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School-Based Services for Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

Maura Miglioretti

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SCHOOL-BASED SERVICES FOR CHILDREN WITH PEDIATRIC ACUTE-ONSET
NEUROPSYCHIATRIC SYNDROME (PANS)

A Dissertation

Submitted to the School of Education

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Maura A. Miglioretti

August 2019

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Maura A. Miglioretti

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**DUQUESNE UNIVERSITY
SCHOOL OF EDUCATION**

Department of Counseling, Psychology, and Special Education

Dissertation

Submitted in partial fulfillment of the requirements for the degree
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June 21, 2019

**SCHOOL-BASED SERVICES FOR CHILDREN WITH PEDIATRIC ACUTE-ONSET
NEUROPSYCHIATRIC SYNDROME (PANS)**

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ABSTRACT

SCHOOL-BASED SERVICES FOR CHILDREN WITH PEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANS)

By

Maura A. Miglioretti

August 2019

Dissertation supervised by Ara J. Schmitt, Ph.D

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is an emerging disorder affecting school age children causing deleterious cognitive, social, emotional, and academic effects. Most frequently, children with PANS demonstrate severe, rapid-onset obsessive-compulsive symptoms in addition to a variety of other psychiatric disturbances. Symptoms are known to significantly impact a child's educational experience. Despite this, little is known about the educational impacts related to the disorder or the supports provided to children with the diagnosis. This research sought to identify the school related impairments of children with PANS, the school-based services provided for children with PANS, and the relationships between obsessive compulsive symptoms and school-based service provision. Results showed that children with PANS often receive educational services, but that these services are provided most frequently as part

of a preexisting service agreement. Further, services are minimally related to primary obsessive-compulsive symptoms even in children receiving services only after PANS diagnoses, despite these symptoms being significantly impairing in the sample population. The presence of comorbid diagnoses was found to be most closely correlated with school-based service provision in this sample.

DEDICATION

This dissertation is dedicated to my family and friends, both near and far, who have loved and supported me throughout my educational career. I would not have been able to get through the last 5 years without the unwavering support and macabre humor that you all have provided. Thank you all for believing in me when I didn't believe in myself.

This dissertation is also dedicated to the children and families affected by poorly understood and much debated chronic health conditions. You are the motivation behind this work. I am humbled by your strength and perseverance.

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To my family and friends, “thank you” will never be enough. I love you all dearly. Lastly, to my dearest friend and cohort arch nemesis (you know who you are), thank you for pushing me, motivating me, and allowing me to “compete” with you for the last 5 years. I wouldn’t be here without you.

TABLE OF CONTENTS

	Page
Abstract.....	iv
Dedication.....	vi
Acknowledgement.....	vii
List of Tables.....	xi
CHAPTER I: INTRODUCTION.....	1
Research Questions and Hypotheses.....	7
CHAPTER II: LITERATURE REVIEW.....	9
PANS as a Neuropsychiatric Disorder.....	10
Etiology.....	11
Presenting Symptoms.....	13
PANS Diagnostic Criteria.....	15
Disorders that Co-occur with PANS.....	17
PANS Treatment.....	17
Medical Treatment.....	17
Psychological Treatment.....	18
Theoretical Framework: The Biopsychosocial Model of Chronic Illness.....	20
School-based Implications of PANS within the Biopsychosocial model.....	22
Observable Changes in the School Setting.....	23
Biological Implications in the School Setting.....	23
Psychological Implications in the School Setting.....	24
Obsessive-Compulsive Behaviors.....	24

Emotional Changes.....	25
Speech Language Changes.....	25
Social Changes.....	25
Changes in Appearance.....	26
Changes in Executive Functioning.....	26
Sensory Changes.....	26
Changes in Movement and Motor Skills.....	27
Educational System as a Social Context of Service Delivery.....	28
Special Services and PANS: IDEA and Section 504.....	29
Psychoeducational Evaluations.....	29
Section 504.....	30
IDEA.....	30
Special Services.....	32
Challenges of Treating PANS in Schools.....	35
The Current State of Educational Research.....	36
CHAPTER III: METHODS.....	40
Participants.....	40
Accessing Participants.....	40
Research Design.....	41
Measures.....	41
Children’s Yale-Brown Obsessive-Compulsive Scale (CY-BOCS)	42
Variable Definitions.....	44
Data Analysis.....	44

Research Questions.....	45
CHAPTER IV: RESULTS.....	48
Demographic Information.....	48
Analyses.....	48
Disease Specific Characteristics.....	48
Treatments.....	49
Comorbidities.....	49
Symptom Specific Information.....	50
Obsessive Compulsive Symptom Profile.....	50
School-Related Information.....	53
Relationships Between Disease Factors and Educational Placement.....	57
Post-Hoc Analyses.....	59
CHAPTER V: DISCUSSION.....	60
Discussion of Findings.....	61
Implications of this Study.....	68
Study Limitations and Future Directions of Investigation.....	71
Summary.....	72
References.....	74
Appendix A.....	82

LIST OF TABLES

	Page
Table 1. OCD symptom severity of children with PANS based on the CY-BOCS.....	51
Table 2. Obsessions experiences by children with PANS.....	51
Table 3. Compulsions experienced by children with PANS.....	52
Table 4. School based services for total survey population.....	54
Table 5. Service agreements for children with PANS provided only after PANS diagnosis	54
Table 6. IDEA disability category under which children with PANS are eligible for special education.....	55
Table 7. Related services received by children with PANS as part of their IEP.....	56
Table 8. Regression coefficients.....	59

Chapter I: INTRODUCTION

Federal law ensures that the public education system aids in the social, emotional, and cognitive development of children with disabilities. Through the application of the Individuals with Disabilities Education Act (2004) and Section 504 of the Rehabilitation Act (1973), children with disabilities are provided with an equal opportunity to benefit from their education through the provision of accommodations and modifications to their educational programming. Schools provide services for children across a range of disabilities, including those with developmental, medical, and psychiatric impairments. Highly trained school personnel help to identify children with disabilities through their knowledge of child development, psychoeducational assessment, and intervention. The identification of and service provision for children with psychiatric disturbances in schools requires school personnel to become aware of the educational implications of various disabilities, including those only recently emerging in the literature. Lack of understanding and knowledge of these disabilities can lead to a denial of educational rights and a loss of educational opportunities for children affected by illness. Emerging disorders and their educational implications must be therefore studied to increase levels of awareness and understanding among school-based professionals, and to thereby improve educational opportunities for children.

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is an emerging disorder affecting school age children causing deleterious cognitive, social, and emotional effects. PANS is estimated to affect 1 in 200 children- as many as pediatric cancer and pediatric diabetes (PANDAS Network, 2016). PANS is characterized by the acute onset of atypical thoughts, feelings, and behaviors after infection with a common childhood

illness. This poorly understood disorder is thought to be related to an autoimmune response triggered by infection. While many childhood infections are proposed to cause PANS, a large body of research has shown that the disorder develops most frequently after infection with the bacteria that causes strep throat (Allen, Leonard, & Swedo, 1995; Swedo et al., 1998).

Most frequently, children with PANS demonstrate severe, rapid-onset obsessive-compulsive symptoms in addition to a variety of other psychiatric disturbances. Children with post-strep PANS, known as Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS), are estimated to account for approximately 25% of children diagnosed with obsessive-compulsive disorder (OCD) and tic disorders alone (Swedo et al., 1998). Although OCD is the most common neuropsychiatric manifestation of PANS, one in five children with PANS has a primary manifestation of severe food avoidance or restriction (Pandas Physician Network, 2016). As many as 70% of children with PANS experience tics (Murphy et al., 2015; Swedo et al., 2015). Children must demonstrate a rapid onset of one of these primary psychiatric manifestations and additional neuropsychiatric symptoms in two of seven defined symptom domains to be diagnosed with PANS. PANS is also known to cooccur with other neuropsychiatric disorders (Swedo et al., 1998). This complex symptom profile causes significant difficulties in meeting social, behavioral, and academic expectations, and impair a child's ability to live a normal life.

First-line treatments for the disorder are medical in nature. They primarily include the use of antibiotics to combat infection and immunomodulation to mitigate unwanted immune responses leading to neural inflammation (Frankovich et al., 2017). Still, the

psychiatric effects of the disorder are often most concerning to onlookers and can persist even after these first-line treatments are utilized. In many cases youth remain symptomatic, experience only partial remission of symptoms, or experience symptom recurrence after treatments have stopped. Behavioral symptoms of PANS can sometimes be treated with psychiatric medications, but children with PANS are highly sensitive to their side effects (Brimberg et al., 2012; Thienemann et al, 2017). Optimal outcomes are achieved through the use a multidisciplinary approach, combining medical intervention with intensive Cognitive Behavioral Therapy tailored to the individual needs of the child (CBT; Nadeau, 2015).

A multidisciplinary treatment approach with psychological and educational supports is recommended per PANS treatment guidelines (Thienemann et al., 2017). The biopsychosocial model supports these recommendations. This model utilizes an integrated perspective for understanding the complex interplay of the multidimensional factors influencing a person's health and well-being (Engel, 1977). Based on a systems approach, treatment of disease under the biopsychosocial model attempts to relieve patient distress caused by illness or disease through treatment of the whole person, rather than treatment of disease alone. The model accounts for the reciprocal nature of an individual's personal characteristics, their disease process, and their social environment (Engel, 1980). When applying the biopsychosocial model to PANS, one must recognize how the biological underpinnings of the disorder manifest in psychological disturbances. Cortical inflammation and changes in cell signaling and neurotransmitter release due to autoimmune action create the observable psychological symptoms that are characteristic of the disorder: acute-onset OCD and other associated symptoms. Symptoms present

themselves in the social context of the home and school environment and can be exacerbated by the addition of environmental stressors. Identification and treatment of the disorder thus requires a multidimensional patient (student)-centered approach, focusing not only on the biological underpinnings of the disorder but also on the psychiatric manifestations and their psychosocial consequences.

Experts in the field hold that most children with PANS demonstrate a need for some sort of educational accommodation (Thienemann et al., 2017). Schools have a legal obligation under No Child Left Behind (2001) to be a source of support for children with complex medical needs or who are otherwise suspected to have a disability (20 U.S. C. § 1412 (a) (3)). This obligation is often met using classroom accommodations, special education, and school nursing plans. Even without formal services in place, school-based professionals are a critical member of the interdisciplinary team for treating chronic childhood illnesses. For children with educational impairments requiring special education services, the PANS/PANDAS consortium suggests that individual education plans (IEPs) or accommodation plans should be written with the child's most severe days in mind, rather than waiting for symptom exacerbations to implement services (Thienemann et al., 2017). This suggestion is in line with Section 504 of the Rehabilitation Act (Pub. L. No. 93-112, et seq., 87 Stat. 394). Children with educational impairment not requiring specially designed instruction should be afforded an accommodation plan to help reduce the burden of academic and behavioral demands placed on the child with a disabling condition. Even without a formal plan in place, children with disabilities such as PANS are protected from discrimination under Section 504 of the Rehabilitation Act (1973).

Despite these recommendations and the inclusion of deterioration of academic performance as a diagnostic criterion for the diagnosis of PANS, little is known about the school-related impacts of PANS on children or the frequency of school-based service provision. The similarities between PANS, OCD, and tic disorders indicate that educationally focused research on these disorders can help to create a working model for future educational involvement in PANS. Students with conditions such as OCD or Tourette's have been inconsistently served through federal special education law (Individuals with Disabilities Education Act, IDEA, 2004) and Section 504). Children with OCD are known to have educational impairments. Research has shown that children and adolescents suffering from OCD performed significantly worse on the school competence scale of the *Child Behavior Checklist* than other children their age (Sukhodolsky, di Rosario-Campus, Skahill, Katsovich, & Pauls, 2005). Children with OCD report that their two most common difficulties are focusing on class work and completing homework (Piacentini, Bergman, Keller, & McCracken, 2003). Researchers have long recommended that children with OCD be served under the IDEA category "other health impairment" (OHI), due to its documented neurological basis (APA, 2000; Blier, Habib & Flament, 2006). Experts in the field of childhood OCD emphasize the importance of school personnel recognizing that OCD is a neurobehavioral disorder, reflecting abnormal central nervous system activity and not willful behavior, and encourage school personnel to view a child with OCD as they would a child with any other disease (March & Mulle, 1998). However, a 2007 study reported that of those students with OCD served under IDEA, 51.4% were qualified under ED, and 31.8% under OHI; 10.3% of students were dually qualified under ED and OHI (Adams, Smith,

Bolt, & Nolten, 2007). Data suggested that those who viewed OCD as an emotional disorder often classified students under ED, while those who believed OCD is medical in nature classified students under OHI (Adams, Smith, Bolt, & Nolten, 2007). In contrast, children with the tic disorder Tourette's Syndrome which is believed to result from disruption in similar neural pathways as OCD are explicitly listed as eligible for service under the OHI and typically receive services under this category (Adams, 2004).

This brings into question what service provision for children with PANS entails, considering that children with PANS typically demonstrate OCD behaviors and tics in addition to other troubling symptoms. Most would argue that a child with PANS, like a child with OCD or Tourettes, has a disability that is neurobiological in nature could be eligible for service provisions under the OHI category of IDEA, or through Section 504. Anecdotal evidence suggests that many students with PANS receive accommodations or special education services prior to receiving a formal PANS diagnosis, both formally and informally (Candelaria Green, 2015). This is achieved through teacher driven classroom accommodations, or through formal written service agreements. Prior to diagnosis, children with PANS may have received services for other psychiatric or medical diagnoses (Candelaria Green, 2015). These children likely have families who have sufficient financial and social resources to engage in advocacy efforts, and likely attend schools that supported the implementation of services for the child with or without a formal diagnosis (Candelaria Greene, 2015).

