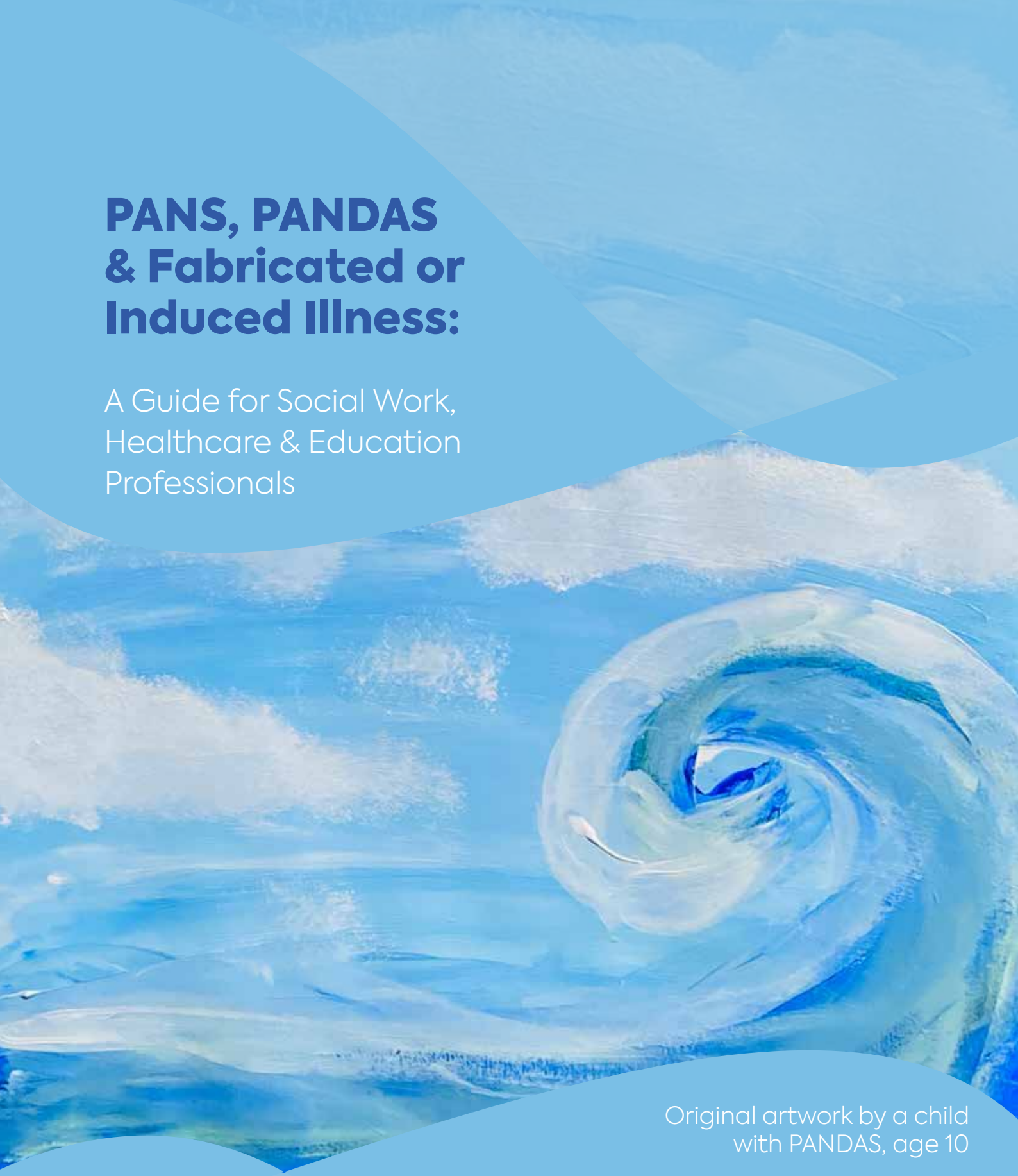
PANS, PANDAS & Fabricated or Induced Illness:

A Guide for Social Work, Healthcare & Education Professionals



Original artwork by a child with PANDAS, age 10

PANS PANDAS UK
awareness support education

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CONTENTS:

Executive summary

This guide is relevant to healthcare, social work and educational professionals who may come into contact with children and young people presenting with acute onset neuropsychiatric symptoms. It introduces the medical disorders termed PANS and PANDAS and explores the reasons why a disproportionate number of UK families living with these conditions are subject to safeguarding referrals and allegations of Fabricated or Induced Illness (FII).

There is little evidence-based research into FII, and none specifically regarding FII and PANS and PANDAS. This guide, in section one, presents an initial exploration of the context behind the circumstances that families managing these conditions find themselves within. Section two outlines how the clinical presentation of PANS and PANDAS gives cause for misplaced safeguarding and FII concerns to arise. Section three provides more information and detail for healthcare, social work and educational professionals.

For convenience, the structure of this guide is designed so that it may be read as a whole, or professionals may choose to refer to the introductory and final commentary in addition to the section relevant to their profession.

KEY POINTS:

- There is low awareness and understanding of PANS and PANDAS amongst healthcare, social work and education professionals in the UK.
- PANS and PANDAS symptoms and the resultant impacts of these conditions upon a child and their family's functioning can easily be misinterpreted as safeguarding and FII 'red flags'.
- A combination of PANS or PANDAS context- and condition-specific factors align to create a situation which is complex and challenging for professionals and families alike.
- A collaborative and open-minded approach to any professional assessment of children presenting with PANS or PANDAS and their families is crucial.

SECTION ONE
What are PANS and PANDAS?

PANS and PANDAS are post-infectious disorders in which severe symptoms of obsessive-compulsive behaviours, tics or eating restrictions develop suddenly [1-3]. In PANS the primary symptoms are accompanied by at least two additional secondary symptoms which may include changes in normal behaviours, personality and mood, decreased cognitive ability and functioning at school, enhanced sensory sensitivities, anxiety or sleep and urinary disturbances.

