things and understand things in ways that do not occur to most people because an unconscious social structure does not limit their thinking. For example, I often think my son would make a great entomologist. He has a vast knowledge of insects, and he has not internalized the social phobias most of us have towards bugs. Whereas the sight of a Madagascar hissing cockroach can make me feel ill, he is quite comfortable letting one walk up and down his arm. He also has a near encyclopedic knowledge of American railroads. He is especially interested in the business aspect of their operations, such as mergers. He actually writes papers on how to make railroads run more efficiently. Oddly enough, some of his improvements highlight how the social structure of the railroading industry often inhibits growth and innovation.

[5] While the goal of entering a symbiotic relationship with my son was to help him understand the world as most people do (i.e., to essentially reprogram some of his thinking), the relationship had an unforeseen effect on me. He helped me understand and experience the world from a different perspective. His influence has indelibly changed my approach to teaching and my thinking as a music theorist. The methods I used to teach my son how to navigate through the world with his disability all have altered and improved how I teach certain subjects. For example, I had to learn to create theories to explain social situations, which is not the way most people learn how to interact socially. The goal of social theorizing was to help him understand the importance of social interactions on an emotional level. This method has become an important part of my method of teaching undergraduates about 20th century music. Now, most teachers of atonal music use theory to explain the structure of the music, but they do not use the same theory to help students form an emotional connection to the music. However, the absence of an emotional response other than a negative response is perhaps the biggest obstacle I face in teaching these students to appreciate music of a very unfamiliar nature. Furthermore, I am not happy settling for an intellectual understanding accompanied by an absence of emotional connection, although this method appears to face a pervasive cultural bias since there appears to be an expectation that an emotional response must be unfiltered. That is, one does not have to teach people in a theoretical manner what joy is, for example. Any music, therefore, that appears to lack this direct unfiltered appeal to the emotions is immediately suspect, perhaps even branded as intellectual due to its perceived lack of emotional content.

[6] Well, I never thought I would have to teach a person to experience empathy. Empathy should be one of those unfiltered appeals to the emotions requiring no theorizing and no instruction. Nevertheless, a demonstrated lack of empathy is perhaps the hallmark and most dysfunctional aspect of children afflicted with Asperger's syndrome. The affliction forces these children to take a different road to emotional understanding, and their high cognitive ability points the way. These children do understand the emotions of others intellectually, and they intellectually understand the importance of emotional interactions. They just do not translate that knowledge into practice. Their pathway to emotional understanding begins with theorizing. This is why I took this approach with my son. The key is to find a conduit and build a bridge between their theoretical knowledge and their emotions. In my son's case, this turned out to be cartooning. He reacted to the exaggerated emotional content of cartoons, such as *Fairly Odd Parents*. I would sit with him for hours and sew together the threads of his theoretical understanding with the content of the cartoons to which he was reacting. This proved to be a very successful approach for him. In fact, he now wants to be a cartoonist. He even has a website with over 600 drawings he has done, and he has a little fan base.

His therapist has even remarked that it is unusual for a child with Asperger's syndrome to have such a highly developed sense of humor.

[7] I have found a similar approach in my undergraduate atonal theory class to be an effective way of building a conduit between theory and meaning in atonal music. The conduit in the classroom situation is demonstrating a theoretical concept in another medium first, before you demonstrate its structuring influence in music. I often use films to first illustrate an unfamiliar theoretical concept. That is, I find analogs in films for music theoretical concepts in both the techniques of creating a movie and the manner in which a movie unfolds a story. Often students find a concept easier to understand both in its technical aspects and in its relevance to expression in the visual medium. Visual information is often easier to follow and the visual medium offers many more points of connection to their own experiences, especially compared to music they have neither heard nor performed. The visual medium opens the door to understanding and acceptance. Finally, the emotional content that the music in a movie highlights offers students a starting point for building and internalizing their own emotional dialog with a piece of music. A wonderful example of a film that brings all these elements together is *Fantastic Voyage*. Leonard Rosenman's brilliant atonal score is, in fact, the perfect expression of wonderment and discovery the film's story wants to convey.

[8] The theoretical approach to understanding prompted by my son's disability has also made me rethink the concept of talent. In the article "Music Theory, Phenomenology, and Modes of Perception" Lewin provides a general model of a perception: $p=(EV, CXT, P-R-LIST, ST-LIST)$. The most interesting part of this model is CXT, which as Lewin says is "a culturally conditioned theoretical component that makes us responsive to categories we call beats, keys, tonics, dominants, et al." The culturally conditioned component of this model interests me, because, for the most part, people seem to internalize these concepts in the same way they internalize their knowledge of social interaction, in a kind of unconscious behavioral model. This is especially true in instrumental teaching, where a teacher demonstrates something and a student demonstrates understanding by repeating the behavior. Instructors dub a student as talented because he or she can repeat the behavior with very little additional instruction. This process appears to reward students who have a knack for a particular mode of transmitting knowledge. Somehow, I would like to see the concept of talent expanded to include many more modes of transmission, so we do not miss differently-abled students whose contribution might open new directions in both music making and research.

[9] Lewin's model of a perception, with its culturally-conditioned theoretical component and its relationship to disability in general, offers the possibility of also opening research to new perspectives that may not always reflect mainstream thought. I know that in my own research an awareness of these ideas has often made me reflect on the motivation behind following a particular line of inquiry. In addition, when I am facing a problem in analysis or in theory building, I actually find myself wondering how would my son approach this, or how would somebody with different cognitive functioning try to understand this to gain a different perspective. In the future, I hope to develop these ideas into actual theoretical models. I see these theories developing not as theories that incorporate disabilities, but theories that filter information in many different ways. In fact, theories already perform this function. A transformational theory shows different relationships than a traditional pitch-class set analysis, for example. Incorporating disability into the mix simply expands the types of filters that are culturally acceptable.

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Prepared by William Guerin, Cara Stroud, and Tahirih Motazedian, Editorial Assistants