Due to the lack of extant research on the educational impacts and educational services provided to children with PANS, the focus of this research is on the educational supports provided to children suffering from the disorder. The purpose of this research is to

identify the educational impacts suffered by children with PANS who have primary OCD symptoms, and the mechanisms by which these children are served in schools. To date, no research has been published in this regard. This research seeks to answer the following research questions:

1. What severity of OCD symptoms (i.e., obsessions and compulsions, respectively) do children with PANS display? It is hypothesized that children with PANS will display moderate to severe obsessions and compulsions, with some children only obsessions, and others displaying both obsessions and compulsions.
2. What is the obsession symptom profile of children with PANS? It is hypothesized that children with PANS will most often present with contamination fears/obsessions, aggressive obsessions, and obsessions related to perfection (symmetry, exactness, just right feelings).
3. What is the compulsion symptom profile of children with PANS? It is hypothesized that children with PANS will present contamination related compulsions such as handwashing and ritualized showering (associated with contamination), as well as checking behaviors, ordering/reordering (associated with symmetry), and repeating rituals.
4. With what frequency do children with PANS receive special services in school (i.e., special education, Section 504 Plan, or no formal service agreement)? Children with PANS are predicted to most frequently receive section 504 service agreements through their school districts.
5. Of children with PANS that are eligible for special education, under what eligibility category or categories do the children qualify? Children with PANS are predicted to most frequently receive services for PANS as part of an existing service agreement for another disability. Children with PANS are predicted to most frequently receive services under the IDEA category “other health impairment” when receiving services for PANS alone.

6. What related services do children with PANS who are eligible for special education receive at school? Children with PANS are predicted to receive psychological services, counseling services, and school health services related to their disability.
7. Does obsession and/or compulsion severity predict the existence of a formal service agreement at school? It is hypothesized that children with PANS will demonstrate both obsessions and compulsions, but that observable compulsive behavior will predict the presence of a formal service agreement.

Chapter II: LITERATURE REVIEW

Schools have played a pivotal role in providing school-based services for children with a range of disabilities, including attention deficit-hyperactivity disorder (ADHD), autism, and other brain-based disorders. School personnel are similarly called upon to understand the developmental and educational implications of emerging disorders, and apply their knowledge of assessment and intervention techniques to individual student needs. One such emerging disorder is pediatric acute-onset neuropsychiatric syndrome (PANS). Affecting an estimated 1 in 200 children, PANS likely affects as many children as pediatric cancer and pediatric diabetes (PANDAS Network, 2016).

Pediatric acute-onset neuropsychiatric syndrome is characterized by the acute onset of obsessive-compulsive disorder or severely restricted eating comorbid with a variety of atypical thoughts, feelings, and behaviors (Swedo, Leckman, & Rose, 2012). This increasingly researched disorder is most often related to infection with the bacteria that causes strep throat, but is theorized to be triggered by a multitude of common childhood infections (Cooperstock, Swedo, Paternack, & Murphy, 2017). Children with post-strep PANS, known as pediatric autoimmune neuropsychiatric disorder associated with streptococcus (PANDAS), are estimated to account for approximately 25% of children diagnosed with obsessive-compulsive disorder (OCD) and tic disorders (Swedo et al., 1998). If left untreated, the immune response triggering acute neuropsychiatric symptoms in PANS can develop into a chronic autoimmune disorder with severe neuropsychiatric consequences. PANS symptoms are often so severe that they affect a child's ability to live a normal life. Symptoms often impair academic performance, social relationships, and disturb homelife. Despite these impairments and federal laws protecting students with disabilities, anecdotal evidence suggests that many children with

PANS experience significant difficulties gaining support at school due to a lack of knowledge of the disorder and its effects (Alleman, 2015). All this said, the more favorable outcomes for children with PANS are tied to early diagnosis and treatment using both medical and psychosocial interventions (Thienemann, et al., 2017). These facts serve as a call-to-action for school-based mental health providers to understand the emotional, behavioral, and cognitive correlates of PANS, and to understand how to best serve children and families affected by the disorder. For the purposes of the following literature review, the focus will be on PANDAS, which is a subtype of PANS with the most extensive body of research. The estimated prevalence of PANDAS itself indicates that most school personnel will work with one or more students affected by PANS during their career (Dornan, 2015).

PANS as a Neuropsychiatric Disorder

In the 1980s, researchers at the National Institute of Mental Health (NIMH) identified a subset of children with OCD who displayed a sudden onset of emotional and behavioral symptoms following typical childhood infections such as strep throat, which is caused by Group A streptococcus (GAS) bacteria (Allen, Leonard, & Swedo, 1995). These individuals were categorized as having a pediatric infection-triggered autoimmune neuropsychiatric disorder (PITANDs). Neuropsychiatric responses to GAS infections had been previously documented by researchers in cases of Sydenham's Chorea (SC) and for this reason, GAS became the most researched infectious trigger. A sudden onset of emotional and behavioral symptoms preceded by GAS infection was labeled pediatric autoimmune neuropsychiatric disorders associated with streptococcus (PANDAS). PANDAS was first described in 1998, after 50 children exhibiting five

distinct clinical criteria separate from children with pure OCD or SC were identified at a clinic specializing in the treatment of OCD (Swedo et al., 1998). Since the original identification of the disorder, other pathogens have been suspected to cause an autoimmune response and lead to the same symptom profile. Since the original discovery of PANDAS, the National Institute of Health (NIH) has developed the diagnostic label “pediatric acute-onset neuropsychiatric syndrome” (PANS) to encompass all suspected infectious triggers. PANDAS is therefore included under the PANS umbrella and is the only infection-specific diagnostic category outlined at this time.

Etiology

Streptococcal infection is the most well-researched infection causing PANS symptoms. When a temporal relationship between streptococcal infection and behavioral symptom onset can be made, a child will receive a diagnosis of PANDAS rather than PANS. Post-streptococcal illnesses are well documented throughout history, and include rheumatic fever, Sydenham’s chorea, and rheumatic heart disease (Cunningham, 2000). Post-streptococcal illnesses are thought to arise from an autoimmune reaction in a genetically susceptible individual. As such, PANDAS and PANS are considered autoimmune disorders. This autoimmune response is theorized to result from repeated infection with certain strains of GAS that cause the immune system to mistakenly attack the host’s own cells (Murphy & Pichichero, 2002). While strep is the most common infectious agent, onset and exacerbation of PANS symptoms has been reported after upper respiratory tract infections, influenza, gastrointestinal infections, dental infections, herpes simplex, varicella, Epstein-Barr, enterovirus, and in children with Kawasaki disease and anaphylactoid purpura (Allen et al., 1995; Swedo et al., 1998; Murphy et al,

2014; Frankovich et al., 2015; Cooperstock et al, 2017). *Mycoplasma pneumoniae* and Lyme borreliosis are additional suspected pathogenic causes of PANS (Cooperstock et al., 2017).

Researchers have theorized that increased virulence of an infection in a susceptible host causes the body's immune cells to mistakenly interact with human brain tissue, causing inflammation and increased cell signaling (Cox, Zuccolo,... & Cunningham, 2015; Geidd, Rapoport, Garvey, Perlmutter, & Swedo, 2000). In the case of PANS/PANDAS, the brain tissue targeted by the immune system is within the basal ganglia, which is also implicated in OCD and movement disorders and is responsible for the production and projection of dopamine (Kirvan, Swedo, Snider, & Cunningham, 2006; Lewin, Storch, Mutch, & Murphy, 2011; Pearlman, Vora, Marquis, Najjar, & Dudley, 2014; Williams & Swedo, 2015). Recent research has shown a relationship between autoimmune responses in the basal ganglia and heightened activation of intracellular signaling molecules in patients with OCD and Tic disorders with evidence of GAS infection (Cox et al., 2015). This signaling molecule, which is responsible for modulating dopamine release, is thought to be a mediator of motor and behavioral manifestations of some neuropsychiatric disorders like PANDAS (Moretti, Pasquini, Mandarelli, Tarsitani, & Biondi, 2008). Evidence strongly suggests that the antibody production induced by GAS infections can target dopamine receptors, and as such are implicated in a variety of movement disorders (Kirvan, Swedo, Snider, & Cunningham, 2006; Cox, et al., 2013; Brimberg, et al., 2012). Methods to interrupt autoimmune activation of intracellular signaling are a current focus of clinical trials in PANS medical

research (PPN, 2016). A parallel autoimmune mechanism is implicated in all types of PANS.

Presenting Symptoms

Most children with PANS present primarily with acute-onset OCD symptoms. OCD is characterized by recurrent obsessions and/or compulsions that cause marked distress and/or interference in one's life (American Psychiatric Association, 2013). Obsessions are repetitive and persistent thoughts, images, or urges that are intrusive and unwanted. Compulsions are repetitive behaviors, rituals, or mental acts that an individual feels compelled to perform in response to an obsession, or according to rules that are rigidly applied to a situation. Typically, those with OCD have both obsessions and compulsions, with the compulsions being performed to relieve stress associated with obsessional thoughts, or to prevent a feared event from occurring. Obsessions and compulsions are time consuming, defined as occurring for more than one hour per day. There are individual differences in the time and distress associated with OCD symptoms, as well as individual differences in the specific content of obsessions and compulsions. Symptom severity is often measured through self-report rating scales. Certain themes are present across individuals, including contamination fears and cleaning compulsions, symmetry obsessions and counting or reordering compulsions, forbidden or taboo thoughts, and harm-related fears.

Although OCD is the most common neuropsychiatric manifestation of PANS, one in five children with PANS primarily presents with severe food avoidance or restriction, as opposed to OCD (PANDAS Physician's Network, 2016). Food avoidance/restriction is theorized to be related to contamination fears or other obsessions that lead children to

refuse both food and water. Children with PANS may experience involuntary, mood-incongruent episodes of crying or laughing, irritability, aggression, temper tantrums/rage episodes, speech regression, selective mutism, stuttering, and impulsive or compulsive behavior. Sexual or violent thoughts and impulses are common in children with PANS (Frankovich et al., 2015). Children can experience self-injurious thoughts and behaviors, with some children making suicide threats and attempts. These symptoms often cause parents to seek treatment for their children due to their concerning nature.

Other neuropsychiatric symptoms, including severe separation anxiety, generalized anxiety, emotional lability, or depression are present in children with PANS (Swedo et al., 1998; Murphy & Pichichero, 2002; Swedo et al., 2015). As many as 70% of children with PANS/PANDAS experience tics (Murphy et al., 2015; Swedo et al., 2015). Many children also experience developmental regression during symptom exacerbation, where they have temper tantrums, poor motor skills, poor planning abilities, lack of self-care, and difficulty engaging with same-aged peers. In 2012, the National Institute of Mental Health (NIMH) cited the most common secondary symptoms of PANS to include sleep disturbances, motor hyperactivity, sensory abnormalities, concentration difficulties, loss of academic abilities (specifically, math and visual spatial areas), urinary frequency, enuresis, fine/gross motor changes (changes in handwriting), joint pain, and general lethargy (NIMH, 2012).

Generally, after the first exposure to an infectious trigger the child's symptoms return to baseline (either no symptoms, or pre-PANS behavior). After each successive exposure to infection, a child's symptoms dramatically increase (Chang et al., 2015). Likewise, after each successive exposure, the child's symptoms return less and

less near baseline. Even children who are exposed to a pathogen but do not develop a full-blown illness experience symptom exacerbation due to the production of antibodies by the child's immune system (Chang et al., 2015). *Figure 2.0* shows the episodic course of PANS (NIMH, 2012).

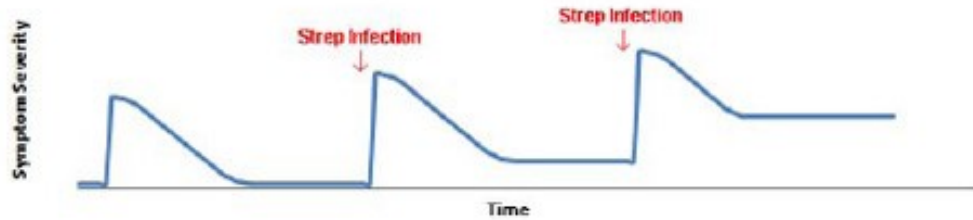


Figure 2.0 Episodic nature of symptom exacerbation after immune response to infection (NIMH, 2012).

PANS Diagnostic Criteria

To be considered for a diagnosis of PANS, a child must meet the *Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition* (DSM-V) criteria for either OCD or an avoidant-restrictive food intake disorder (ARFID) (DSM-V, 2013; PPN, 2016). PANS is considered a “diagnosis of exclusion” by researchers, meaning that other possible conditions must be ruled out first before making a diagnosis. As a diagnosis of exclusion, a formal diagnosis of PANS can take a prolonged period of time while other disorders are considered, and lab tests are performed. Anecdotal evidence suggests that a formal PANS diagnosis often has a “lag time” of between one and nine years (Candelaria Green, 2015). PANS diagnosis is limited to cases in which the onset and simultaneous presentation of symptoms after infection is acute, and occur in multiple domains (Chang et al., 2014).

PANS diagnostic criteria outlined by the NIH include three broad characteristics. First, abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake. Second, concurrent presence of additional neuropsychiatric symptoms, (with similarly severe and acute onset), from at least two of the following seven categories: a) anxiety, b) emotional lability and/or depression, c) irritability, aggression, and/or severely oppositional behaviors, d) behavioral (developmental) regression, e) deterioration in school performance (related to attention deficit/ hyperactivity disorder (ADHD)-like symptoms), memory deficits, cognitive changes), f) sensory or motor abnormalities, g) somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency. Third, symptoms must not be better explained by a known neurologic or medical disorder, such as Sydenham Chorea (Swedo et al., 2012). Once meeting the criteria for PANS, children are considered for a PANDAS diagnosis when there is evidence of Streptococcus being the infectious trigger.

PANS impairments fall into three descriptive categories: mild, moderate to severe, and extreme or life threatening (Frankovich et al., 2017). These categorical descriptors are based on the level of impairment caused by obsessive compulsive or other behavioral symptoms and the risk the child poses to self and others because of their behaviors. Likewise, the trajectory of the disorder is defined as either an acute flare, relapsing-remitting, or chronic-static/chronic-progressive (Frankovich et al, 2017). These descriptors are used to help medical professionals employ best practice strategies to combat the biological mechanisms of the disorder. Many children in an acute flare are responsive to immunological or pharmacological intervention, and their symptoms are adequately controlled through these measures. Commonly, the disorder waxes and wanes

with each new infection. In some cases, temporary post-infectious immune response becomes a chronic autoimmune condition that require aggressive and persistent medical treatment. Even fewer experience a disease course that causes neurocircuitry damage and are resistant to immunological or pharmacological interventions (Frankovich et al, 2017).