"PANS" stands for Paediatric Acute-onset Neuropsychiatric Syndrome. It can be triggered by a variety of infections, including viral infections such as glandular fever, herpes simplex, chicken pox, influenza or SARS-CoV-2, and bacterial infections such as Mycoplasma pneumoniae, Borrelia burgdorferi, Borna disease virus and Toxoplasmosis gondii [4-9].

"PANDAS" stands for Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. PANDAS is a subtype of PANS. It specifically refers to cases where an onset of neuropsychiatric symptoms is linked to a Group A Streptococcus (GAS or 'strep') infection, such as in scarlet fever, strep throat, tonsillitis or peri-anal strep [1, 10]. However, post onset, viral infections or other illnesses could also trigger symptom exacerbations [1, 11].

OVERVIEW OF PANS AND PANDAS CRITERIA FOR DIAGNOSIS

PANDAS Diagnostic criteria

1. Presence of OCD or a tic disorder
2. Symptoms first present between 3 years and puberty
3. Acute symptom onset or dramatic symptom exacerbation and relapse and remit
4. Link with Group A streptococcal infection
5. Neurological signs

PANS Diagnostic criteria. There is no age limit

1. Abrupt, dramatic onset of OCD or severely restricted food intake.

2. Additional neuropsychiatric symptoms also present (similar severe and acute onset), from at least 2 of the following:

- Anxiety
- Emotional lability and/or depression
- Somatic signs and symptoms, including sleep disturbances, enuresis, urinary frequency
- Irritability, aggression, and/or severely oppositional behaviours
- Behavioural (developmental) regression
- Sensory or motor abnormalities
- Decline in school performance (due to ADHD-like symptoms, memory deficits, cognitive change)

3. Symptoms are not better explained by a known neurologic or medical disorder

What does neuropsychiatric mean?
A neuropsychiatric condition is one that involves both neurology (encompassing disorders of the brain and spinal cord) and psychiatry (encompassing mental health disorders). Neuropsychiatric symptoms tend to impact brain function, emotion and mood.

The underlying cause of PANS and PANDAS is suspected to be an abnormal immune and/or inflammatory response to infection [12]. Genetic susceptibility, developmental and environmental factors are also thought to contribute to individual children developing these conditions [13].

Both the timing of onset and the specific profile of accompanying secondary symptoms vary between children [14, 15] but, in conjunction with the primary symptoms, can interfere with schooling, rapidly become extremely debilitating and reduce the quality of life for the child and family. Physical symptoms such as urinary difficulties, rashes, joint and stomach pain, headaches and fevers may also be present. Both PANS and PANDAS are considered rare but are increasingly being recognized as causes of sudden onset childhood neuropsychiatric symptoms [5, 12, 16].

Both PANS and PANDAS are described as being "relapsing and remitting" in nature – i.e., the pattern of symptoms and their severity increases and decreases over time in response to illness. Each period of relapse is colloquially referred to as a "flare". Early treatment is recommended [12]. If they remain untreated, individuals with PANS or PANDAS may develop chronic (long term) symptoms [17].

CONTEXT

Levels of awareness and understanding of PANS and PANDAS amongst healthcare, social work and education professionals in the UK are low. There are four broad reasons for this. These are relatively recently identified and described conditions. Historical professional disagreements have slowed efforts to progress scientific and medical awareness, understanding and research. Research that has taken place has often been limited by small sample sizes, restrictive eligibility criteria, and other methodological challenges, leading to an incomplete picture of these conditions. Finally, because PANS and PANDAS have symptom profiles which overlap with other disorders, misdiagnosis is possible [2, 12, 15, 18].

Children and young people with undiagnosed and/or untreated PANS or PANDAS may struggle to attend school, experience significant decline in their cognitive and physical functioning, and experience severe psychiatric symptoms. Many children with PANS or PANDAS develop special educational needs and disabilities (SEND), having previously not needed any SEND support. In the absence of suitable training about these conditions, health, education and social work professionals are unlikely to consider that the constellation of symptoms a child presents with could be indicators of PANS or PANDAS. These symptoms, and the resulting breakdown in normal functioning within the family, can instead be easily misinterpreted as safeguarding 'red flags'.

63% of children developed school attendance problems after the onset of PANS or PANDAS symptoms.

(Parent survey, PANS PANDAS UK, 2022)

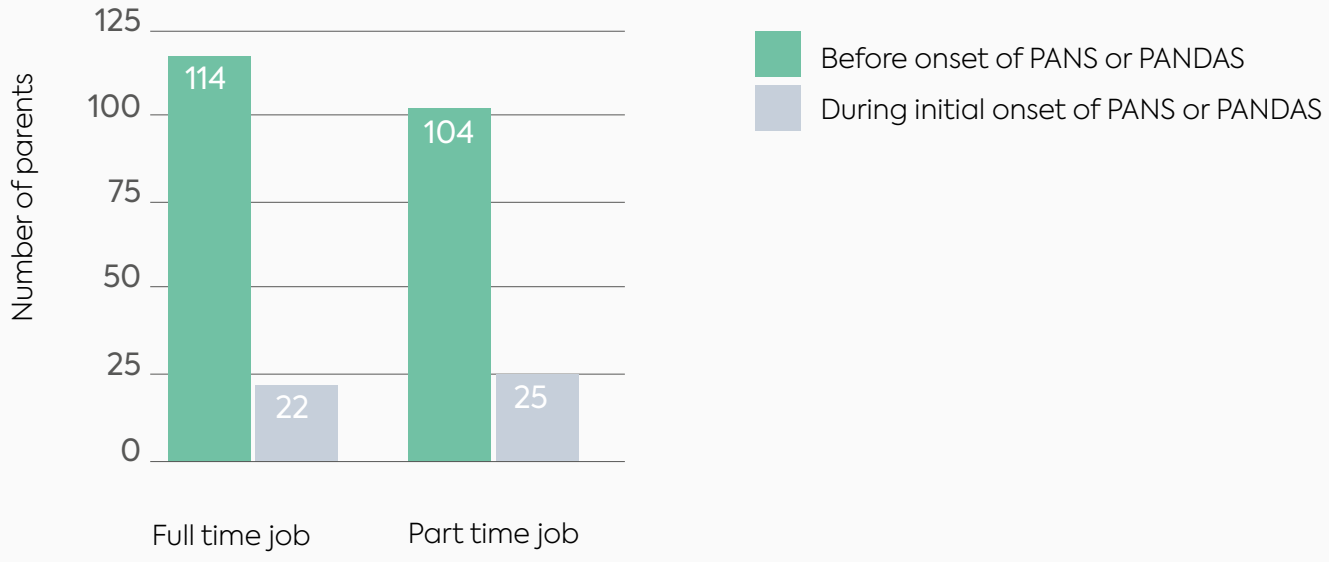
Parents and carers of children with PANS or PANDAS experience elevated levels of burden, stress, anxiety, and depression [14, 19, 20]. This is due to the severity of their child's PANS or PANDAS symptoms, the personality and behavioural changes which occur, the resulting impacts on family life, and the need to navigate a healthcare system which often does not have the resources needed to investigate a possible medical cause for the acute onset of neuropsychiatric symptoms.

