If it's not autism—could it be 'pathological demand avoidance syndrome'?

British researchers say they have identified a category of children who exhibit unusual symptoms often mistaken for, but actually quite different from, autism. These children need to be identified, Elizabeth Newson et al. say, because their educational needs are much different from those of children with autistic spectrum disorders.

Newson and colleagues have identified 150 children with a group of symptoms the researchers have categorized as "pathological demand avoidance syndrome." These children's behavior revolves around avoiding any demands placed on them, and unlike autistic children, they are able to use verbal skills and social manipulation to achieve this goal. According to Newson et al., "Demand avoidance may seem [their] greatest social and cognitive skill, and most obsessional preoccupation." To escape from demands, the children use a number of ploys including distraction ("Look out the window!"), excuses (I'm sorry, but I can't," ""I'm too hot," "I'm going blind," "My hands have gone flat"), hiding, withdrawing into fantasy play ("My teddy bear doesn't like this game"), talking or singing to drown out demands, or even screaming or physical attacks.

"The central salient characteristic of [these children], which made them strikingly difficult for their parents and teachers, was an obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allowed social manipulation as a major skill," the researchers say. "Despite our reluctance to use the word 'manipulative' in speaking of children, it was impossible not to recognize this shared quality, especially as it contrasted so clearly with autistic children."

Like autistic children, children with PDA often have delayed motor skills. However, the researchers say, this may be due to passivity, as the children appear to be "actively passive" in order to resist demands. PDA children often exhibit delayed speech early in development and then catch up spontaneously and quickly in language skills by the age of six, although their speech content remains very odd.

Unlike autism-spectrum children, children with PDA seem to exhibit normal social behavior. However, they are very shallow and abnormally uninhibited. Many appear to have no sense of right and wrong, and most seem to lack a sense of pride, shame, or responsibility. They are very capable at symbolic play and role-playing, and often use these abilities to escape from demands.

In addition, PDA children have frequent, rapid mood swings and may even exhibit contradictory moods (for instance saying "I hate you" while hugging). Many are aggressive, and a number become suicidal in adulthood. They are extremely impulsive, and will change their behavior instantly if they sense that someone is placing a demand on them. They are extremely obsessive, particularly about avoiding demands, and function poorly in school because so much of their energy is focused on this obsession.

Newson and colleagues say that unlike autism spectrum disorders, which affect far more boys than girls, PDA affects an equal number of males and females. Some children with PDA have seizures, and most exhibit "soft" neurological signs. They are less likely than autistic children to exhibit stereotypical movements, walk on their toes, reverse pronouns when they speak; or avoid eye contact, and while some are echolalic, this behavior tends to be temporary.

> Newson and colleagues say the hallmark of children with PDA is "an obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allows social manipulation as a major skill."

Newson et al. say, "The 'recognition factor' for these criteria is striking, both by parents whose child has previously had an 'atypical autism' diagnosis, and by those whose children have been seen as extraordinarily difficult and 'odd' but not diagnosable." Teachers also find the description useful in planning educational programs, the researchers say, because the techniques that work with children on the autism spectrum are counterproductive with PDA children.

"While autistic/Asperger children are helped by rules, routine and consistency," Newson et al. say, "children with PDA need variety, flexibility and novelty. A central principle is that 'what works today may not work tomorrow, but it might work in a week's time:' the child recognizes strategies once they have worked, and avoids them determinedly on the next occasion, so that it is necessary to have ready a whole repertoire of different ideas, and to adapt them wherever necessary."

In addition, they say, teachers, find it effective to use an indirect approach in getting PDA children to accept demands. "For instance, where we would simplify language with an autistic child, often a much more complex sentence will camouflage a demand for a PDA child: 'I wonder whether it would be a good idea if we....' tends to be more effective than 'Do this for me please.'" Also, children with PDA sometimes respond better to demands if they are allowed to use dolls, toys, or puppets to act out the desired response.

The researchers stress that PDA, like autism, is clearly a biological disorder. "However difficult the behavior ... the child is not wilfully being naughty, and cannot easily behave differently," they say, "though we may be able to help him or her to improve over time."

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"Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders," E. Newson, Kathryn Le Maréchal, and Claire David, *Archives of Disease in Childhood*, Vol. 88, 2003, 595-600. Address: Elizabeth Newson, Early Years Diagnostic Centre, 272 Longdale Lane, Ravenshead, Nottingham NG15 9AH, UK, diagnostic-centre@sutherlandhouse.org.uk. Supporting material is available online at the website of *Archives of Disease in Childhood*, http://adc.bmjjournals.com/cgi/content/full/archdischild%3B88/7/595/DC1.

Editorial: Autism is treatable!

(continued from page 3)

and a challenge:

I urge that the Federal Government undertake the evaluation of autistic children who have been treated by the doctors in our Defeat Autism Now! (DAN!) movement, as compared to children treated by physicians who adhere to the conventional, much less effective treatment modalities.

I propose that the NIH fund immediately, on a high-priority basis, a low-cost telephone or mail questionnaire survey of 1,000 parents of autistic children, divided into two groups:

Group A. Parents whose autistic children have been patients, for one year or longer, of 25 DAN! doctors selected by the Autism Research Institute. Twenty patients would be selected randomly from the pool of autistic patients treated by each of the 25 DAN! doctors.

Group B. Similar to Group A, except that the children would be from the practices of 25 pediatricians selected by NIH or the American Academy of Pediatrics.

The survey would ask for such information as:

1. The child's symptoms, pre- and post-treatment.

2. Any objective criteria of improvement (e.g., mainstreamed? IQ improvement? Speaking? Number of words/sentences? etc.).

3. The parents' rating of improvement (10-point scale).

4. Which treatments were provided?

5. Which treatment modalities have helped the child most?

The parent responses to questions 1, 2, and 3 would be analyzed by judges who are blind to whether the patients were in Group A or Group B. This would be an excellent launching pad for a long-neglected and long-needed federal program of research on effective autism treatments.

The hour is late — let's move ahead!