Disorders that Co-occur with PANS

Many children with PANS have other pre-existing neuropsychiatric conditions. In the first study of children with PANDAS, researchers identified a number of co-occurring mental health diagnoses, including attention deficit hyperactivity disorder (40%), oppositional defiant disorder (40%), conduct disorder (40%), major depression (36%), dysthymia (12%), separation anxiety (20%), avoidant disorder (8%), “overanxious disorder” (28%), specific phobia (16%), eating disorder (2%), enuresis (12%) and encopresis (10%) (Swedo et al., 1998). PANS is not explicitly included in the DSM-V but can be diagnosed in addition to any DSM disorder. Within the DSM-V, there is a recognition of PANDAS under the diagnostic label “Obsessive-Compulsive and Related Disorder Due to Another Medical Condition,” in which it is stated that PANDAS has a substantial research base but remains controversial due to a poorly understood etiology and the need for further research to be conducted (DSM-V, 2013).

PANS Treatment

Medical treatment. Anecdotal evidence presented by members of the PANS/PANDAS consortium supports the use of interventions that serve to counteract the effects of unwanted immune responses or reduce the effects thereof (Frankovich et al., 2017). These treatments can reduce OCD symptoms as well as reduce the duration of flare-ups (Pearlmutter et al., 1999; Spartz et al., 2017). Because PANS is the result of

immune action, antibiotics are often used to prevent infections and the immune response associated with them. The use of antibiotics has been shown to quickly reduce behavioral symptoms resulting from flareups (Falcini et al., 2013; Murphy & Pichichero, 2002; Murphy et al., 2004; Snider et al., 2005; Stagi et al., 2014). Behavioral symptoms of PANS can sometimes be treated with psychiatric medications, which can relieve symptoms associated with motor impairments, obsessive compulsive behaviors, anxiety, and aggression (Brimberg et al., 2012; Thienemann et al, 2017). However, PANS/PANDAS patients may be more susceptible to adverse effects of these medications than other children (Murphy et al., 2006; Thienemann et al., 2017). Even with these medical interventions, some youth remain symptomatic, experience only partial remission of symptoms, or experience symptom recurrence after treatments have stopped (Nadeau, 2015).

Psychological treatment. Children with PANS have attenuated behavioral impulse control, which is evident in their difficulties with emotion regulation, oppositionality, and developmental regression. This results in difficulty habituating to feelings of distress and inhibiting behavioral responses in the face of anxiety and allows for the primary symptoms of OCD to be maintained over time. This means that even when not in an acute episode, children with PANS can experience chronic OCD symptoms and other emotional difficulties. Children with PANS are often initially seen for psychiatric symptoms and usually receive a psychiatric or psychological evaluation before receiving a medical evaluation. The optimal outcomes for all children, especially children experiencing resistance to pharmacological intervention, are achieved through

the medical treatment with the addition of intensive cognitive behavioral therapy (CBT; Nadeau, 2015).

Because of its effectiveness in treating childhood onset OCD, CBT has been proposed as a potentially efficacious treatment of PANS symptoms (Nadeau, 2015). Behavioral theory holds that in cases of OCD and PANS alike, obsessive-compulsive symptoms are maintained through a combination of classical and operant conditioning, where a specific setting or event becomes paired with anxiety, resulting in a classically conditioned relationship between a previously neutral stimulus and the conditioned response (anxiety). Once established, this maladaptive relationship is strengthened or maintained through operant conditioning; the child avoids the conditioned stimulus or engages in rituals when exposed to the stimulus to achieve relief of stress, which reinforces the conditioned relationship. Research suggests that behavioral strategies are highly effective in treating the OCD symptoms associated with PANS/PANDAS, even in those who are resistant to antibiotic treatment (Nadeau et al., 2015; Storch et al., 2006). Exposure/response prevention (ERP), a form of CBT, is the single most empirically validated treatment protocol for child and adult OCD (March and Mulle, 1998; Lebowitz et al, 2011).

Although some children with PANS are treated promptly, experience symptom remission, and are able to maintain relief with brief medical intervention, many children with PANS will experience lifelong behavioral symptoms and symptom exacerbation. PANS therefore requires a multidimensional treatment approach that considers biomedical, psychological, and social factors similar to that used in other chronic medical conditions. A multidisciplinary treatment approach, including psychological and

educational supports, is recommended per PANS treatment guidelines (Thienemann et al., 2017). Considering the developmental impact of childhood health and mental health conditions, the treatment of conditions such as PANS requires increased awareness and collaboration among professionals.

Theoretical Framework: The Biopsychosocial Model of Chronic Illness

Engel's (1977) biopsychosocial model represents an integrated perspective for understanding the complex interplay of the various factors influencing a person's health and well-being. The model opposes the traditional reductionist biomedical model of disease, bringing the emotional and social aspects of disease impact into focus and emphasizing the doctor-patient relationship and the larger role of the health care system (Henningsen, 2015). Based on a systems approach, the biopsychosocial model attempts to relieve patient distress caused by illness or disease through treatment of the whole person, rather than treatment of disease alone. The model accounts for the reciprocal nature of an individual's personal characteristics, their disease process, and their social environment, placing these unique natural "systems" along a continuum (Engel, 1980). Engle (1977) holds that an individual can only be adequately treated if all levels of that individual's functioning are considered.

The model focuses on three major systems: biological, psychological, and social, all viewed from a patient-centered perspective. All domains influence and are influenced by the individual (Sperry, 2008). Each of these domains interact with each other in a reciprocal fashion, and individual differences in disease manifestation are related to individual differences in the various systems influencing the person. Those viewing disease and illness from a biopsychosocial perspective recognize that symptoms of illness

can result from biological, psychological, and social factors. Likewise, those treating disease from a biopsychosocial perspective would address factors from each system contributing to disease presentation in order to mitigate symptoms.

The biological domain refers to organ system functioning, including but not limited to central nervous system processes. This domain is one that medicine traditionally intervenes upon when treating illness and disease. The biological domain is the focus of disease etiology. In the case of PANS, the disorder is autoimmune in nature. The etiology of the disorder guides medical treatment, which for PANS includes pharmacological and immunomodulatory intervention.

The psychological domain refers to conscious and subconscious psychological processes such as information processing and communication with the outside world. It also includes the internal representation of the self, cognitions, and behavior (Sperry, 2008). In PANS, the psychological focus would be on the psychiatric manifestations of the disorder, namely, the unique behavioral and cognitive symptom profile. The psychological manifestations of PANS require assessment and intervention through standardized measures and evidence-based practice. Through understanding and mitigation of the psychiatric components of the disorder, patients have the greatest opportunity for complete symptom remission.

The social domain refers to a person's relationship with family, friends, and other community institutions. In PANS, social systems are highly impacted by the disorder. Family life is disrupted, learning is disturbed, and age appropriate social relationships are hindered. For patients to have optimal treatment outcomes, all individuals involved in providing care must work collaboratively toward the common

goal of symptoms remission. This includes individuals working within a child's school, who have the most contact with the child on a daily basis. Schools must communicate with parents and medical professionals to understand the implications of the disorder on a child's ability to meet expectation for learning and behavior, and if needed, must have a plan in place for how to best help a child suffering from educational losses as a result of their disorder.

When applying the biopsychosocial model to PANS, one must recognize the biological underpinnings of the disorder manifest in psychological disturbances. PANS has a theorized autoimmune origin, leading to cortical inflammation and changes in cell signaling and neurotransmitter release. These changes create the observable psychological symptoms that are characteristic of the disorder: acute-onset OCD and other associated symptoms. Symptoms present themselves in the social context of the home and school environment and can be exacerbated by the addition of environmental stressors. Identification and treatment of the disorder thus requires a multidimensional patient-centered approach, focusing not only on the biological underpinnings of the disorder but also on the psychiatric manifestations and their psychosocial consequences.

School-based Implications of PANS within the Biopsychosocial Model

To understand PANS within the social context of school, one must take into consideration the complex interplay of the behavioral manifestations of the disorder and expectations for social, behavioral and academic achievement. A child with PANS experiences significant emotional, behavioral, and cognitive changes as a result of the disorder. These changes cause a failure to meet expectations for academic performance and behavior, thus requiring intervention. The reciprocal nature of the biological,

psychological, and social aspects of the disorder require interdisciplinary collaboration and support to reduce the effect of PANS on educational opportunity and to improve treatment outcomes.

Observable changes in the school setting. The following are a non-exhaustive outline of observable changes in the school setting, as revealed by previous medical research, and an unpublished survey of parents, service providers, and children affected by PANS conducted by a visiting researcher at the University of California-Berkley (Candelaria Green, 2015). All of the following symptoms may be present with or without changes in academic performance. The performance of students experiencing symptoms without deterioration of academic performance should not be ignored; many students, as noted below, experience perfectionism and thereby become obsessed with their grades, assignments, and overall performance at school. At school in particular, children with PANS often display academic strengths and weaknesses. It is not uncommon for winter report cards to show worse grades than other report cards, due to increased exposure to infectious agents. In particular, math scores may be affected by these seasonal variables. With or without overt changes in academic performance, children with noticeable social, emotional, and behavioral difficulties need supports.

Biological implications in the school setting. Biological changes in the central nervous system of children with PANS cause changes in emotions, cognitions, and behaviors. It is important to remember that all symptoms of PANS are the result of biological changes. Within the school setting, biological implications of the disorder include frequent absences due to medical appointments, frequent visits to the school

nurse, and a need for medication management. Neurological changes due to the disorder may result in a multitude of psychological changes as evidenced below.

Psychological implications in the school setting. The following symptoms, while directly resulting from biological changes, are psychological in nature and may manifest as such in the classroom. These are emotional and behavioral components of the disorder that are most easily influenced by psychosocial factors and are able to be reduced through behavioral intervention or other classroom modifications or accommodations.

Obsessive-compulsive behaviors. Children with PANS most frequently display symptoms of OCD, such as repetitive counting, organizing, and perfectionistic tendencies (Swedo et al., 2012). Children often fixate on certain sensory experiences, like the pressure of their pencil on their hands, or contamination fears. Children with PANS and OCD often display contamination fears that can manifest in restricted eating, fear of swallowing their own saliva, or excessive hand washing. Frequent “checking” behaviors are common, and children often ask adults whom they trust questions related to their obsessions. Children also can become increasingly concerned about how others perceive them, and make attempts to appear perfect, blend in, or look “normal”. For this reason, many children may do well at hiding OCD symptoms at school, but upon returning home or to another private, safe space, they will relieve repressed compulsions (Candelaria Green, 2015). Children often ask to use the bathroom excessively, perhaps to engage in compulsive behaviors in private. Children can experience such severe obsessions and compulsions that they engage in self harm, suicidal ideations, and suicide attempts

(Chang et al, 2015). At times, children with symptoms may appear defiant due to rigidity in adhering to rituals, repressed compulsions, or other emotional changes.

Emotional changes. Children with PANS may experience a variety of emotional changes (Thienemann et al., 2017). These include mood incongruent fits of crying or laughing, and mood lability. They may express somatic concerns related to increases in anxiety, or have panic attacks. Children may become increasingly aggressive or seem overly sensitive to criticism. They can become excessively reactive to changes in routine, and experience behavioral regression in coping skills, and social skills (Candelaria Greene, 2015). Children may appear explosive, anxious, depressed, or otherwise unable to control their mood and affect.

Speech and language changes. Children with PANS may appear less conversational for a variety of reasons including attention difficulties and social anxiety. They may experience a regression in their language abilities, miss social cues in conversation, have a lessened sense of humor, or have trouble articulating their needs. They may also exhibit echolalia or unexpected sounds or pauses in language due to OCD related issues (Candelaria Greene, 2015).

Social changes. Children with PANS may have changes in their relationships with friends. They may argue with others or become aggressive. They may have reduced social interaction due to either peer avoidance, or avoidance by peers. They can experience bullying related to other symptoms; such bullying can occur from peers but also by teachers who reprimand children for engaging in compulsions or tics (Candelaria Greene, 2015).

Changes in appearance. Children affected by PANS may exhibit an increase in absenteeism and tardiness due to a myriad of factors including insomnia, separation anxiety, or plain school refusal related to other emotional factors. Children may exhibit changes in posture, skin color, and grooming. They may have evidence of skin picking, cuts and bruises due to self-harm, or bald spots/hair thinning due to trichotillomania (Candelaria Green, 2015). Children with PANS and other medical illnesses may have dilated pupils and can also look excessively tired either as a secondary symptom to insomnia or anxiety, or due to increased levels of cell signaling proteins in the child's bloodstream related to their illness (Murphy et al., 2015; Parker-Athill, Ehrhart, Tan, & Murphy, 2015).

Changes in executive functioning. Children may experience difficulties with executive functions such as attention, planning, and organization (Lewin et al., 2011). They can become increasingly forgetful and have poor time management skills. These students can be extremely distracted, take longer to transition, and lose things frequently. Children with executive functioning deficits as a result of PANS or any other disorder have a diminished ability to multitask and have trouble following multistep instructions.

Sensory changes. Children with PANDAS in particular have displayed impairments in visuospatial memory (Lewin et al., 2011). PANS may cause problems with depth perception, tracking, and visual memory. In class, children may take longer than normal to read, and have trouble remembering visual information (Candelaria Greene, 2015). They may also experience a difficulty reading body language and facial expressions as a result of a combination of visual and social difficulties. They may have

an increased number of error on math assignments due to misreading “+” and “-” signs, and have marked changes in handwriting due to both poor motor planning and poor visual processing (Candelaria Greene, 2015). Children with PANS also may have auditory processing difficulties, and can have trouble following verbal directions, trouble with phonics, and difficulty conversing with others. They may experience sensory defensiveness or sensory overload, or have difficulties orienting themselves in space. They may have poor body awareness or poor motor control as a result. PANDAS children in particular often experience a frequent need to urinate, or experience enuresis. *Figure 2.1* displays regression in writing skills during acute symptom exacerbation related to both reduced motor skills and visuospatial skills (Swedo, Leckman, & Rose, 2012).