With limited access to NHS care, many parents pursue private healthcare options and opinion. At the same time, many families are forced into a situation where a parent must leave paid employment to enable them to provide care for their child who may be unable to attend school [21]. Results of a 2022 survey by PANS PANDAS UK (unpublished) found that parents were significantly less able to retain full or part time jobs after their child developed PANS or PANDAS symptoms **(Figure 1).**

The lack of awareness, a reluctance amongst clinicians to consider an underlying medical cause for neuropsychiatric symptom onset and the devastating impacts PANS or PANDAS symptoms can have upon the child, their parents and siblings, all combine to create a uniquely challenging situation for both the families and professionals involved. These factors may align to create a 'perfect storm' for mistaken safeguarding referrals and allegations of Fabricated or Induced Illness (FII) towards the parents/carers of children and young people with PANS or PANDAS.

All professionals should be aware that any child presenting with acute onset neuropsychiatric symptoms should receive a full medical evaluation.

Figure 1. Parents' ability to remain in full or part time employment before and after their child's onset of PANS or PANDAS.



SECTION TWO

PANS, PANDAS and Fabricated or Induced Illness

A growing body of evidence reveals that many parents of children with disabilities are being accused of FII, which has initiated child protection proceedings. Some families with disabled children receive excellent support from Children's social care, particularly when the allocated assessor 'has both the expertise and practice experience of supporting the specific needs of disabled children and their families' [22, p. 8]. In contrast, some parents of disabled children, particularly those who have complained about the practitioners' assessment and subsequent failure to provide the right support, are being wrongfully accused of fabricating the extent of their child's difficulties [22].

FABRICATED OR INDUCED ILLNESS

FII is described by the Royal College of Paediatrics and Child Health (RCPCH) as a clinical situation 'in which a child is, or is very likely to be, harmed due to parent(s) behaviour and action, carried out in order to convince doctors that the child's state of physical and/or mental health and neurodevelopment is impaired (or more impaired than is actually the case)' [23, p. 11].

FII is not a diagnosis, but rather a term created by the RCPCH to address the situation arising when a child is reported by their parents/carers to have symptoms of ill health or disability which are not substantiated by medical evidence. RCPCH guidance does not give research-based evidence to substantiate the prevalence of FII [24]. A summary of the RCPCH alerting signs for FII include [23]:

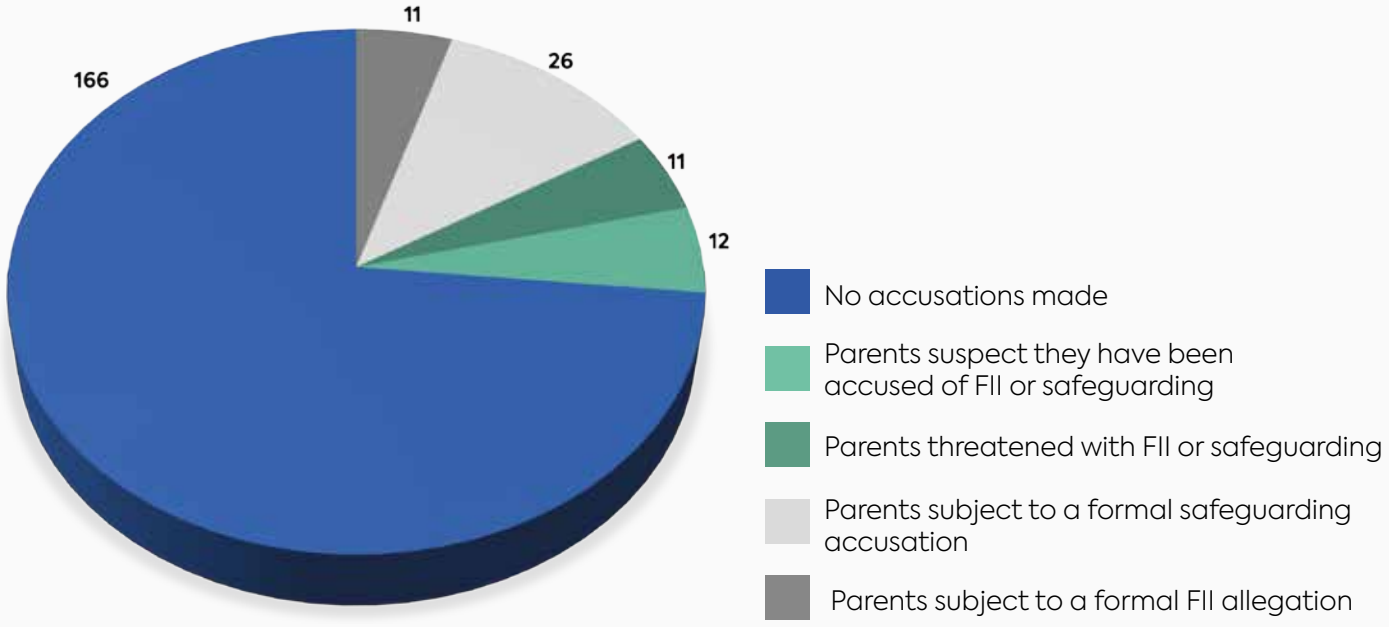
- Symptoms not observed independently in their reported context e.g., a child presents very different behaviours in school compared to at home
- Symptoms not explained by the child's known medical condition
- Repeated reporting of new symptoms
- Frequently presenting and seeking opinions from multiple doctors

