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## Pathological Demand Avoidance

### What is the Pathological Demand Avoidance subtype of Autism?

We often talk about autism as if it is one specific disorder. Yet, it is becoming clear that autism is a *spectrum* of closely related disorders. All autism spectrum disorders have two features in common. The first feature is difficulty with social communication. The second feature is challenges with flexibility. This can cause rigid or repetitive behaviors, movements, interests, or patterns of thinking. A wide array of biological, genetic, and environmental factors contribute to both features. This means there are multiple causes of the features associated with autism. There are also almost certainly multiple different *subtypes* of autism that vary based on the cause, presentation, and strength of each feature.

Recent work in Europe has highlighted a group of children with autism who show a recognizable pattern that might be a subtype of autism. This pattern is: (1) Relatively subtle social communication difficulties, and (2) Very significant challenges with flexibility. These challenges with flexibility are driven by exceptionally heightened anxiety and other symptoms of emotional distress in response to demands (particularly social demands). In the US, these children are often diagnosed with autism and a mood or behavioral disorder. In Europe, these children are diagnosed with the **Pathological Demand Avoidance (PDA)** subtype of autism.

Children with the relatively rare PDA subtype of autism are often more socially skilled than the 'typical' child with autism. For example, children with PDA often make good eye contact. They can often describe and label emotions with a striking level of detail. They are very comfortable with social play styles such as fantasy, role-play, and make believe. They also often show avoidance behaviors that have a clear social component. These avoidance behaviors can include trying to negotiate or verbally coerce others into allowing them to get their own way. This can make children with PDA seem almost *overly* socially aware or even socially 'manipulative.' Children with PDA also often make a good first impression on peers. They tend to have great ideas for games and play. They seem confident and upbeat when they are in control of the situation. For this reason, *making* friends may not be a problem for children with PDA.

However, the 'surface sociability' of children with PDA can mask their subtle but persistent social-communication difficulties. These social communication difficulties include trouble understanding social nuance and difficulties taking others' perspectives in the moment. They can also have a hard time figuring out social roles and patterns when the rules are 'unspoken.' They may also inaccurately interpret complex or ambiguous social information.

Children with PDA have social skills that are fragile. This means their social skills are easily derailed by situational or emotional factors. For example, a child with PDA may seem socially-skilled when they are calm, content, and in control of the situation. Yet, they can seem to completely 'lose' their social diplomacy when they become tired, hungry, overwhelmed, or unsure of themselves. Because of this social fragility, these children can struggle with *keeping* friends over the long-term.

Subtle social challenges are one feature of the PDA subtype of autism. However, the most notable feature of the PDA profile is the behavioral inflexibility. This inflexibility is characterized by frantic, escalated, and persistent attempts to avoid any and all demands. In the context of PDA, a **demand** is anything the child does not want to do, did not expect to have to do, or feels uncomfortable tolerating.

Children with PDA avoid explicit demand, like a clear request to do something they don't want to do. But many of the demands that children with PDA avoid are more *implicit demands*. Implicit demands are things like needing to go along with another's agenda to avoid upsetting the group. Other implicit demands include having to 'shift gears' when plans change, having to tolerate the discomfort of being unsure, or needing to be okay with making a mistake. Other examples include having to handle differences of opinion, needing to persist with a task, or having to tolerate an uncomfortable sensory situation. An implicit demand could also be an expectation an adult holds about how the child 'should' act in a situation.

In general, a demand can be thought of as any situation the child might find uncomfortable and would need to cope with to remain in the situation. Often, the demands that most distress children with PDA have a social element. They particularly struggle with demands for needing to cope with some discomfort so that the situation will be better for *someone else* or for *the larger social group*. For example, a child with PDA may be able to cope with the demands of a challenging favorite activity or difficult videogame she wants to play. Yet she may be overwhelmed when asked to show that same perseverance and stick with a group social activity she finds hard or uninteresting.

Research on children with PDA suggests they have such difficult tolerating social demands because they experience an intense physiological reaction any time they are not in control of a situation. Social demands involve someone else being in control. In a socially demanding situation, someone other than the child is choosing the activity, the agenda, or the need to prioritize. This makes the child with PDA feel like they are not in control of the situation. Feeling *not in control* makes children with PDA feel *out of control*.

### **How does the Pathological Demand Avoidance Subtype of Autism Develop?**

As soon as they're old enough to develop a sense of self and the ability to say 'no' to others' requests, most young children go through a period where they find social demands threatening to their developing autonomy and sense of self. As a result, young children often engage in a developmentally normal period of demand refusal. This is the high-tantrum stage often called the "terrible twos" (though it more typically occurs in children between the ages of three and five).

For most children, this period resolves on its own. The child's nervous system becomes more mature and less reactive. Their knowledge of themselves and others expands, so that demands from others no longer feel like a threat to their autonomy and sense of self. Through this maturation process, most children develop a sense of when to go along with others in order to meet their larger goals of learning and having fun with the group.

However, for the small percentage of children who are eventually diagnosed with PDA, this resolution does not happen. The nervous systems of these children continue to react strongly and negatively to any social demand, as if it is a threat to their very identity. While they often cannot articulate it, these children are receiving an insistent message from their nervous system that says that complying with another's demand could have disastrous consequences. As a result, these children enter the same fight-flight-or-freeze state all people experience in situations of extreme threat or dangerous loss of control of a situation. These children also struggle with developing the social understanding that allows them to know how and when to cooperate with others, even when they want to be a valued part of a group.

As a result, children with PDA are exceptionally stressed and challenged by any and all social demands. They strenuously refuse any demands, often in ways that seem developmentally much ‘younger’ than their chronological age. Essentially, they still having tantrums or **meltdowns** long past the age when other children have outgrown this concern. They also persist with these tantrums, even though the meltdowns interfere with their goals. Over time, children with PDA may develop more sophisticated ways of trying to refuse social demands rather than having a clear tantrum. These can include trying to negotiate, intimidate, withdraw from the situation, passively avoid, or secretly sabotage the demand. However, the same panicky, fight-flight-or-freeze response to the demand and the feeling of a loss of control still underlies all these avoidance behaviors.

### **What is the Best Way to Support a Child with PDA?**

We’ve seen how the PDA subtype of autism involves two intertwined areas of challenge: (1) subtle social difficulties and (2) pronounced emotional and behavioral responses to demands. Children with PDA benefit from a comprehensive approach that addresses both areas of concern simultaneously. This typically involves three steps:

1. **Therapy to Build New Skills:** Individual, family, and occupational therapy aimed at developing the child’s social cooperation skills, emotional awareness, sensory regulation, distress tolerance, and coping skills
2. **Finding the Right Balance:** Modifications to the child’s environment to ensure she is challenged to develop new skills, but not regularly overwhelmed
3. **Nurturing the Child’s Strengths:** Services, strategies, and supports that build on the child’s strengths, such as her cognitive skills, her deep interests, and strong play skills.

Support for a child with PDA needs to be flexible, creative, and delivered at the child’s pace. This means most children PDA need a **team approach** where multiple professionals with experience working with children with complex needs coordinate closely with parents. This team, working together, can decide how to best modify the child’s environment while supporting her development and nurturing her strengths. Because children with PDA have many strengths as well as many vulnerabilities, this support needs to happen in a framework that include the right level of academic challenge, nurturance of the child’s unique interests, and the opportunities for imaginative play that brings out her best.