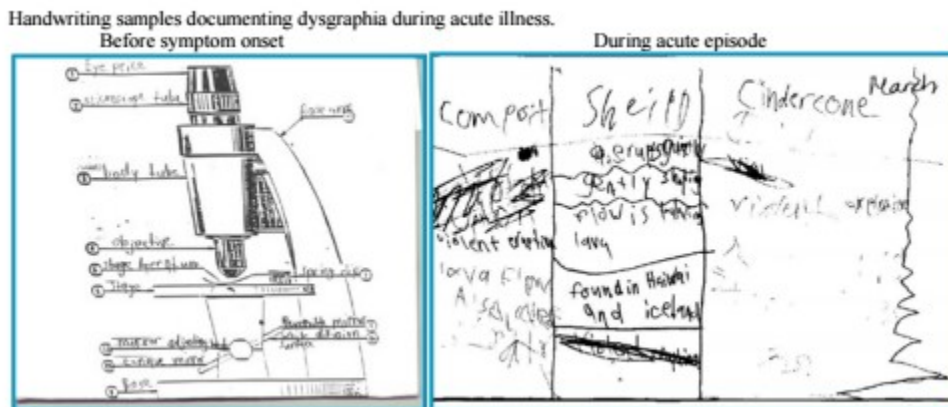


Figure 2.1 Regression of handwriting skills and visuospatial awareness during acute symptom exacerbation (Swedo, Leckman, & Rose, 2012)

Changes in movement and motor skills. Children may appear more fidgety than usual and may exhibit an increase in other behaviors associated with hyperactivity. They may experience vocal and/or motor tics, such as coughing, sound production, head jerking, blinking, or other abnormal movements and noises (Murphy et al., 2015; Swedo

et al., 2015). Children may have trouble maintaining a grip on their pencils. They may hyperventilate, flail their arms, or have unexpected changes in their voice (Candelaria Green, 2015). They may also experience excessively rapid or unusually slow speech as a secondary symptom of anxiety. Children can be increasingly clumsy, have changes in their gait, and appear less coordinated than they did previously. Children with PANS have been shown to have a marked impairment in fine motor skills (Lewin et al., 2011). Notably, children often experience severe regression in their handwriting skills, with artwork and the ability to copy materials being significantly below what is expected of a child their age, as seen in *Figure 2.1* above. Additionally, they may have trouble working with manipulatives. For school psychologists and other similar practitioners, the Rey Complex Figure has been shown to adequately measure motor and visual-spatial deficits in children with PANS (Lewin et al., 2011).

Educational System as a Social Context of Service Delivery

Children with PANS demonstrate a variety of impairments in the school setting that require intervention and support. Drawing upon the biopsychosocial model, the involvement of community institutions such as schools is a critical component in treating any child with a chronic illness, especially one such as PANS which requires multidimensional intervention and support (Engel, 1977; Sperry, 2008). In line with this, PANS treatment guidelines point to the need for educational and family supports, stating that most children with PANS/PANDAS require some type of school accommodation (Thienemann et al., 2017). Schools have a legal obligation to be a source of support for children with complex medical needs or who are otherwise suspected to

have a disability (U.S. Department of Education, 2015). This obligation is often met using classroom accommodations, special education, and school nursing plans.

Special Services and PANS: IDEA and Section 504

When a child is demonstrating emotional, behavioral, or academic difficulties in school, or when a parent is concerned that a child's disability may impair their educational functioning, he or she should be referred to their school psychologist for a psychoeducational evaluation. Schools have an obligation to seek out and identify children with disabilities (Child Find) (20 U.S. C. § 1412 (a) (3)) and must ensure that all children with disabilities receive a free appropriate public education (FAPE). To do so, school personnel are to actively monitor a child's developmental progress academically and behaviorally and swiftly refer students who do not meet expectations for further evaluation. Children with such disabilities are eligible to receive protections against discrimination under Section 504 of the Rehabilitation Act (1973), and if needed can receive related disability services provided under the Individuals with Disabilities Education Act (IDEA; 2004).

Psychoeducational evaluations. When evaluating children suspected of having a disability defined by IDEA (2004), school psychologists are to collect data from multiple sources as a foundation for decision making and consider ecological factors when making decisions per the law and best-practice guidelines (IDEA, 2004; McConaughy & Ritter, 2014; BP1; NASP, 2010). The process of identifying a child for services requires the use of a multidisciplinary team (MDT), which for children with PANS should include family members, health care professionals, mental health professionals, as well as school personnel (Dornan, 2015). Integration of information such as medical information,

classroom behavioral observations, parent report of behavioral or emotional problems, academic records, and performance on cognitive, academic, and neuropsychological assessments is critical. For children with PANS, comparison of information before, during, and after symptoms flare-ups are needed to capture the effects of the disorder.

Section 504. The Office for Civil Rights (OCR) has jurisdiction over public education. Civil rights legislation under Section 504 of the Rehabilitation act of 1973, Subpart D specifically pertains to preschool, elementary, secondary, and adult education programs. Section 504 protects children with disabilities from discrimination in participation in school-based programming. The 2008 amendments to this act indicate that the definition of disability should be interpreted broadly to include a variety of medical and mental health disorders, including chronic illnesses such as PANS. Any student who has a disability that affects a major life activity is afforded protections under this act, and any student who suffers educational losses because of their disability should receive appropriate accommodations. Any impairment that is in remission or that is episodic in nature is considered a disability under the law if it would substantially limit a major life activity when in an active state (U.S. Department of Education, 2015). In regards to PANS, its waxing and waning nature may make educators and administrators hesitant to give students with PANS Section 504 protections because they may believe that the student is not evidencing a disability at the time of the evaluation. However, the law clearly states that even disabilities that are episodic in nature are to be afforded protections (U.S. Department of Education, 2015).

IDEA. The Individuals with Disabilities Education Act (IDEA; 2004) ensures that all children have an opportunity to benefit from their education, and that their education

be appropriately suited to their individual needs. The purpose of IDEA as it stands today is to ensure that children with disabilities are provided with an individualized education designed to meet their unique needs and to prepare them for future education, employment, and independent living (20 U.S. C § 1400(d)(1)). The special educational programming provided for children with disabilities under IDEA is outlined in a child's Individualized Education Plan (IEP), which is a comprehensive document listing areas of needed support, and accommodations, modifications, and services that will be provided to the student. When a child receives special education, they are determined to have a disability falling under one of 13 categories outlined by IDEA: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, visual impairment including blindness. Likewise, these students are eligible to receive services related to their disability. The disability categories most likely to encompass the impairments associated with PANS are Other Health Impairment (OHI) and Emotional Disturbance (ED) (IDEA, 2004). The IDEA definitions of these two categories follow:

Other health impairment (OHI) means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and (ii) Adversely affects a child's educational performance.

Emotional disturbance (ED) means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:

(A) An inability to learn that cannot be explained by intellectual, sensory, or health factors.

- (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
 - (C) Inappropriate types of behavior or feelings under normal circumstances.
 - (D) A general pervasive mood of unhappiness or depression.
 - (E) A tendency to develop physical symptoms or fears associated with personal or school problems.
 - (ii) Emotional disturbance includes schizophrenia.
- Children with PANS suffer from psychiatric symptoms that have a clear

neurobiological origin. The onset of these symptoms is acute, but the illness itself is often chronic, maintaining a waxing and waning course. Likewise, children with PANS suffer a myriad of symptoms that reduce their ability to benefit from their education. Children with PANS could therefore meet the criteria to be considered a child with a health impairment under IDEA (2004). Children with such disorders often suffer negative social, emotional, behavioral, and academic effects. According to the IDEA definition of OHI, children suffering from PANS who display negative educational effects would be eligible for special education services. Considering the explicit listing of disorders such as RF and Tourette's Syndrome in federal law, and the etiological and behavioral similarities of PANS and these disorders, it is a clear argument for the eligibility of children disabled by PANS to receive special education services.

Children with the symptoms of PANS who are undergoing the diagnostic process and are without a formal diagnosis are likely to be categorized as emotionally disturbed. Each child's individual needs are unique, with some children experiencing more emotional symptoms than others. Even with a formal diagnosis, some children may be categorized as emotionally disturbed due to the nature of their symptoms. Practitioners should take care not to falsely identify a child with a neurobiological illness as a defiant,

disruptive child, and should take care to not try to punish children for behaviors resulting from their disease.

Special services. When a child qualifies for special education services either due to PANS or due to another comorbid disability, this child will receive an IEP. If a child is determined to have a disability but is not in need of specially designed instruction, they may be eligible to receive general accommodations through a Section 504 plan. The PANS/PANDAS consortium suggests that IEPs or Section 504 accommodation plans should be written with the child’s most severe days in mind (Thienemann et al., 2017). Accommodations and modifications should be individually tailored to the child, however, typical accommodations may include those for separation anxiety, OCD, urinary frequency, dysgraphia, dyscalculia, and slowed processing speed. Other services for children with PANS may include a positive behavior support plan (PBSP) or a health plan. Children with IEP’s are eligible to receive related services, defined as services designed to enable a child with a disability to receive a free appropriate public education as described in their IEP and as required to assist a child with a disability to benefit from their special education (IDEA, 2004). These related services are described in *Table 1* below.

Related Service	Definition
Audiology	Identification of children with hearing loss, determination of the degree of hearing loss, and the provision of habilitative activities related to hearing loss.
Counseling services	Services provided by qualified social workers, psychologists, guidance counselors, or other qualified personnel.

Early identification and assessment	The implementation of a formal plan for identifying a disability as early as possible in a child's life.
Interpreting services	Services for children who are deaf or hard of hearing, such as sign language transliteration services.
Medical services	Services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services.
Occupational therapy	Services provided by an occupational therapist Including (A) Improving, developing or restoring functions impaired or lost through illness, injury, or deprivation; (B) Improving ability to perform tasks for independent functioning if functions are impaired or lost; and (C) Preventing, through early intervention, initial or further impairment or loss of function.
Orientation and mobility services	Services provided those who are blind or visually impaired to enable those students to attain systematic orientation and safe movement in school, home, and in the community
Parent counseling and training	Assisting parents in understanding the special needs of their child and helping parents to acquire skills necessary to support the implementation of the child's IEP.
Physical therapy	Services provided by a physical therapist
Psychological services	Includes psychological and educational assessment, consultation with school staff members in planning educational programming, planning psychological counseling services, and developing positive behavioral interventions.

Recreation	Includes therapeutic recreation services
Rehabilitation counseling services	Services focusing on career development, employment preparation, independent living skills, and integration into the workplace or community. Includes vocational rehabilitation services.
School health/nursing services	Health services as needed to enable child to benefit from education as outlined in IEP
Social work services	Services to help parents and service providers partner in improving child's educational outcomes. Addresses problem with child's living situation if applicable.
Speech-language pathology	Includes identification, evaluation, diagnosis, and treatment of speech-language impairments.
Transportation	Includes travel to and from school and in and around school building. Includes specialized equipment as needed.

Table 1. Definitions of IDEA related services

Challenges of Treating PANS in Schools

The unfortunate reality of the provision of services under IDEA and 504 is that many children have disabilities that are difficult to detect or are easily misidentified. Impairments may not present themselves on standardized assessments if the child's disability has a waxing and waning nature such as in PANS. Children with PANS can be easily misidentified as defiant, learning disabled, or inattentive. Misidentification and a lack of understanding of the neurobiological correlates of a child's disability could lead to ineffective interventions and poor outcomes. Children with PANS likewise have "invisible disabilities", such as anxiety, or are evaluated by their teachers to be a "model student" due to OCD related perfectionism and organization, and thus are never identified

as needing additional support. Parents may choose to withdraw their children from school while they are fighting PANS because of perceived lack of support or understanding of their child's needs. These points underscore the importance of school-based practitioners being aware of a variety of types of abnormal behavior and be sensitive to a child's individual needs.

The Current State of Educational Research

Educational research on children with PANS is minimal at best. Anecdotal research suggests that many students with PANS receive accommodations or special education services prior to receiving a formal PANS diagnosis, both formally and informally (Candelaria Green, 2015). This is achieved through modifications in the classroom by teachers, or through written service agreements based on eligibility under other areas of need. Prior to diagnoses, the children surveyed received services for other conditions such as ADHD, anxiety, Tourette's, or other psychiatric or medical diagnoses (Candelaria Green, 2015). Children with PANS who receive accommodations often have parents who have the time and resources to address their child's needs, have some sort of diagnostic proof of a medical or psychological impairment, and are able to effectively communicate their child's needs to the school. These children also have a supportive school community that accepted the parents' concerns as legitimate, supported the implementation of services for the child with or without a diagnosis, and fought to secure services for the child through any avenue possible (Candelaria Greene, 2015). This information points out how academic assistance for children with PANS, and other disabilities, is often obtained.

Likewise, it points out that other students with a lack of resources, lack of parental involvement, or lack of access to medical or mental health care can easily fall through the cracks and suffer significant social, emotional, and academic effects. It is equally important to point out that without a medical diagnosis for the causes of a child's behaviors of concern, children can suffer deleterious labelling effects that will further hinder their development. Taken together, the above anecdotal evidence underscores the importance of early detection, evaluation, and intervention, as well as the importance of collaboration between educational, mental health, and medical professionals.

Students with behaviorally- and neurobiologically-similar conditions, such as OCD or Tourette's, have been inconsistently served through federal special education law (IDEA) and civil rights law (Section 504). For instance, students with Tourette's Syndrome are explicitly listed as eligible for service under the IDEA category OHI. Yet, children with OCD, a relatively similar disorder in both manifestation and etiology, are often served under Emotional Disturbance (ED; Adams, 2004). A 2007 study reported that of those students with OCD served under IDEA, 51.4% were qualified under ED, and 31.8% under OHI; 10.3% of students were dually qualified under ED and OHI (Adams, Smith, Bolt & Nolten, 2007). Nearly 50% of psychologists surveyed in this study indicated that ED was the most appropriate category for these students. This is in stark contrast to research recommendations that children with OCD be served under the OHI category due to its documented neurological basis (APA, 2000; Blier, Habib & Flament, 2006). Data suggests that those who view OCD as an emotional disorder often classify students under ED, while those who believe OCD is medical in nature classify students under OHI (Adams, Smith, Bolt, & Nolten, 2007).

Most would argue that a child with PANS, like a child with OCD, has a disability that is neurobiological in nature and thus considered under IDEA as a child with an Other Health Impairment (OHI), and would be eligible for service provisions under IDEA or Section 504. This also underscores the importance of school psychologists and other school professionals to understand brain-based behavior. Additionally, although most children with OCD are served through IDEA or Section 504 accommodations, other children with documented maladaptive behavior associated with their disorder receive no support at all (Adams, Smith, Bolt, & Nolten, 2007). Sukhodolsky, di Rosario-Campus, Skahill, Katsoyich, and Pauls (2005) found that children and adolescents suffering from OCD performed significantly worse on the school competence scale of the Child Behavior Checklist than other children their age. Children with OCD report that their two most common difficulties are focusing on class work and completing homework (Piacentini, Bergman, Keller, & McCracken, 2003).