Factitious Disorder Imposed on Another

Situations exist when parents exaggerate the extent of their child's difficulties, and in very rare cases, they will fabricate an illness. Such a situation is a known psychiatric disorder called Factitious Disorder Imposed on Another (FDIoA). This disorder used to be called Munchausen syndrome by proxy. Factitious Disorder Imposed on Another/ Munchausen Syndrome by proxy are extremely rare psychiatric diagnoses. For social workers, healthcare professionals and education safeguarding leads, it is crucial to understand the difference between FDIoA and FII. FII is not a clinical diagnosis and is not included in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, whereas FDIoA is. Notably, FDIoA cases are extremely rare and require a robust diagnosis by an appropriately qualified clinician [25].

The findings of a survey undertaken by the charity PANS PANDAS UK in 2022 found that approximately 1 in 5 parents of 217 children who had experienced the onset of PANS or PANDAS symptoms, have been accused

Figure 2. Experiences of the parents of 217 children either diagnosed with PANS or PANDAS or having experienced the onset of PANS or PANDAS symptoms, and accusations of FII or Safeguarding. Numbers refer to numbers of parents experiencing FII and safeguarding accusations. Some parents have experienced more than one type of accusation.



or threatened with FII or safeguarding concerns **(Figure 2).** Given this apparent disproportionate number of families with PANS or PANDAS against whom such allegations have been made, it is crucial to consider why this may be happening.

Referrals of families of children with neurodevelopmental conditions or certain medical conditions for suspected FII were highlighted by a report published in 2022 by the British Association of Social Workers (BASW) [26]. A key basis for FII referrals appears to be that children have symptoms that a clinician believes do not have a medical explanation. Such a situation may fit the description of a "perplexing presentation" - which is an alerting sign of possible FII. The proposed assessment criterion for FII is likely to cast suspicion on many families who are not harming their children. This includes families with children and young people with disabilities and illnesses that are undiagnosed, where their presentations have been misunderstood and subsequently misdiagnosed, or who have not responded well to treatments.

Having a medical condition that is associated with divided medical opinions is also a further vulnerability factor for FII accusations. Medical situations involving dispute, controversy and developing knowledge are not limited to PANS and PANDAS, but are found in a range of illnesses including, but not limited to, Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS), Pathological Demand Avoidance (PDA), Ehlers Danlos Syndrome (EDS), and, more recently, Long Covid [26].

Perplexing presentations

This term has been introduced to describe the situation where there are alerting signs of possible FII (not yet amounting to likely or actual significant harm) and where the actual state of the child's health and neurodevelopment is not yet clear, but there is no perceived risk of immediate serious harm to the child. The essence of alerting signs is the presence of discrepancies between reports, presentations of the child and independent observations of the child, implausible descriptions and unexplained findings or parental behaviour [23].

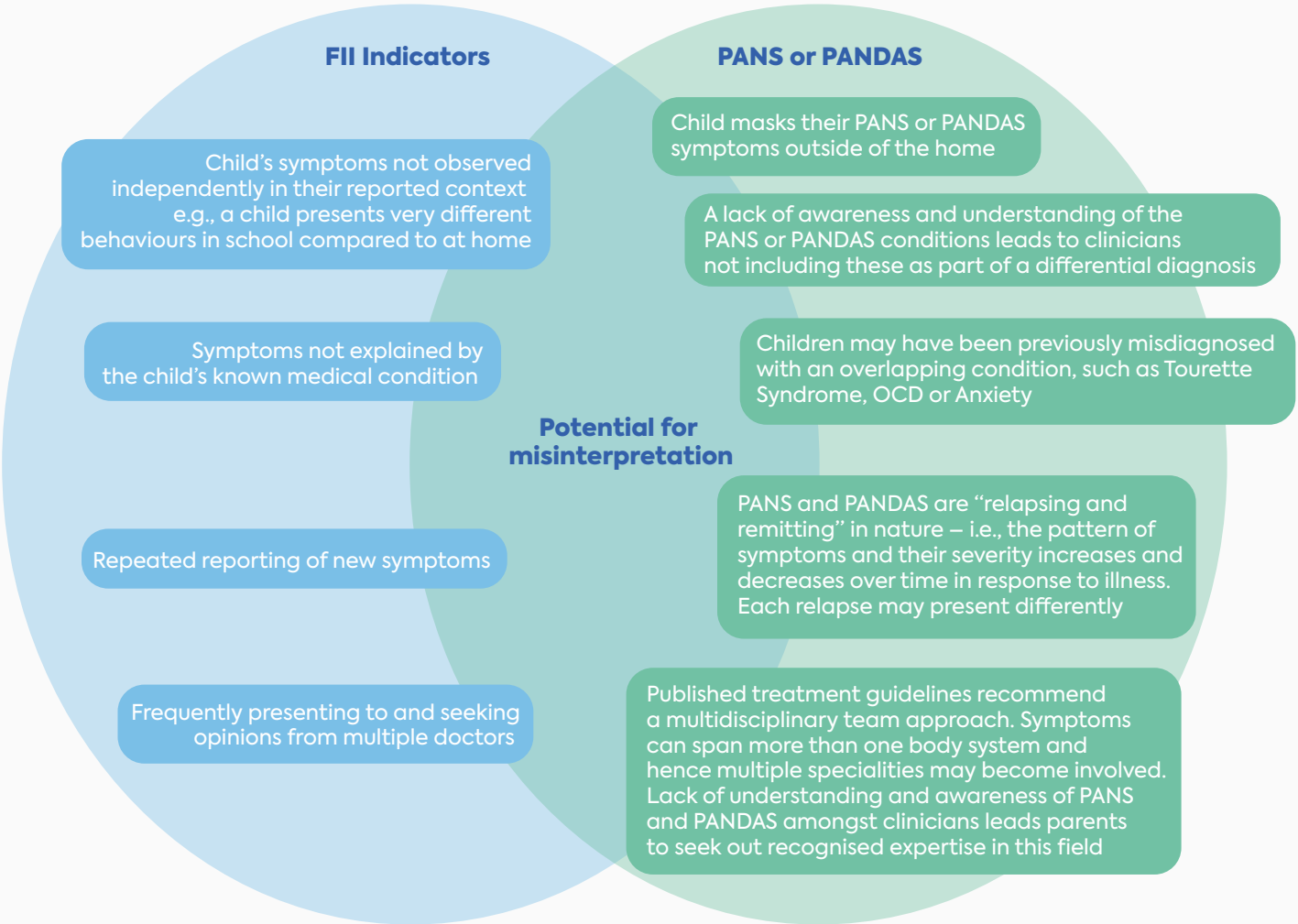
PANS, PANDAS AND FABRICATED OR INDUCED ILLNESS

