

## Background

### Research Question:

**How do parents perceive the educational experiences of their children who have PANDAS or PANS?**

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Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are recently discovered conditions in which students experience abrupt onset of neurological and psychiatric symptoms. Symptoms are thought to result from an autoimmune reaction, often resulting from strep or other infection, that leads to brain inflammation (Swedo, Leckman & Rose, 2012; Chang et al, 2015). Children with PANDAS and PANS are at high risk for academic and behavioral difficulties in school (Tona & Posner, 2011; Candelaria-Greene, 2014), but there is a dearth of research on how these disorders impact student success or family experience. This study examines how parents perceived the educational experiences of their children who have PANDAS or PANS.

## Methods

### Methodology:

- General qualitative, interpretive study
- Grounded in phenomenological approach to capture the “lived experience” of families of children with PANDAS or PANS through interviews (Kvale & Brinkmann, 2014).
- 60-90 minute interviews with 12 parents of children diagnosed with PANDAS or PANS.

### Participants:

- Recruited in partnership with a national research and advocacy organization.
- Twelve parents met selection criteria (one or more child, ages 6-18, with a PANDAS or PANS diagnosis) and participated.
- Two participants had multiple children with PANDAS/ PANS diagnoses.

Figure 1: Participant and Child Traits

\*Age of onset unclear; best guess by parent.

Participant	Child's Age at Symptom Onset, as described by parent	Child's Age at Interview	Currently Taught at Home (homeschool or home and hospital)	Ever Taught at Home (more than 30 days)
1	8	16	Y	Y
2	4	7	N	Y
3	4*	10	N	N
4	5	12	Y	Y
5	7	16	N	Y
6	9	12	N	Y
7	2*	13	Y	Y
8	6	11	Y	Y
9	7	16	N	N
10	4	10	N	Y
11	12	14	N	N
11	11	11	N	N
12	3	17	N	Y
12	6	15	N	Y
12	7	14	N	Y

## Results

Qualitative analysis identified themes, grouped into broad categories (representative quotations follow):

### School-related experiences at home

**Stress:** “I used to relay the story of him ... literally crawling up the stairs to his bed because he would be so mentally exhausted from holding it together all day at school.”

**Resilience and coping:** “We have a name for it, the ‘worry bully.’ So I say, Is the worry bully getting to you? And he says, yes.”

### School experiences

**Communication:** “I’d like schools to know they have the power to make or break relationships with families who have PANDAS.”

**What school “looks like”:** Approximately half the parents reported their children were homeschooled or received home and hospital services due to physical illness, immunocompromised status, or unremitting anxiety.

School accommodations and supports most frequently mentioned included flexible attendance, flexible school schedules, access to “safe spaces” in schools, specialized behavior plans, sensory supports such as special seating or fidgets, extended time, use of keyboards and laptops, and expedited transitions to home teaching.

## Results

### Perceptions of the child

**Sudden onset:** “Out of nowhere he would just cry for hours and...say he wanted to wash. He never had anything like that before.”

**Child’s awareness:** One parent reported her child saying he had “strobe lights in my brain.” Another described her son saying his brain was “feeling puffy” when symptomatic.

**Behavior and disability.** “My kids were just fine, they didn’t look sick... I think it would have been easier if PANDAS wasn’t such an invisible disability. ...When you see him missing silly questions or looking like he’s not concentrating, you need to look a little differently into why that might be happening.”

### Preliminary Conclusions

- Parents report a variety of challenges related to their children’s school experiences when dealing with PANDAS or PANS.
- Parents report that it can be difficult for both families and school personnel to distinguish among student choices, challenging behaviors and neurological symptoms.
- Parents perceive strong communication with school staff and proactive school planning to be essential to school success of their children with PANDAS and PANS.