School-based practitioners should have knowledge of the emotional, behavioral, and academic correlates of PANS, just as they do with any other childhood disorder. Any sudden onset of severe atypical behavior by a child should be recorded and communicated with the child's parents. Persistence of these symptoms, especially after illness, should be addressed by a physician. School-based professionals present an ideal source of information for physicians when diagnosing PANS. Likewise, teachers with knowledge of a child with PANS should be cognizant of the effects PANS can have on education and should swiftly refer a child in need to a school psychologist or student services team for a psychoeducational evaluation. School psychologists are equipped with the assessment and intervention skills to assess the needs of children with PANS and

to make appropriate intervention recommendations. Collaboration between school and medical professionals is essential for developing effective intervention plans and supports for students with PANS. PANS has clear neurobiological correlates and is considered to be a chronic autoimmune disease with psychiatric manifestations, making a clear argument for civil rights protections and accommodations provided under Section 504. Should a child with PANS demonstrate an educational need, there is clear evidence for special education consideration under the category OHI. Current educational practices, supports, and procedures for children with PANS are widely unknown due to a lack of research in this area. This lack of research, and evidence of apparent need for educational support, calls school psychologists and other school-based practitioners to action.

Chapter III: METHOD

The following chapter outlines the methods of data collection and analyses used in this research. Participants, research design, survey measures and operationally defined variables of interest, and research questions are described below.

This study utilized a cross-sectional survey design to identify current trends in educational service provision for children with PANS/PANDAS. This type of survey design is often used to measure levels of a particular variable of interest at a given time. A power analysis was conducted to identify a sample size that would adequately reduce the risk of type I ($\alpha=.05$) and type II ($1-\beta=.95$) error and would allow for a medium effect to be detected. Power analysis indicated that a sample size of 197 was needed to detect a medium sized effect.

Participants

Study participants were caregivers of children in grades K-12 currently enrolled in primary or secondary school in the United States with a self-reported diagnosis of PANS or PANDAS. Participants were recruited for participation through online parent support communities through the social media platform FaceBook. Specific inclusion criteria included: A) being the primary caregiver for one or more children formally diagnosed with PANS/PANDAS and, B) child(ren) in criterion A receive an education within the Unites States.

Accessing Participants. A snowball sampling technique was utilized. This technique allowed for participants to recruit other participants from acquaintances belonging to the same demographic group of interest, therefore increasing the number of individuals contacted for participation. The survey was shared as an access link via

online support groups for parents of children with PANS. Support group administrators agreed to post the survey link to their respective support communities after this researcher evidenced having received IRB approval.

Research Design

The current research utilized the survey method. Survey research generates quantifiable information about individual characteristics of members of a given population. Survey research methodology can allow for generalizations to be made about a larger population by drawing inferences based on data gathered from a small portion of that population, assuming the representativeness of the sample population (Rea & Parker 2014). The data collected in the current research focused on the experiences of children with PANS within the education system. The expected return rate for survey data collection was approximately 30% due to issues such as self-selection bias which reduces response rates (Rea & Parker, 2014). However, because the survey was delivered through an online platform and using snowball sampling it was impossible to calculate a true response rate for this survey.

Measures

Data were gathered through a survey delivered through Qualtrics, a well-established online research tool. The Qualtrics platform allows researchers to have participants respond to surveys remotely and stores the respondent information in a way that ensures participant confidentiality. An introductory statement about the purposes of the research and informed consent about research participation was provided. Consent was considered to have been granted if participants choose to proceed to complete the survey questionnaire. Initial questions included screening criteria for inclusion. For

example, respondents were asked if their child has been formally diagnosed with either PANS or PANDAS; Only participants indicating “yes” were able to continue through the remaining questions in the survey. Survey questions pertaining to a) general demographic information, b) general PANS diagnostic information, c) general educational information and, d) OCD symptom severity were included. Survey questions designed to yield demographic information and PANS diagnostic information were designed by the researcher. These questions included those such as age at symptom onset, age at diagnosis, primary behavioral symptom manifestation, and suspected infectious trigger. OCD symptom severity information were obtained using a publicly available validated behavior rating scale measure described below. All survey items were in a multiple-choice format; some survey responses prompted respondents to provide additional information in free text.

Children’s Yale-Brown Obsessive-Compulsive Scale (CY-BOCS).

This research utilized a parent-report modification of the Children’s Yale-Brown Obsessive-Compulsive Scale (CY-BOCS) to gather information about OCD symptom severity. The CY-BOCS is an extension of the adult Yale-Brown Obsessive-Compulsive scale (Y-BOCS; Goodman, Price, Rasmussen, & Mazure, 1989). The CY-BOCS was originally designed as a clinician delivered semi-structured inventory targeting OCD symptom severity. Self-report and parent-report have become popular modifications to the original delivery method of the inventory, which remove limitations to administration associated with the need for a trained clinician to be present to administer the assessment tool. All forms of the CY-BOCS are comprised of two subscales: Obsession Severity and Compulsion Severity. Each scale consists of five items: distress, frequency, interference, resistance, and symptom control. The items are rated on a 5-point likert scale. Scores are

then calculated for both Obsession Severity (range = 0–20), Compulsion Severity (range = 0–20), and a Total score (range = 0–40).

The CY-BOCS has high levels of internal consistency ($\alpha = 0.87–0.90$) (Scahill et al., 1997; Storch et al, 2004). Alphas for the Obsession Severity (.80) Compulsion Severity (.82) similarly high (Storch et al 2004). Adequate to high inter-rater reliability has been shown for the CY-BOCS Total Score (0.84), Obsession Severity Score (0.91) and Compulsion Severity Score (0.66). The CY-BOCS also demonstrates convergent and divergent validity (Scahill et al., 1997).

The parent report version (CY-BOCS-PR), which was utilized in this study, has demonstrated similarly high levels of internal consistency. For the CY-BOCS-PR total score and obsession severity scale ($\alpha = 0.86$ and 0.83). Cronbach's α for the CY-BOCS-PR compulsion severity scale was acceptable ($\alpha = 0.70$) (Storch et al., 2006). The CY-BOCS-PR was strongly related to the CY-BOCS total score ($r = 0.72$, $CI = 0.56–0.83$). The CY-BOCS-PR obsession severity scale was strongly related to the CY-BOCS total score ($r = 0.77$, $CI = 0.64–0.86$). The CY-BOCS-PR compulsion severity scale was modestly related to the CY-BOCS compulsion score ($r = 0.44$, $CI = 0.20–0.64$). Together, these indicate high levels of convergent validity with the original version of the measure (Storch et al., 2006). Correlation between the obsession and compulsion severity scales for the CY-BOCS-PR ($r=0.68$) suggest that the scales represent unique but interrelated dimensions (Storch et al., 2006).

The full survey with both the researcher-designed items and the parent-report CY-BOCS items is included in Appendix A.

Variable Definitions

Within this study there were multiple variables of interest. Those included in parametric analyses include obsession severity, compulsion severity, overall OCD symptom severity, educational placement, and service agreement presence. Obsession severity is measured on a scale of 0-20 per scores on the CY-BOCS, with higher scores indicating greater impairment. Compulsion severity is measured on a scale of 0-20 per scores on the CY-BOCS, with higher scores indicating greater impairment. OCD symptom severity is measured on a scale of 0-40 per scores on the CY-BOCS; total scores are then classified as subclinical (0-7), mild (8-15), moderate (16-23), severe (24-31), or extreme (32-40) per scoring criteria on the CY-BOCS. Educational placement is defined by the type of service agreement in place for a given child, either no services, Section 504 plan, or IEP. Service agreement presence is defined by the simple presence of any type of formal service agreement.

Other variables in the study were used for describing characteristics of the sample population; these included diagnostic labels, suspected infectious triggers, comorbid diagnoses, primary and secondary PANS symptoms per diagnostic criteria, medical treatments, obsession and compulsion types as described in the CY-BOCS, school based impairments, and school based services.

Data Analysis

After the data collection, data was cleaned and coded into statistical analysis software (SPSS). Data cleaning included removal of data from participants who did not meet criteria for participation in the survey, as well as removal of individuals who provided incomplete survey responses. Examples of those not meeting criteria would be

respondents who are not primary caregivers of a child with a formal diagnosis, primary care givers of a child without a formal diagnosis, or parents of children who not receive an education in the United States. The methods of analysis in this research included simple descriptive statistics, chi-square analyses, and binary logistics regression.

Research Questions

The current study sought to answer the following questions based on parent-report.

Analyses for each research question are documented below.

This research sought to answer the following research questions:

1. What severity of OCD symptoms (i.e., obsessions and compulsions) do children with PANS display?
2. What is the obsession symptom profile of children with PANS?
3. What is the compulsion symptom profile of children with PANS?
4. With what frequency do children with PANS receive special services in school (i.e., special education, Section 504 Plan, or no formal service agreement)?
5. Of children with PANS that are eligible for special education, under what eligibility category or categories do the children qualify?
6. What related services do children with PANS who are eligible for special education receive at school?
7. Does the type of educational service provided relate to overall symptom severity?
8. Is the presence of a formal service agreement predicted by the impairments associated with obsessions, compulsions, and/or by a combination of the two?

The above research questions were answered using the following statistical analyses:

1. Research question 1 was answered using frequency calculations. The total number of children in the sample who exhibit subclinical, mild, moderate, severe, and

- extreme levels of OCD related impairments per parent report on the CYBOCS was calculated.
2. Research question 2 was answered using frequency calculations. The total number of children in the sample who each distinct obsession type per parents report on the CYBOCS was calculated.
 3. Research question 3 was answered using frequency calculations. The total number of children in the sample who each distinct compulsion type per parents report on the CYBOCS was calculated.
 4. Research question 4 was answered using frequency calculations. The total number of children in the sample who receive no services, Section 504 accommodations, or special education was calculated as a percentage of the sample population.
 5. Research question 5 was answered using frequency calculations. The total number of children in the sample who receive services under each respective disability category was calculated as a percentage of the sample population.
 6. Research question 6 was answered using frequency calculations. The total number of children in the sample who receive the above listed services was calculated as a percentage of the sample population.
 7. Research question 7 was answered using a Chi-Square test. This allowed for the researcher to determine if different types of educational service agreements relate to overall OCD symptom severity.
 8. Research question 8 was answered using a binary logistics regression equation. The utilization of a logistics regression allowed the researcher to predict educational services (group membership) based on the contribution of each

independent variable (impairment level due to obsessions and compulsions). The overall variance in educational placement accounted for by the model and the individual contribution of each independent variable was determined by the regression equation.

Chapter IV: RESULTS

Descriptive statistics are presented on the demographic characteristics of the sample population. Additional information about diagnosis, symptoms, and associated school related impairments are also presented to help better understand the needs of the population. Analyses were conducted to evaluate relationships between symptom presentation and school-based services. Post-hoc analysis was performed to further explore the data.

Demographic Information

A total of 314 potential participants accessed the survey via Qualtrics. Of these, 281 met inclusion criteria (i.e., parent or guardian of a child diagnosed with PANS/PANDAS/PITANDS who receives an education in the United States). There were 73 incomplete responses which were removed from the data set, which left a total of 208 participants in the finalized sample; this exceeded the number required for power to detect a medium sized effect. Parents/guardians answered questions about their children. Demographic information for these children is as follows: 60.1% of the population were male; Ages ranged from 5-19 years of age, with a median age of 10 years.

Analyses

Disease specific characteristics

108 children within the sample were diagnosed with the umbrella diagnosis of either “PANS” or “PITANDS”. 140 (67.3%) children were diagnosed specifically with PANDAS. This overlap indicated that some children have received multiple diagnoses. 100% of children included in the sample first exhibited symptoms at or by age of 14, with

91.8% showing symptoms at or by age 10. The time between symptom onset and diagnosis ranged from <1 year to 13 years, with an average elapsed time of 2.28 years.

A variety of suspected infectious triggers were reported including: streptococcus (63.9%) Lyme (11%), and mycoplasma (15.4%). 13.9% of parents reported other or unknown triggers for their children including bartonella, babesia, coxsackie, CMV, HV6, EBV, HeP6, Candida, common cold, parasitic infection, and sinus infection. One parent reported symptoms triggered by the prescription drug Singulair. Two people additionally reported environmental triggers.

Treatments

Parents were surveyed regarding the forms of treatment accessed to manage symptoms. 61% of the sample reported receiving psychotherapy or counseling. 87% are treated with antibiotics, 26% with IVIG, 3.8% with plasmapheresis, 33.7% with steroids, and 38.9% with psychiatric medications. Other less frequently utilized medical interventions include Rituxan/rituximab, anticonvulsants, antihistamines, antivirals, anti-inflammatories, naloxone/naltrexone, anti-parasitics, antifungals, and dextromethorphan. 2 individuals report using stem cell transplantation. 4 individuals report tonsil/adenoid removal. 53.4 % of children are treated with other interventions including homeopathies and alternative medicine approaches. 5 parents reported that their child receives no treatment.

Comorbidities

Participants in this study report a high number of comorbid diagnoses. Comorbid psychiatric or neurodevelopmental diagnoses include ADHD (35.6%), autism spectrum disorder (14.9%), major depressive disorder (5.8%), generalized anxiety disorder

(45.2%), separation anxiety disorder (13.9%), oppositional defiant disorder (16.3%), and specific learning disorder (8.2%); other notable psychiatric disorders include conversion disorder, bipolar disorder, PTSD, and Tourette's syndrome. 19.7% of participants within the sample reported also being diagnosed with one or more additional chronic health conditions. These included asthma, seizure disorders, food allergies, celiac disease, psoriasis, bleeding disorders, autoimmune disorders, chronic inflammatory demyelinating polyneuropathy, hypogammaglobulinemia, migraines, eosinophilic esophagitis, postural orthostatic tachycardia syndrome, IgA deficiency, hypothyroidism, mast cell activation syndrome, dystonia, and diabetes.

Symptom specific information

90.4% of children in the population demonstrate primary symptoms of OCD, 54.8% of children demonstrate vocal, motor, or complex tics, and 39.4% demonstrate symptoms of ARFID; this overlap indicates that some children have multiple primary manifestations. Secondary symptoms include anxiety (96.6%), emotional lability or depression (82.7%), irritability, aggression, or oppositional behaviors (88.9%), deterioration of academic performance (72.6%), sensory or motor difficulties (71.6%), somatic symptoms (76%).