Since PANDAS was first described in 1998 [1], considerable medical discussion has surrounded this clinical concept and that of PANS, which was first described in 2012 [3, 12]. Different bodies of expertise disagree about the diagnosis, treatment approaches and cause of these two conditions. This disagreement often leads to patients not being evaluated for PANS or PANDAS (or any other medical condition that might cause abrupt onset of neuropsychiatric symptoms), clinicians struggle to identify and treat affected patients, patients are unable to access treatment options that would address possible underlying infectious or inflammatory causes, and parents and caregivers are left to search for answers through the internet and family-organised support groups.

MEDICAL DISPUTE

Dispute can arise between local medical professionals and the parents of children presenting with a symptomology indicative of PANS or PANDAS. Parents, who find themselves in extraordinary circumstances and wish for possible medical reasons for their child's onset of neuropsychiatric symptoms to be ruled out, resort to seeking opinion from out-of-region clinicians with expertise in these conditions. Through the lens of FII, such action by the parents can easily be interpreted as an 'alerting sign' **(Figure 3).**

Figure 3. Overlap between FII indicating signs and PANS or PANDAS



UNEXPLAINED SYMPTOMS

Possible indicators of FII also include a child experiencing symptoms which cannot be explained by their known medical condition and not responding well to treatments. This is particularly problematic within the context of PANS and PANDAS. Through lack of awareness, children with PANS or PANDAS may be misdiagnosed with other conditions that have overlapping symptom profiles (for example, obsessive-compulsive disorder (OCD), Tourette Syndrome or Attention deficit hyperactivity disorder (ADHD)). As a result, treatment response in these children may be poor due to their diagnosis and associated treatment plan being incorrect or incomplete; because they are based on a misdiagnosis of a condition that the child does not have or which is only part of the clinical picture.

RESPONSE TO MEDICATIONS

A further complicating factor is that many medications (such as antidepressants and antipsychotics) given for psychiatric conditions are known to be poorly tolerated by patients with PANS and may cause intolerable side effects when prescribed at standard doses [27]. If medical understanding of the expected response to some medications by children with PANS or PANDAS is low, parents who accurately report a lack of response to medications or intolerable side effects may be unfairly viewed as being dishonest about their observations.

A RELAPSING AND REMITTING ILLNESS

The symptoms of PANS and PANDAS relapse and remit over time. During relapses, or "flares" (periods of neuropsychiatric deteriorations), children may become severely ill and incapacitated for weeks to months. During remission, symptoms usually decrease significantly, occasionally completely resolving or the child may just have residual symptoms [2, 17]. The severity, duration and character of symptoms during relapse events varies in children over time [15, 28, 29]. The observed variability in symptoms during each relapse is important in the context of vulnerability to FII accusations.

MASKING

The potential of FII to be indicated in situations involving PANS or PANDAS is further exacerbated by the presence of 'masking' in these children. Parents of children with PANS or PANDAS report that their children internalise their difficulties and "hold it together" in certain contexts and settings (such as at school or during medical appointments [30]).

75% of children with PANS or PANDAS mask their symptoms fully or partially at school. 50% mask their symptoms at medical appointments.

(Parent survey, PANS PANDAS UK, 2022)

This leads to further misinterpretations as the child's masking of their symptoms gives the false impression that parents are fabricating or exaggerating the child's symptoms because education, health, and social work professionals are not seeing the extent of the child's possible tics, confusion, anxiety, frustration, and distress because they manage to constrain their symptoms and emotions in certain situations.

"My daughter masks almost entirely in the school setting. The really difficult thing to get people to understand about masking, is that just because PANS/PANDAS symptoms aren't visible in school – it doesn't mean that they aren't being experienced by her in school.

When we asked to have an Individual Health Care Plan put in place to support her medical condition, we were told that the school would not do this as she was "no different to her peers". This was so hard to deal with, as not only could we not get our daughter the help that she needed, but our parenting was being questioned in place of acceptance of a medical diagnosis.

There is always a price to pay for masking – and that price is always paid at home, back in her safe place, where she can finally let it all out".
Parent of a child with PANS.

Recent research has situated masking as 'a survival strategy used to keep oneself safe from negative experiences and therefore can be both a conscious and sub-conscious 'act" [31]. The conceptualisation of masking as an innate response to perceived danger is relevant to children with PANS or PANDAS. It would be easy to assume that a child with severe symptoms of PANS or PANDAS would not have capacity to hide or camouflage these symptoms in certain situations. However, understanding that this masking may not only be a choice but could also be an innate sub-conscious survival instinct might encourage observations of the child from a more holistic and accepting standpoint.

