Anxiety and the Developmentally Disabled
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This article discusses anxiety in people with developmental disabilities. It is based on my experience as both a consultant and as a direct provider of psychiatric services.

Kaplan and Sadock, in Synopsis of Psychiatry 8th Edition, define anxiety as "feeling of apprehension caused by anticipation of danger, which may be internal or external" (pg 279). It serves as a warning signal.

The experience of anxiety has two components, a physiological one and a psychological/behavioral one. We are all familiar with physical manifestations of anxiety (dizziness, sweating, shaking, rapid heart rate, fast breathing, upset stomach, pacing). We are also familiar with the psychological/behavioral (such as feeling nervous or frightened, having recurrent thoughts, having selective attention, acting to avoid the anxiety-provoking situation).

When is anxiety "normal" and when is it of concern? Normal anxiety would seem an advantageous response to a threatening situation, such as an individual about to see a new health-care provider when prior experiences were unpleasant. On the other side, pathological anxiety would seem to be an inappropriate response to a particular situation. I evaluated one individual who was unable to leave his home following his mother's death; it was thought that this was related to her prior well-intentioned prohibition against leaving the house without her. It is this level of anxiety that is described in the DSM IV (Diagnostic and Statistical Manual, 4th edition), the diagnostic standard for American psychiatrist. It classifies anxiety disorders by their predominant features, such as with panic attacks, specific phobias, obsessions/compulsions, or generalized worry.

For anxiety to be understandable, it is most helpful for the involved individual to be able to describe what they are thinking/feeling/reacting to. This works well for those individuals who are verbal. What about those for whom language is not the main form of communication? As with other areas of assessment in non-verbal individuals, we must surmise the presence of anxiety by behavior, particularly agitated behavior. Stereotyped mannerisms such as rocking or hand-flapping, aggression towards self (in the form of self-injurious behavior) or others (such as hitting or biting) come to mind. However, we do not necessarily think of refusal to participate in some activity as being anxiety-driven, although it might represent the attempt to avoid a fearful situation.

The MGH Guide to Psychiatry in Primary Care (pg. 25) suggests that pathological anxiety belongs to one of three categories, that associated with medical illnesses, that associated with primary psychiatric illnesses, and that associated with situational/environmental factors. It is from this perspective that I discuss individual stories.

I have been involved in the evaluation and ongoing care of a number of individuals with developmental disabilities for whom anxiety has been a prominent component. I would like to say that I have always been able to identify anxiety quickly, as well as quickly address it. However, I would not be truthful if I
made that claim. It is those individuals who have been non-verbal who have been the most challenging and instructional for me. The remainder of this article describes three of my most respected teachers.

M is a man who was referred for an evaluation and who has since become one of my ongoing patients, because of long-standing problems with self-injurious behaviors; specifically he would bang his head and face to the point of causing physical damage. A variety of medications had been prescribed in an attempt to decrease this obviously distressing behavior. At the time of the consult, he was on two anti-psychotics, two antidepressants, and two anti-anxiety medications in addition to 7 non-behavioral medications to treat his other medical problem. Through a comprehensive evaluation, which included a family physician, a psychiatrist, a social worker, and a systems expert, it was hypothesized that pain was a large part of his self-injurious behavior. Although it took several visits to identify the specific source of pain, once it was adequately treated, he calmed down considerably. We have since been in the process of decreasing his psychotropic medication; one year after seeing him, two of his medications have been safely eliminated and we are working on eliminating the third.

M taught me that what looks like anxiety, in the form of agitated behavior, may be pain-driven. It has been a valuable lesson as I have been able to consider this factor more quickly in subsequent individuals.

A is a woman who was referred for ongoing psychiatric treatment because of long-standing aggressive outbursts, which were believed to be caused by "atypical psychosis". She came with a reputation of being one of the harder to treat individuals, as evidenced by her having failed "everything" that had been prescribed, both in the community as well as the institution. I was surprised when I first met her as I found her to be a creatively expressive individual. While she seemed to be more comfortable in the role of an infant, her ability to clearly identify her distress was striking. Over the course of the 9 months I've been directly involved in her care, I have come to appreciate how large a part anxiety plays in her life. Whereas at first she came to appointments only with two providers, one who occupied her attention while the other talked with me, in her most recent appointment we had a conversation about her love of coffee.

J is a man who was being treated for a chronic anxiety disorder. When he was referred to me, a striking part of his history was that he required 2:1 staffing whenever he left home because of the likelihood of having an outburst in the community.

Within a short period of time, however, the focus of treatment became his explosive outbursts at home, not in the community. It became clear that J's time at home was largely unstructured. A possible explanation then became that his explosiveness at home was an expression of his boredom. When more structure was created for him, he became less explosive. He now is able to go on outings with only one staff. Additionally, his most recent incident at home was more than a month ago. J taught me that situational factors are very important parts of any assessment.

Preparing this article has been a very useful experience for me. Not only has it required that I collect and organize my thoughts, it has given me an opportunity to once again work through my performance anxiety. I hope that it will stimulate a similar amount of self-reflection and awareness for the reader.