Obsessive Compulsive Symptom Profile

Obsessive compulsive symptoms were the primary symptoms of interest in this study and were measured using the CY-BOCS. Research question one sought to identify the severity of OCD symptoms displayed by children with PANS. The severity of obsessive- compulsive symptoms in this population ranges from subclinical to extreme, with the majority of children experiencing moderate symptoms (Table 1).

Table 1. *OCD symptom severity of children with PANS based on the CY-BOCS*

Symptom Severity	Frequency	Percent
Subclinical	11	5.3
Mild	47	22.6
Moderate	79	38.0
Severe	58	27.9
Extreme	13	6.3

Research questions 2 and 3 sought to identify the obsessive symptoms and compulsive symptoms experienced by children with PANS. These are reported in Tables 2 and 3 below.

Table 2. *Obsessions experienced by children with PANS*

Obsession Type	Frequency	Percent
Contamination	96	46.2
Harm related	98	47.1
Sexual	24	11.5
Hoarding	79	38.0

Magical thinking	31	14.9
Somatic	64	30.8
Religious	23	11.1
Other/miscellaneous	127	61.1

Table 3. *Compulsions experienced by children with PANS*

Compulsion Type	Frequency	Percent
Washing/cleaning	49	23.6
Checking	63	30.3
Repeating rituals	66	31.7
Counting	34	16.3
Ordering	60	28.8
Hoarding	64	30.8
Superstitious behaviors	29	13.9
Rituals involving others	102	49.0
Miscellaneous	112	53.8

School-related information

99.5% of children in the sample were school aged, with only one child attending PreK. All children in this study are students in the United States. 70.2% of children attend a public school, 11% of children attend a private or parochial school, 4.8% of children attend a charter school, and 2.4% of children attend cyber school. An additional 10.6% of children are currently homeschooled.

Parents report that their children frequently miss school, with 48.5% missing greater than 1 month of school due to symptoms or doctor appointments. 41.3% of children have been withdrawn from their school at some point to attend an alternative placement; these include homeschooling (29.3%), charter or private school (4.3%), or to cyber school (7.2%).

98.6% of parents report that their children experience difficulties at school. These difficulties include attention problems (75%), hyperactivity/impulsivity (52.4%), handwriting difficulties (62%), social difficulties (63.9%), organizational problems (58.7%), aggression (29.3%), anxiety (87.5%), withdraw/depression (41.3%), sensory sensitivities (61.5%), memory problems (53.8%), poor work completion (53.4%), poor test performance (43.3%), defiance (38.5%), oral expression difficulties (35.6%), oral comprehension difficulties (38.5%), reading difficulties (36.1%), math difficulties (50.5%), spelling difficulties (30.3%), written expression difficulties (41.8). 10.1% include difficulties not otherwise described including elopement, slow processing speed, fatigue, incontinence, separation anxiety, and general school avoidance.

Research question 4 sought to identify with what frequency children with PANS receive special services in schools. Of the sample surveyed, 73.1% of children have been

referred for a psychoeducational evaluation at some point in their life, with most of these evaluations being requested by a parent (76.3%). Placement data is reported in the tables below (Table 4 and 5). 40.9% of children with service agreements had their plan in place prior to PANS diagnosis; 62.9% of these children had their plans modified after being diagnosed with PANS. For children who only received services after the diagnosis of PANS, the majority (60.3%) received a Section 504 Plan as opposed to an IEP. Within the total sample of children with IEPs, 8.2% are placed in a self-contained special education classroom and 12.5% have received homebound instruction at some point due to PANS symptoms. For children with no services in place, 61.8% presently attend a public school, 17.1% attend a private school, and 11.8% are homeschooled, 5.3% attend charter schools, 2.6% attend cyberschool, and 1.3% attend a school for children with disabilities.

Table 4. *School based services for total survey population*

Service Plan	Frequency	Percent
IEP	71	34.1
Section 504 plan	61	29.3
No services in place	76	36.5

Table 5. *Service agreements for children with PANS provided only after PANS diagnosis*

Service Plan	Frequency	Percent
IEP	31	39.7

For children with an IEP, qualification for services for the overall population are reported to fall under a variety of disability categories, many related to preexisting conditions. Research questions 5 sought to identify the eligibility categories under which children with PANS receive special education services. For children with an IEP put in place only after PANS diagnosis, results for disability category are reported in the table below (Table 6).

Table 6. *IDEA disability category under which children with PANS are eligible for special education*

IDEA Category	Frequency	Percent
Autism	3	8.1%
SLD	1	2.7%
Blind	0	0%
Visual Impairment	0	0%
Deaf	0	0%
Hearing Impairment	0	0%
Other Health Impairment	16	43.2%
Emotional Disturbance	5	13.5%

Multiple Disabilities	3	8.1%
Traumatic Brain Injury	1	2.7%
Speech language impairment	3	8.1%
Intellectual Disability	0	0%
Orthopedic Impairment	0	0%
Don't know/Unsure	5	13.5%

Research question 6 sought to identify the related services provided to children with PANS who have an IEP. IEP Supports provided for children with PANS who did not have a preexisting service agreement are described below (Table 7).

Table 7. *Related services received by children with PANS as part of their IEP*

Service	Frequency	Percent
Reading support	9	29.0
Math support	15	48.4
Writing support	12	38.7
Behavior support	17	54.8
Audiology	0	0

Counseling	13	41.9
Interpreting	0	0
Medical	0	0
Occupational therapy	7	22.5
Orientation mobility	0	0
Parent counseling/training	1	3.2
Physical therapy	2	6.4
Psychology	10	32.3
Recreation therapy	1	3.2
Rehabilitation	0	0
School health/nursing	3	9.7
Speech/language	5	16.1
Transportation	4	12.9
Assistive technology	8	25.8
Early identification	2	6.5

Relationships between disease factors and educational placement

Research question 7 sought to identify if there exists a relationship between educational placement and OCD symptoms severity. Chi square analysis results indicate that there was no significant relationship between overall OCD symptom severity classification and educational placement, $\chi^2(8)=10.232, p=.249$. Even when eliminating members of the sample populations with a preexisting service agreement, Chi-square results show that there is no relationship between obsessive compulsive symptoms severity and educational placement, $\chi^2(8)=10.883, p=.208$.

Research question 8 sought to further evaluate if there is any predictive value of obsessive symptoms and compulsive symptoms on school-based service provision. To do so, a logistics regression was attempted, however, the variance inflation factor (VIF=2.196) indicates moderate colinearity of the data; this is likely related to the nature of the measure used. When looking at the predictive value of obsessive-compulsive symptoms on the presence of any school based service agreement, logistics regression results indicated that the overall model fit of two predictors (impairments due to obsessions and impairments due to compulsions) was questionable (-2 Log Likelihood=265.003), but was statistically reliable in distinguishing between children who received a service agreement and those who did not [$\chi^2(2)=8.082, p=.018$]. The model correctly classified 68.3% of cases. Regression coefficients are presented in table 8. *Wald* statistics indicated that only impairments associated with compulsions contribute meaningfully to the model. However, odds ratio for this is fairly small indicating little change in the likelihood of receiving a formal service agreement based on severity of compulsive behaviors. Obsessive compulsive behaviors account for a very small proportion of the estimated variance in school-based service provision (Nagelkerke $R^2=.052$). Because of

the multicollinearity of the predictor variables in this equation, it is likely that this estimated variance is inflated and should be interpreted with caution.

Table 8. *Regression coefficients*

	B	S.E.	Wald	Df	Sig.	Exp(B)
Obsessions	-.054	.056	.932	1	.334	.947
Compulsions	.117	.047	6.168	1	.013	1.125
Constant	.006	.410	.000	1	.989	1.006

Post-Hoc Analysis

When evaluating the relationship between comorbid diagnoses and the presence of a service agreement, Chi-square analysis results indicate a significant relationship between the presence of comorbid diagnoses and the provision of some type of school based services, $X^2(1)=7.804, p=.005$. Based on the odds ratio, the odds of having a formal service agreement (either and IEP or a section 504 plan) were 2.54 times higher with the presence of at least one comorbid diagnosis. For children with a plan only put in place after PANS diagnosis, this finding continues to hold true, $X^2(1)=7.572, p=.006$. Based on the odds ratio, the odds of having an IEP (as opposed to a 504) was 11.47 times higher for children with at least one comorbidity for those who did not have a preexisting service agreement.

Chapter V: DISCUSSION

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is a poorly understood condition estimated to affect 1 in 200 children (PANDAS Network, 2016). Most often, children with PANS present with symptoms of obsessive-compulsive disorder (OCD). Though OCD is the most common primary symptom of PANS, children can also present with complex tics, avoidant-restrictive food intake disorder (ARFID) and a multitude of other psychiatric symptoms (Murphy et al., 2015; Swedo et al., 2015). These symptoms cause pervasive social, emotional, and academic impairments. Children suffering from PANS require medical and psychiatric intervention for symptom relief.

A multidisciplinary treatment approach, including educational supports, is recommended per PANS treatment guidelines (Thienemann et al., 2017). Experts in the field hold that most children with PANS demonstrate a need for some sort of educational accommodation (Thienemann et al., 2017). Anecdotal evidence suggests that many students with PANS often receive accommodations or special education services prior to receiving a formal PANS diagnosis. This is typically due to the presence of other psychiatric or medical diagnoses (Candelaria Green, 2015).

Many children with PANS suffer symptoms that diminish their ability to meaningfully benefit from their education; academic decline is explicitly listed as a known secondary symptom of the disorder per diagnostic criteria (Swedo et al., 2012). Previous research cites impairments in handwriting, mathematics, attention/concentration, and executive functioning skills, specifically (Candelaria Green, 2015). Emotional symptoms additionally impact educational performance, including obsessive-compulsive symptoms, generalized anxiety, depression, and separation anxiety.

Symptoms of PANS vary significantly among individuals, however, OCD is cited as the single most common manifestation of PANS. OCD symptoms are known to have a tremendous impact on educational performance, with children with OCD displaying worse outcomes on measures of school competence than other children their age (Sukhodolsky, di Rosario-Campus, Skahill, Katsovich, & Pauls, 2005). For this reason, OCD symptoms associated with PANS were the primary focus of this research in terms of their relationship to school-based services. At this time limited research on the school-based supports provided to children with PANS exists. This study sought to identify the pathways through which children with PANS receive school-based services, and to make recommendations for future best practice.

Discussion of Findings

The results of this study were somewhat unexpected, yet helpful in understanding this complex disorder and how it presents itself in schools. Pertaining to the first research question, as indicated in previous research, the majority of the sample (90.4%) presented with primary obsessive-compulsive (OC) symptoms. Many children also present with tics (54.8%) or symptoms of ARFID (39.4%). This study documents that while OCD is the primary symptom manifestation of PANS, most children with PANS have multiple primary symptoms. The number of children within this study that experience symptoms of ARFID is nearly double that reported by previous research (Pandas Physician Network, 2016). One might speculate that tics and ARFID develop secondary to OCD, almost as if they are a manifestation of OCD itself. Within this study only 15 of the 114 children with tics experience tics without OCD, and only 3 of the 82 children experiencing ARFID experience ARFID without OCD. Research has previously

suggested that ARFID symptoms are related to OCD symptoms, such as fears of eating contaminated food or swallowing one's own saliva; this claim is supported within this research study, but would need to be further investigated with a larger sample to confirm the relationship. The cooccurrence of OCD, tics, and ARFID in PANS might be understood in the context of basal ganglia dysfunction, which is implicated in both OCD and tic disorders (Pearlman, Vora, Marquis, Najjar, & Dudley, 2014).

Regarding the second research question, children with PANS present with varying levels of OC symptoms per parent report, ranging from subclinical symptoms (5.3%) to extreme symptoms (6.3%), with the majority of children experiencing moderate symptoms (38.0%). Children in the sample presented with varying types of obsessions. Most frequently, parent report of child obsessions fell in the "miscellaneous" category, such as a need to know or remember, intrusive sounds/words/music, or a fear of saying certain things (61.1%). Contamination fears (46.2%) and harm related fears (47.1%) were the next most frequent obsessive themes. With respect to research question three, children in the sample also presented with varying types of compulsive behaviors. The "miscellaneous" category dominated with 53.8% of children presenting with compulsive behaviors like mental rituals, need to tell/confess, and "just right" compulsions. Rituals involving others (49%), repeating rituals (31.7%), hoarding (30.8%), and checking behaviors (30.3%) were the next most common compulsions. As hypothesized, these findings are similar to what may be expected of OCD in childhood. Main differences in the findings of this research and previous childhood OCD research regard the involvement of others in rituals, and contamination related rituals. It is possible that this difference is related to the ways in which parents categorized their child's behaviors

when answering questions on parent rating scales, like the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). Overall, children with PANS present with similar obsessions and compulsions as children with typical OCD.

A main contribution of this study to the literature pertains to knowledge of school-based impairments and service implementation for children with PANS. As anticipated, a large number of children within the sample (72.6%) experience deterioration of academic performance as a secondary symptom of PANS per diagnostic criteria. A striking 98.6% of children with PANS within the sample currently experience difficulties at school. Over 50% of the sample population experience attention problems, hyperactivity/impulsivity, organizational problems, memory problems, anxiety, sensory sensitivities, social difficulties, handwriting difficulties, math difficulties, poor work completion, and poor test performance.

With respect to the fourth research question, despite the educational problems experienced by nearly every child within this study, only 34.1% of children with PANS have an individual education program (IEP) and 29.3% of the sample had a Section 504 Plan. Therefore, 46.5% of the children with PANS did not have a formal school services plan. Of children only receiving services after PANS diagnosis, the majority (60.3%) received a section 504 plan. This finding is consistent with the research hypotheses; it was assumed that most children would receive a 504 plan due to the waxing and waning nature of the disorder, the difficulty assessing for impairments during remission, and the likelihood that in some cases accommodations alone are sufficient support. The relatively large percentage of children receiving no services raises concern about the long-term educational impact PANS has on children. More parents explicitly cited deterioration of

academic performance than report their child having received an IEP or 504 plan combined. Nearly all children within the sample had some type of difficulty at school, with most suffering multiple difficulties. The number of children served compared to the number experiencing academic difficulty associated with PANS raises questions as to why children with PANS frequently do not receive formal services.