PANS PANDAS PARENTS AND FII

"Please listen to the parents, they know their children, they don't want something to be wrong but can see when something isn't right. Please support them in every way that you can, having children with an illness which is not supported by the NHS is hugely draining and a massive burden of responsibility."
Parent of a child with PANS (PANS PANDAS UK, Parent Survey 2022)

Several overseas studies have investigated parent experiences of advocating for a child with PANS or PANDAS. Themes of frustration about the lack of scientific knowledge about the disorders, their causes, and which treatments are effective are evident [14, 20, 32]. Parents perceive that they are not heard by members of the healthcare community, are met with scepticism and feel blamed for causing the symptoms displayed by their child [19, 30].

Some professionals, when confronted by cases they do not understand, can rapidly shift the blame to parents, accusing them of an unsubstantiated FII 'diagnosis', a quasi-diagnosis, placing parents in the disempowering position of "guilty until proven innocent". Parents have reported experiencing immense trauma and distress because they know there is something wrong with their child and yet professionals rapidly form an opinion that the child's difficulties are created and falsified by their parents. Little weight is lent to the idea that it is natural for parents to be anxious when their child is unwell, nor that it is equally natural to seek to become better-informed about the possible causes of the change in their child.

Instead, a culture of parental blame is on the increase where "warrior parents" are quickly categorised as "difficult" and "unwieldy" when they must fight to have the needs of their child met and for medical investigations to be

performed to rule out organic reasons for the acute onset of their child's changed personality, behaviours and neuropsychiatric symptoms.

Parents (in particular mothers) are frequently labelled as 'over-anxious' with the insinuation that it is this, rather than any organic cause, which is at the root of the child's difficulties. The existence nationwide of a default position for those assessing disabled children that assumes parental failings has been discussed in a 2021 publication by the Cerebra charity. This position locates the problems associated with a child's impairment in the family – a phenomenon referred to as 'institutionalising parent carer blame' [22].

The current lack of PANS and PANDAS specialist clinicians within the NHS often results in parents seeking varying degrees of private medical input or being passed from one NHS service to the next with multiple rejected referrals. This, coupled with recommendations for multidisciplinary input and often poor communication between specialists, means that parents must become a central point of contact and organise and advocate for different inputs from different professionals.

This makes the parent the de facto 'expert by experience' but equally puts them at risk of accusations of interference in care, doctor shopping and/or overmedicalisation. Parents are, out of necessity, acting in a capacity which they would never have chosen, yet it is this very role which increases the likelihood that their parenting will be called into question. Parents find themselves in a situation where they are a) caring for a child who has suddenly become acutely unwell, b) at the same time seeking medical support but finding little capacity within the NHS to investigate a medical reason for the onset of acute neuropsychiatric change in a child, as well as c) finding that if they disagree with or question initial medical advice, request second medical opinion or request further referrals – they fall under suspicion or accusations of FII.

The impact of facing an FII claim at the same time as managing a sick child is profound and long lasting, leading to parents coming under enormous strain. Subsequent parental diagnoses of depression, anxiety and post traumatic stress disorder were reported to PANS PANDAS UK as part of their 2022 survey into FII and PANS or PANDAS.

Some parents choose to engage the support services of an external advocate with training in situations of FII (or safeguarding). The participation of such an individual, who is not directly involved as part of the family or with simultaneously caring for a very unwell child, usually represents a positive coping mechanism by the parent and can help alleviate what can otherwise be an incredible burden of multiple acute responsibilities.

> *"Being told I must have done something bad to my son that caused the sudden abrupt change in him was truly devastating. Not only were we in shock and not sure what had happened to him, but was worried sick being threatened with an investigation…Being summoned to the hospital as part of the investigation on the basis of a GP's say so caused unnecessary anxiety that I didn't need at the time in addition to my son's new health condition."*
> Parent of a child with PANS.

SECTION THREE
Professional Awareness of PANS and PANDAS

HEALTHCARE PROFESSIONALS

SUMMARY

- PANS and PANDAS are medical disorders which have historically suffered from low awareness, poor understanding, and professional disagreement.
- There is currently a lack of consensus about the diagnosis and treatment of PANS and PANDAS in the UK.
- All children presenting with acute onset neuropsychiatric symptoms should receive a full medical evaluation. Other known medical conditions, including other neuroinflammatory, autoimmune, and metabolic disorders, can also present with an acute onset neuropsychiatric presentation.
- A collaborative, multidisciplinary approach to evaluating these children is recommended, along with an increased understanding of the challenges their families face.

The lack of awareness and understanding of the PANS and PANDAS disorders amongst healthcare professionals can cause difficult situations to develop in the medical management of a child presenting with an acute onset of neuropsychiatric symptoms.

PANS and PANDAS fall within the relatively new field of immunopsychiatry, based on the idea that certain psychiatric conditions can be caused by an underlying immunological or inflammatory condition [11]. Illness prior to or during the onset of the first PANS or PANDAS symptoms is often evident, with fever, sore throat, upper respiratory infections, otitis media, sinusitis, impetigo, gastroenteritis, headache and fatigue commonly being reported [17]. The onset of PANS or PANDAS symptoms, or the start of a period of symptom exacerbation, can often be assigned to a particular day or week, at which time the symptoms seemed to “explode” in severity [11]. However, not all cases of PANS or PANDAS present in such an abrupt manner.

The concurrent development in a child of previously unseen symptoms and behaviours that fall within several different categories is specific to the PANS and PANDAS conditions **(Table 1)**. Some children can become extremely ill, experiencing destructive rage outbursts, debilitating compulsions, motor and vocal tics, school dysfunction, self-harm and psychosis [17].

Abrupt onset of symptoms

The clinical concept of PANS and PANDAS involving an acute onset can be used to differentiate these conditions from other diagnoses. The acute onset has historically been reported in the medical literature as a rapid escalation of symptoms within 72 hours. This time frame arose, in part, in order to facilitate the selection of specific cohorts for research studies concerning the PANS and PANDAS conditions. However, a gradual onset has been documented for some children with PANS [15] and more recent consensus discussion has proposed a subacute onset of symptoms over a period of less than 3 months [5].