Within the sample of this study, 152 of the 208 children had been referred for a psychoeducational evaluation at some point in their lives. Of these children, 138 received an evaluation, with 10 parents reporting that their child's school refused to complete an evaluation. Once evaluated, only 6 children were found to be completely ineligible for services, suggesting that if a child with PANS does receive an evaluation, he or she is likely to receive some type of service agreement. The large service gap is hypothesized to be related to children never being referred for a psychoeducational evaluation. These would include ChildFind issues such as parents being unaware of their rights to request an evaluation or failure of schools to identify a child in need. Likewise, some children may have never been referred for evaluation due to low levels of visible academic impairment.

Interestingly, 40.9% of children with PANS had a service agreement in place prior to receiving a PANS diagnosis. Only 62.9% of those children had their plans modified after their diagnosis. This finding is in line with previous research which suggests that many children receive services prior to the diagnosis of PANS (Candelaria Green, 2015) and, therefore, a multitude of disability categories including autism, specific learning disability, visual impairment, other health impairment (OHI), emotional disturbance, multiple disabilities, traumatic brain injury, and speech language impairments are

accessed. For children that received an IEP only after PANS diagnosis, the most frequent disability category under which children were eligible for services was other health impairment (OHI; 43.2%). This was hypothesized under research question 5 and primary symptoms of PANS logically align with the definition of OHI under Individuals with Disabilities Act (IDEA, 2004). One could additionally make an argument for qualification under emotional disturbance or multiple disabilities, depending on comorbid diagnoses for the particular child. Some children receive services under autism, speech language impairment (SLI) and traumatic brain injury (TBI). These disability categories are seemingly less fitting for children with PANS without other comorbid problems. For example, when looking at the individual data for the child qualified under TBI, there was no note of the child having experienced a traumatic brain injury anywhere in the data. For children categorized as SLI, though Children with PANS are known to exhibit changes in their speech and language skills, categorizing children under SLI for services does not appear to address the breadth of impairments associated with the disorder in the school setting nor does it fit with the core etiology of the disorder (Candelaria Greene, 2015).

Exploration of research question six revealed that children with PANS who had an IEP received a variety of related services. Most common related services include positive behavior support plans, math support, writing support, reading support, assistive technology, speech/language services, and counseling. It was anticipated that children with PANS would receive school health services and psychological services more frequently due to the nature of PANS. However, within this sample, a number of other services were reported. This likely reflects the high degree of comorbidity of PANS and other disabilities.

With respect to children with an IEP in place only after the diagnosis of PANS, the services received generally do appear to be related to symptoms of PANS. Most common services include math support, positive behavior support, school counseling services, and writing support. Though these were not the supports hypothesized to occur with greatest frequency, they do seem appropriate based on presenting concerns. Children with PANS are known to suffer deterioration of academic performance and are reported to have specific difficulty in writing and mathematics. Positive behavior support and school counseling services likely relate to the severity of emotional and behavioral symptoms associated with the disorder. It appears that when students did qualify for services, they received a variety of supports. Of note, however, 37.1% of students with a service plan did not have their plans modified after PANS diagnosis. It is possible that children with service plans had supports in all areas of need as required by the law prior to diagnosis. Also possible is that schools did not recognize additional areas of need associated with PANS diagnoses. Unfortunately, the data gathered within this study does not permit further exploration of this observation.

Because children with PANS most frequently present with OCD, these symptoms were selected to be explored as a potential variable associated with the provision of educational services. Within research question seven, it was hypothesized that children with more severe OCD symptoms would be more likely to receive a service agreement, with more severe symptoms being associated with higher-level services (i.e., IEP with related services, as opposed to a Section 504 Plan). Despite the large percentage of children within the sample suffering obsessive compulsive symptoms and the modal severity falling within the “moderate” category on the CY-BOCS, analyses revealed no

significant relationship between symptom severity classification and type of educational service provided. This was surprising as one might expect more severe symptoms to require intervention of increased intensity.

This finding held true even for children who only received a service agreement after formal PANS diagnosis. However, when looking at the individual contributions of obsessive symptoms and compulsive symptoms, logistics regression indicated that these symptoms do contribute somewhat to having some type of service agreement (either IEP or 504). Impairments associated with compulsions were found to contribute to service provision, while the presence of obsessions did not. Obsessions by definition regard an internal state of distress and are not easily observed. On the other hand, compulsive behaviors are observable by others and are perhaps disruptive to not only the child, but the child's teachers and classmates. Still, the contribution of these symptoms in the prediction of service provision is miniscule.

Because OCD symptoms severity was not found to contribute to the type of service provided, other possible explanations were explored. Observed within the raw data was that children with PANS had a number of significant comorbidities, including psychiatric disorders, autoimmune disorders, and other various health conditions. Because of this observation and the observation that many children with service agreements received their service agreements prior to formal PANS diagnosis, it was possible that comorbid diagnoses are likely a contributing factor to the provision of school-based services. Chi-square analyses were significant and proved this to be true within the sample. Children with just 1 comorbid condition were 2.54 times more likely to receive a service agreement than children with no comorbid diagnosis. Even when looking at children with

no preexisting service agreement this finding held true. Although the majority of children who received a service agreement after PANS diagnosis received a Section 504 plan, the odds of receiving an IEP was 11.47 times greater if the child had at least one comorbid diagnosis.

Findings such as the above bring into question what information was considered when children with PANS were evaluated for services. Children with comorbidities have a greater number of problems and the accumulation of the problems likely result in more severe educational impairment. If this assumption is true, schools would recognize the intensity of educational needs and likely find curricular modifications and related services – as provided in an IEP – was necessary. However, it could also be speculated that children with PANS only qualified for an IEP if schools can see a clear and easily understood explanation for academic impairments, such as a comorbid diagnosis of a more common disorder. There were many factors that seemed to contribute to the lack of school-based services for children with PANS in this sample. Regardless, there existed a large service gap for children with a debilitating disorder that need be remedied.

Implications of this Study

When looking at the results of research questions 1, 2 and 3 it remains evident that OCD is the primary symptom cluster of the disorder that appears to be related to impairment in functioning. However, there is a great deal of variability in the secondary symptom presentation making each child unique in their symptom presentation and associated impairments. With such heterogeneity, it proves difficulty to categorize children behaviorally, psychologically, and academically. This heterogeneity may lead to confusion or misunderstanding of the needs of individual children with PANS in schools.

When taken in combination with the findings of research question 4 that illuminate a large gap in educational service provision, the importance of identifying children with disabilities based on unexpected academic, behavioral, or emotional impairments rather than based on the presence of some type of diagnosis is underscored.

Special education law requires that children with academic, behavioral, or emotional differences be identified by their school as a child needing a psychoeducational evaluation to determine the presence of a disability (IDEA, 2004). School personnel are to assess in all areas of suspected disability. Because of the nature of PANS, psychoeducational evaluations need be robust and may need to occur over multiple sessions. Reliance on cognitive and academic achievement measures alone is not adequate to identify impairments associated with PANS in the school setting. Rather, assessments should include multiple pieces of data collected over time including work samples, behavioral observations, parent rating scale data, and input from the child's physician, psychologist, or psychiatrist indicating their specific areas of disability. Results of research question 5 demonstrate that once a child receives an evaluation, they are likely to receive some type of service agreement, either an IEP or a Section 504 plan. Lack of referral for an evaluation was found to be the main reason behind children having no services in place. This points to the importance of children being appropriately identified and evaluated by school personnel.

Any child with a disability, including those with chronic health conditions, are protected from discrimination in the provision of curriculars and extracurriculars under Section 504 of the Rehabilitation Act (1973), regardless of the outcome of the psychoeducational evaluation. If a child is found to be eligible for services, the services

need be individually tailored for the child's unique needs as indicated by the data gathered as part of the psychoeducational evaluation. When completing a Section 504 plan, it is of utmost importance to remember that symptoms tend to ebb and flow. Service agreements should be written with the child's worst days in mind (Thienemann et al., 2017). When completing an IEP, it is imperative that the child receive services in all areas of need. As indicated by the results of research question 6, children with PANS have a variety of areas of need and require multiple types of services to ensure they receive FAPE. Still, children with PANS within the sample appeared to receive related services that would address the breadth of symptoms associated with PANS. Results of research questions 7 and 8 indicate that though OCD symptoms are impairing, they are not the impairments that drive service agreements. However, when reviewing the services received by children with PANS, it still appears as though these needs are addressed in many children through behavioral support, psychological services, or counseling. Though occurring in many of cases, this support does not occur in all cases. An argument can certainly be made for all children with PANS needing some type of emotional or behavioral support at school- it is the goal of this research that these needs be better addressed for children moving forward.

Future research should focus on knowledge and experience of school psychologists and other school-based providers with PANS. Because children appear to be receiving services due to other diagnoses rather than due to PANS alone, there is a question of school-based provider knowledge and understanding of children with this disorder. Anecdotal evidence has suggested that schools are largely unaware of PANS and its associated impairments. If this is true, it would be difficult for schools to

individually tailor assessments and interventions to meet the needs of children with PANS. As such, more research is needed in this area. School psychologists, counselors, and teachers would benefit from continuing education on PANS and how it may present in schools. Numerous texts exist with focus on recommendations for educational services for children with PANS. Resources are readily available for school-based personnel to consume. It is recommended that school-based providers become aware of the disorder and its presentation to better service children suffering from a poorly understood disorder.

Study Limitations and Future Directions of Investigation

Several notable limitations to this study are present. First, the nature of survey research allows room for response error and response bias. Because the respondents in this study are parents and not medical or psychological practitioners, information pertaining to symptoms presentation, clinical significance of symptoms, and educational services could be inaccurate. Likewise, it is possible that parents who were motivated to take this survey feel strongly that their children suffer significant impairments due to their symptoms and their responses to questions could be somewhat inflated; similarly, this fact could have created a degree of selection bias. Second, because the “participants” in this study are reporting on behalf of their children, there is an additional inherent degree of error particularly with regard to obsessive compulsive symptoms. Obsessive symptoms are particularly difficult for parents to describe on behalf of their children due to the internal process of obsessions. They are not readily observable by third parties, and thus reporting on this information requires parents to have open dialogue with their children regarding their internal experience. Third, though parents are generally

knowledgeable about their child's educational services, there are a number of responses that indicate some confusion in educational services, disease characteristics, and behavioral symptoms. With a population like this, it is difficult if not impossible to determine if the sample is truly representative, particularly with the survey distribution method and snowball sampling which makes it impossible to determine a response rate. Additionally, the children within this study have been educated within their respective school systems, and school decision making is not generalizable to all schools across the United States. As such, results should be interpreted to reflect individuals' perceptions of their child's educational experiences and areas of need.

Summary

The results of this study identify a variety of significant academic, emotional, and behavioral difficulties experienced by children with PANS. Despite the evidenced impairments, a large percentage of children with PANS go without school-based services. Those who do receive services seem to receive them based on the presence of other medical or psychiatric diagnoses, rather than the primary symptoms of PANS. It is possible that a general lack of knowledge and understanding of PANS contributes to the gap in services provided to children with PANS. Like all children, children with PANS are guaranteed access to a free and appropriate public education. Through the application of the Individuals with Disabilities Education Act (2004) and Section 504 of the Rehabilitation Act (1973), children with disabilities are provided with an equal opportunity to benefit from their education through the provision of accommodations and modifications to their educational programming. Schools provide services for children across a range of disabilities, including those with developmental, medical, and

psychiatric impairments. The identification of and service provision for children with psychiatric disturbances in schools requires school personnel to become aware of the educational implications of various disabilities, including those only recently emerging in the literature. Lack of understanding and knowledge of these disabilities can lead to a denial of educational rights and a loss of educational opportunities for children affected by illness. It is thereby recommended that school-based personnel increase their awareness and understanding of PANS and other emerging disorders in order to best serve children within their community.

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Appendix A

INCLUSION CRITERIA

1. Are you the primary care giver of a child currently in grade k-12 diagnosed with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and/or Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)?
 - a. **Yes**
 - b. No
2. Does your child attend school in the United States?
 - a. **Yes**
 - b. no

Survey Questions

1. What is your child's gender?
 - a. Male
 - b. Female
 - c. Gender Variant
 - d. Not listed
 - e. Prefer not to specify
2. What is your child's current age in years?
 - a. (select age from dropdown menu, range 5-21)
3. In what grade is your child currently enrolled at school?
 - a. (select grade from dropdown menu, grade k-12)
4. Was your child ever retained (held back) in school?
 - a. Yes
 - b. No
5. What type of school does your child presently attend?
 - a. Public
 - b. Private/parochial (not a private school specifically for children with disabilities)
 - c. Private school specifically for children with disabilities
 - d. Charter
 - e. Cyber
 - f. Homeschooled
 - g. Other _____
6. What was your child's age in years when they first exhibited PANS/PANDAS symptoms?
 - a. (Select from dropdown menu, range <3 years-21)
7. How old was your child (in years) when they were diagnosed with PANS/PANDAS? _____ ?
8. What grade was your child enrolled in when they first exhibited PANS/PANDAS symptoms?
 - a. (select from dropdown menu, range preK-12)

9. My child has been diagnosed with (select all that apply):
- PANS
 - PITANDS
 - PANDAS
10. (Qualtrics logic, If PANS) What is the suspected infectious trigger?
- Lyme
 - Mycoplasma pneumonia,
 - Influenza
 - other (write in)
11. My child's PANS/PANDAS primary symptoms include (check all that apply):
- Obsessive compulsive disorder
 - Vocal, motor, or complex tics
 - Avoidant/restrictive food intake disorder
12. My Child's other symptoms of PANS/PANDAS include (check all that apply)
- Anxiety
 - emotional lability or depression
 - irritability, aggression, or severely oppositional behaviors
 - deterioration of school performance
 - sensory or motor difficulties
 - somatic symptoms (includes sleep disturbances, wetting/bed wedding, urinary frequency)
13. My child's medical treatment (NOT school treatment) for PANS/PANDAS includes (check all that apply)
- psychotherapy/counseling
 - antibiotics
 - Intravenous Immunoglobulin (IVIG)
 - Plasmapheresis
 - therapeutic plasma exchange
 - steroids
 - psychiatric medication (such as Prozac, Celexa, Lexapro, Adderall, Concerta, Vyvanse, Strattera, Ativan, Risperidone, Haloperidol etc.)
 - other (write in): _____
 - no treatment
14. My child has also diagnosed with.... (check all that apply)
- Attention deficit hyperactivity disorder
 - Autism spectrum disorder
 - Major depressive disorder
 - Generalized anxiety disorder
 - Separation anxiety disorder
 - Oppositional defiant disorder
 - Specific learning disorder
 - Other developmental or psychiatric disorder (list) _____

15. If your child been diagnosed with any other chronic illness (such as diabetes, epilepsy, asthma, etc.), please list _____

16. CYBOCS Obsessions Checklist

The following are common “obsessions” experienced by children with OCD. OBSESSIONS are thoughts, ideas, or pictures that keep coming your child’s mind even though you do not want them to. They may be unpleasant, silly or embarrassing. AN EXAMPLE OF AN OBSESSION IS: the repeated thought that germs or dirt are harming you or other people, or that something unpleasant might happen to you or someone in your family or someone special to you. These are thoughts that keep coming back, over and over again.

Please indicate obsessions your child has experienced, either now or in the past. Check all items that apply.

Contamination Obsessions

- Concern with dirt, germs, certain illnesses (e.g., AIDS)
- Concerns or disgust with bodily waste or secretions (e.g., urine, feces, saliva)
- Excessive concern with environmental contaminants (e.g., asbestos, radiation, toxic waste)
- Excessive concern with household items (e.g., cleaners, solvents)
- Excessive concern about animals/insects
- Excessively bothered by sticky substances or residues
- Concerned will get ill because of contaminant
- Concerned will get others ill by spreading contaminant (aggressive)
- No concern with consequences of contamination other than how it might feel
- Other (Describe) _____

Aggressive Obsessions

- Fear might harm self
- Fear might harm others
- Fear harm will come to self
- Fear harm will come to others (may be because something child did or did not do)
- Violent or horrific images
- Fear of blurting out obscenities or insults
- Fear of doing something else embarrassing
- Fear will act on unwanted impulses (e.g. to stab a family member)
- Fear will steal things
- Fear will be responsible for something else terrible happening (e.g. fire, burglary, flood)
- Other (Describe) _____

Sexual Obsessions [routine or repetitive sexual thoughts that your child would rather not have or finds disturbing]

- Forbidden or perverse sexual thoughts, images, impulses
- Content involves homosexuality
- Sexual behavior towards others (Aggressive)
- Other (Describe) _____

Hoarding/Saving Obsessions

- ___ Fear of losing things
 ___ Other (Describe) _____
- Magical Thoughts/Superstitious Obsessions*
 ___ Lucky/unlucky numbers, colors, words
 ___ Other (Describe) _____
- Somatic Obsessions*
 ___ Excessive concern with illness or disease
 ___ Excessive concern with body part or aspect of appearance (e.g., dysmorphophobia)
 ___ Other (Describe) _____
- Religious Obsessions (Scrupulosity)*
 ___ Excessive concern or fear of offending religious objects (God)
 ___ Excessive concern with right/wrong, morality
 ___ Other (Describe) _____
- Miscellaneous Obsessions*
 ___ The need to know or remember
 ___ Fear of saying certain things
 ___ Fear of not saying just the right thing
 ___ Intrusive (non-violent) images
 ___ Intrusive sounds, words, music, or numbers
 ___ Other (Describe) _____
17. How much time does your child spend thinking about these things? If obsessions occur as brief, intermittent intrusions, time by determining how frequently they occur. Consider both the number of times the intrusions occur and how many hours of the day are affected). • How frequently do these thoughts occur?
- NONE
 - less than 1 hr/day or occasional intrusion
 - 1 to 3 hrs/day or frequent intrusion
 - greater than 3 and up to 8 hrs/day or very frequent intrusion
 - greater than 8 hrs/day or near constant intrusion
18. How much do these thoughts get in the way of school or doing things with friends? • Is there anything that your child doesn't do because of them? (If currently not in school determine how much performance would be affected if patient were in school.)
- No interference
 - slight interference with social or school activities, overall performance not impaired
 - definite interference with social or school performance, but still manageable
 - causes substantial impairment in social or school performance
 - incapacitating
19. How much do these thoughts bother or upset your child? (Only rate anxiety/frustration that seems triggered by obsessions, not generalized anxiety or anxiety associated with other symptoms.)
- Not bothered at all
 - infrequent, and not too disturbing

- c. frequent, and disturbing, but still manageable
 - d. very frequent, and very disturbing
 - e. near constant, and disabling distress/frustration
20. How hard does your child try to stop the thoughts or ignore them? (Only rate effort made to resist, not success or failure in actually controlling the obsessions.
- a. makes an effort to always resist, or symptoms so minimal doesn't need to actively resist.
 - b. tries to resist most of the time
 - c. makes some effort to resist
 - d. yields to all obsessions without attempting to control them, but does so with some reluctance
 - e. completely and willingly yields to all obsessions
21. When your child tries to fight the thoughts, can he/she beat them? How much control does he/she have over the thoughts?
- a. Complete control
 - b. usually able to stop or divert obsessions with some effort and concentration.
 - c. sometimes able to stop or divert obsessions
 - d. rarely successful in stopping obsessions, can only divert attention with difficulty experienced as completely involuntary, rarely able to even momentarily divert thinking

22. Compulsion checklist

The following are common compulsions experienced by children with OCD. COMPULSIONS are things that your child feels he/she has to do although they may know that they do not make sense. Sometimes your child may try to stop from doing them but this might not be possible. They might feel worried or angry or frustrated until they have finished what you have to do. AN EXAMPLE OF A COMPULSION IS: the need to wash your hands over and over again even though they are not really dirty, or the need to count up to a certain number while you do certain things."

Please indicate compulsions your child has experienced, either now or in the past. Check all items that apply.

Washing/Cleaning Compulsions

- Excessive or ritualized handwashing
- Excessive or ritualized showering, bathing, toothbrushing, grooming, or toilet routine
- Excessive cleaning of items; such as personal clothes or important objects

- Other measures to prevent or remove contact with contaminants
- Other (Describe)

Checking Compulsions

- Checking locks, toys, school books/items, etc.
- Checking associated with getting washed, dressed, or undressed.
- Checking that did not/will not harm others
- Checking that did not/will not harm self
- Checking that nothing terrible did/will happen

- Checking that did not make mistake
- Checking tied to somatic obsessions
- Other (Describe)

Repeating Rituals

- Rereading, erasing, or rewriting
- Need to repeat routine activities (e.g. in/out doors, up/down from chair)
- Other (Describe)

Counting Compulsions

- Objects, certain numbers, words, etc. Describe: _____

Ordering/Arranging

- Need for symmetry/evening up (e.g., lining items up a certain way or arranging personal items in specific patterns)
- Other (Describe)

Hoarding/Saving Compulsion [distinguish from hobbies and concern with objects of monetary or sentimental value]

- Difficulty throwing things away, saving bits of paper, string, etc.
- Other (Describe) _____

Excessive Games/Superstitious Behaviors

- behaviors like stepping over certain spots on a floor, touching an object/self certain number of times as a routine game to avoid something bad from happening
- other (Describe) _____

Rituals Involving Other Persons

- The need to involve another person (usually a parent) in ritual (e.g., asking a parent to repeatedly answer the same question, making mother perform certain meal time-rituals involving specific utensils).
- Other (Describe)

Miscellaneous Compulsions

- Mental rituals (other than checking/counting)
 - Need to tell, ask, or confess
 - Measures to prevent any of the following...
 - harm to self
 - harm to others
 - terrible consequences
 - Ritualized eating behaviors
 - Excessive list making
 - Need to touch, tap, rub
 - Need to do things until it feels just right (e.g., touch or arrange)
 - Rituals involving blinking or staring
 - Trichotillomania (hair-pulling)
 - Other self-damaging or self-mutilating behaviors
 - Other (Describe)
23. How much time does your child spend doing these things? • How much longer than most people does it take to complete your usual daily activities because of

- the habits? (When compulsions occur as brief, intermittent behaviors, it may be impossible to assess time spent performing them in terms of total hours. In such cases, estimate time by determining how frequently they are performed. Consider both the number of times compulsions are performed and how many hours of the day are affected.)
- a. No compulsions
 - b. spends less than 1 hr/day performing compulsions), or occasional performance of compulsive behaviors
 - c. spends from 1 to 3 hrs/day performing compulsions), or frequent performance of compulsive behaviors
 - d. spends more than 3 and up to 8 hrs/day performing compulsions), or very frequent performance of compulsive behaviors
 - e. spends more than 8 hrs/day performing compulsions), or near constant performance of compulsive behaviors (too numerous to count).
24. How much do these habits get in the way of school or doing things with friends? • Is there anything your child doesn't do because of them? (If currently not in school, determine how much performance would be affected if patient were in school.)
- a. No interference
 - b. slight interference with social or school activities, but overall performance not impaired
 - c. definite interference with social or school performance, but still manageable
 - d. causes substantial impairment in social or school performance
 - e. incapacitating
25. How would your child feel if prevented from carrying out their habits? • How upset would they become? (Rate degree of distress/frustration child would experience if performance of the compulsion were suddenly interrupted without reassurance offered). How upset does your child get while carrying out compulsions until they are satisfied?
- a. Not upset
 - b. only slightly anxious/frustrated if compulsions prevented, or only slight anxiety/frustration during performance of compulsions.
 - c. reports that anxiety/frustration would mount but remain manageable if compulsions prevented. Anxiety/frustration increases but remains manageable during performance of compulsions.
 - d. prominent and very disturbing increase in anxiety/frustration if compulsions interrupted. Prominent and very disturbing increase in anxiety /frustration during performance of compulsions.
 - e. incapacitating anxiety/frustration from any intervention aimed at modifying activity. Incapacitating anxiety/frustration develops during performance of compulsions.

26. How much does your child try to fight the habits? (Only rate effort made to resist, not success or failure in actually controlling the compulsions)
- Makes an effort to always resist, or symptoms so minimal doesn't need to actively resist.
 - Tries to resist most of the time.
 - Makes some effort to resist
 - Yields to almost all compulsions without attempting to control them, but does so with some reluctance.
 - completely and willingly yields to all compulsions
27. How strong is the feeling that your child has to carry out the habit(s)? When they try to fight them what happens? How much control does your child have over the habits?
- Complete control
 - experiences pressure to perform the behavior, but usually able to exercise voluntary control over it
 - moderate control, strong pressure to perform behavior, can control it only with difficulty
 - little control, very strong drive to perform behavior, must be carried to completion, can only delay with difficulty
 - no control, drive to perform behavior experienced as completely involuntary and overpowering, rarely able to delay activity (even momentarily)

Educational Information

28. What difficulties does your child experience at school? (check all that apply)
- paying attention
 - hyperactivity
 - impulsivity
 - hand writing
 - social difficulties
 - organization
 - aggression
 - anxious
 - withdrawn/depressed
 - sensory sensitivity
 - memory problems
 - poor work completion
 - poor test performance
 - defiant/uncooperative
 - Oral expression
 - listening comprehension
 - reading problems
 - basic reading
 - fluency

- iii. reading comprehension
 - r. math problems
 - i. calculation
 - ii. math reasoning
 - s. spelling
 - t. written expression
 - u. poor work completion
 - v. organization of materials
 - w. poor peer relationships
 - x. other (write in)
 - y. no problems.
- 29. Has your child ever been referred for a school-based evaluation to determine eligibility for a Section 504 Plan or formal special education services under the Individuals with Disabilities Education Act (IDEA)?
 - a. Yes
 - i. If yes, who requested/initiated the evaluation?
 - 1. Parent
 - 2. Teacher
 - 3. Child (if adolescent)
 - 4. school administrator
 - 5. medical personnel
 - ii. After your child was referred for evaluation, did a school-based evaluation take place?
 - 1. Yes
 - 2. No
 - a. Why, who refused the evaluation?
 - i. school did not agree
 - ii. parent did not provide permission
 - b. No
- 30. (Qualtrics logic: if yes to 29, and 29aII) What was the result of the evaluation?
 - a. My child is eligible for special education and received an IEP
 - b. My child is eligible for accommodations and received a Section 504 plan
 - c. The school found my child was not eligible for an IEP or a Section 504 (No plan put in place)
- 31. (Qualtrics logic: if a or b to 30) Did your child have an IEP or section 504 plan before being diagnosed with PANS/PANDAS (i.e., IEP or Section 504 Plan)?
 - a. Yes
 - b. no
- 32. (if a to 30) As your child was found eligible for special education services and an IEP was written, the IEP team identified which disability category/categories
 - a. Autism
 - b. Specific Learning Disability
 - c. Blind

- d. visually impaired
 - e. deaf
 - f. hearing impaired
 - g. Other health impairment
 - h. Emotional disturbance
 - i. multiple disabilities
 - j. Traumatic brain injury
 - k. Speech/Language impairment
 - l. Intellectual disability
 - m. orthopedic impairment
 - n. don't know/aren't sure).
33. (Qualtrics logic: if a or b to 30) Was your child's IEP or section 504 plan modified after PANS/PANDAS diagnosis to provide additional services related to their symptoms?
34. (Qualtrics logic: if a to 30) what services are provided for your child as part of their IEP?
- a. Reading
 - b. Writing
 - c. Math
 - d. positive behavior support plan
 - e. Related services including:
 - i. Audiology
 - ii. Counseling
 - iii. Early identification and assessment
 - iv. Interpreting services (deaf/blind)
 - v. Medical services
 - vi. Occupational therapy
 - vii. Orientation mobility services
 - viii. Parent counseling/training
 - ix. Physical therapy
 - x. Psychological services
 - xi. Recreation/therapeutic recreation
 - xii. Rehabilitation counseling/vocational rehabilitation
 - xiii. School health/school nursing services
 - xiv. Speech/language pathology services
 - xv. Transportation services
 - f. assistive technology
35. (Qualtrics: If a to 30) is your child placed in a self-contained special education classroom?
- a. Yes
 - b. no
36. Has your child ever received formal homebound instruction through his/her school due to PANS/PANDAS symptoms?

- a. Yes
 - b. no
37. Have you ever withdrawn your child from their school due to symptoms of PANS/PANDAS?
- a. Yes, to home school
 - b. Yes, to charter or private school
 - c. Yes, to cyber school
 - d. No