TABLE 1. THE PANS AND PANDAS DIAGNOSTIC CRITERIA. [1–3, 11].

PANDAS diagnostic criteria[a]		PANS diagnostic criteria. There is no age limit.	
I.	Presence of OCD or a tic disorder	I.	**Abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake**
II.	Paediatric onset: Symptoms of the disorder first become evident between 3 years of age and the beginning of puberty[b]	II.	**Concurrent presence of additional neuropsychiatric symptoms, (with similarly severe and acute onset), from at least two of the following seven categories:** 1. Anxiety 2. Emotional lability and/or depression 3. Irritability, aggression, and/or severely oppositional behaviours 4. Behavioural (developmental) regression 5. Deterioration in school performance (related to attention deficit/hyperactivity disorder [ADHD]-like symptoms, memory deficits, cognitive changes) 6. Sensory or motor abnormalities 7. Somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency
III.	Acute symptom onset or dramatic symptom exacerbation and episodic (relapsing-remitting) course[c]		
IV.	Temporal association between Group A streptococcal infection and symptom onset/exacerbations (see text for further discussion)		
V.	Association with neurological signs (motor hyperactivity or choreiform movements)[d]	III.	**Symptoms are not better explained by a known neurologic or medical disorder, such as (but not limited to) Sydenham's Chorea,** systemic lupus erythematosus, or Tourette Syndrome
[a] Comorbid symptoms (emotional lability, separation anxiety, age-inappropriate behavior, and nighttime difficulties), also episodic and temporally related to GABHS infections, are documented alongside the diagnostic criteria set out by Swedo et al 1998. [b] As is generally true for rheumatic fever. [c] Symptoms usually decrease significantly between episodes and occasionally resolve completely between exacerbations. [d]Children with primary obsessive-compulsive disorder may have normal results on neurological examination, particularly during periods of remission. Further, the presence of chorea would suggest a diagnosis of Sydenham's chorea, rather than PANDAS.		**Note:** The diagnostic work-up of patients with suspected PANS must be comprehensive enough to rule out these and other relevant disorders. The nature of the co-occurring symptoms will dictate the necessary assessments, which may include MRI scans, lumbar puncture, electroencephalograms, or other diagnostic tests	

Procedures for diagnosing and treating PANS and PANDAS in the UK lack consensus agreement. Levels of awareness and understanding of both conditions are low within the NHS. Hence, for children presenting with the acute onset of neuropsychiatric symptoms, PANS and PANDAS are often not included in possible differential diagnoses, not investigated and are left untreated. Four particular challenges associated with the diagnosis of these conditions exist.

1. Symptoms overlap with a variety of psychiatric disorders, such as OCD, Tourette syndrome, ADHD, depression, and bipolar disorder, making PANS and PANDAS difficult to identify [2].

2. Children presenting with acute onset neuropsychiatric symptoms should receive a full medical evaluation. Often this does not happen in a timely manner as primary care are unable to complete a full evaluation, referral to secondary care is delayed or refused, or the child is only placed onto a waiting list for children and young people's mental health services (CYPMHS).

3. Due to the abrupt onset, the neuropsychiatric symptoms can be misinterpreted as a reaction to acute psychosocial trauma [2], with associated risk of safeguarding concerns being mistakenly raised and medical causes of symptom onset not considered.

4. Diagnosis of PANS and PANDAS are based on clinical data rather than diagnostic markers.

Additionally, establishing the diagnosis of a preceding streptococcal infection to assist in the diagnosis of PANDAS is difficult as 1) patients often come to clinical attention after the "window of opportunity" to detect strep has passed [12], 2) diagnostic approaches to detect current or recent strep infection are not perfect [4, 10, 12], 3) the temporal relationship between a streptococcal infection and PANDAS symptom onset varies, 4) as in Sydenham's chorea and rheumatic fever, some symptom recurrences may not be associated with documented streptococcal infections [1, 11], and 5) this population has a relatively high rate of failure to produce typical antibody responses to infections [33, 34].

Sydenham's chorea and rheumatic fever. In the case of Sydenham's chorea (SC) and rheumatic fever, there is often a delay of 6–9 months between the last documented streptococcal infection and the first appearance of symptoms of Sydenham's chorea; however, relapses follow streptococcal infections at much shorter intervals, often lagging only several days to a few weeks behind. It appears that the pattern is similar for PANDAS [10, 11]. Of note is the situation that, despite having been known and studied for centuries, there are still no standardized therapies or official guidelines for SC treatment, such decisions instead being left to physicians' clinical experience [35]. This situation is similar to that existing for PANS and PANDAS.

Overlap with other disorders

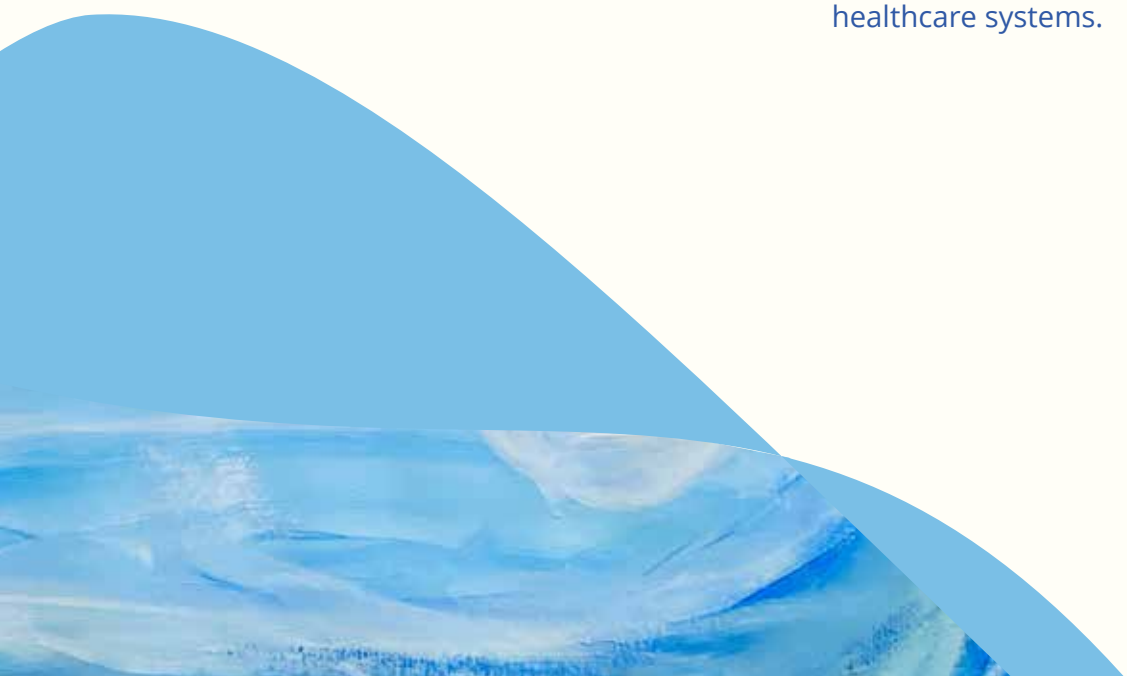
PANS and PANDAS have symptom profiles which overlap with several other diagnoses such as OCD, Tourette Syndrome, depression, bipolar disorder and ADHD. However, PANS and PANDAS can be differentiated from other conditions by [2, 17];

- The acute and dramatic onset of PANS or PANDAS symptoms – parents often describe their child disappearing/changing overnight. This is in contrast to, for example, the gradual onset with a cumulative effect found in OCD.
- The simultaneous presence of multiple new onset symptoms in different psychiatric/ behavioural categories (see Table 1).
- Accompanying physical symptoms such as rashes, headaches, fever, or urinary difficulties.
- Initially, a relapsing and remitting symptom course. Although if not treated over time symptoms can become chronic.
- The average age at onset of symptoms occurs at a younger age than that typically found for other conditions, such as OCD.

Children on the ASD diagnosis-care pathway can also develop PANS or PANDAS. Such children may present with the acute onset of markedly altered, or entirely new, behaviours, which may include a restricted food or fluid intake, compared to their normal presentation [36].

Current consensus treatment recommendations for PANS and PANDAS are set out in international peer-reviewed guidelines [4, 11, 37, 38]. These recommended treatment approaches encompass psychiatric and behavioural interventions, immunomodulatory or anti-inflammatory therapies and antimicrobial intervention to treat or prevent infection.

These treatment approaches remain provisional subject to completion of large scale randomised controlled trials [12]. Key to successful assessment and treatment is a multidisciplinary approach as these conditions encompass infectious disease, immunology, rheumatology, neurology and psychiatry [2, 11, 39]. The recommended multidisciplinary team approach to coordinated care is a challenge to provide within stretched NHS and children and young people's mental health services (CYPMHS) healthcare systems.



PANS PANDAS Working Group (PPWG)
The establishment of the PANS PANDAS Working Group in 2022 (made up of representatives from the British Paediatric Neurology Association, PANS PANDAS UK, the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the Royal College of Occupational Therapy, the British Paediatric Allergy, Infection and Immunology Group, the British Association of Social Workers and the Royal College of General Practitioners) marks a step forward to reaching a consensus in the UK on the treatment of the PANS and PANDAS conditions.

In February 2023 the PPWG released a statement relevant to primary and secondary care physical and mental health NHS services that may come into contact with children and young people presenting with acute onset neuropsychiatric symptoms [40]. The statement addresses the current variation across the UK in the management of patients presenting with PANS and PANDAS. It recommends the development of appropriate service models and pathways, and highlights that all children presenting with acute onset neuropsychiatric symptoms should receive a full medical evaluation. Other known medical conditions, including other neuroinflammatory, autoimmune, and metabolic disorders, can also present with an acute onset neuropsychiatric presentation and should be considered as part of the differential diagnosis process. Clinicians are signposted to existing international peer-reviewed treatment guidelines [4, 11, 37, 38].

MOVING FORWARD: SUPPORTING GOOD PRACTICE

When faced with a situation in which PANS or PANDAS are part of the differential diagnosis for a child's altered presentation, medical professionals should collate and clarify all current medical/health involvement in the child's investigations and treatment, including from GPs, consultants, and private doctors. All other professionals involved with the child should also be consulted, including educational professionals and social workers (if involved) in order to be able to form both historical and current complete descriptions of the child and the child's presentation.

Recommendations from PANS and PANDAS multidisciplinary clinics suggest that it is important not only to include clinician reports in the assessment of PANS, but also to include parent and child reports, as a single perspective is unlikely to capture the full complexity of the child's situation [41].

General measures assessing global disease severity and adaptive functioning are clinically helpful and should be used to complement symptom-specific scales representative of the core symptoms seen in PANS, such as OCD, anxiety, depression and behavioural problems.

International consensus treatment guidelines emphasise that a multidisciplinary approach to the management of the PANS and PANDAS conditions is required, allowing a consideration of possible infective, metabolic, inflammatory and autoimmune pathophysiologies to be made [4, 11, 37-39]. Therefore, clinicians should give due consideration to whether further definitive investigations or referrals for specialist opinions should be made. Consultation with colleagues, tertiary referral centres and specialists is recommended.

SOCIAL WORK PRACTITIONERS

SUMMARY

- Effective liaison with other professionals and organisations is needed to ensure that a child and family receive a full, clear and open-minded evaluation and subsequent appropriate support.
- Careful consideration and assessment of the evidence and reasoning supporting any accusations of safeguarding or FII is required.
- Understanding the impact of PANS or PANDAS symptoms on family functioning and seeking to forge positive relationships with families is key.

When professionals are faced with a situation where PANS or PANDAS could be affecting the health of a child, a clear and open-minded assessment is required. The principles and parameters of a good assessment are explained in the HM Government Working Together to Safeguard Children (2018) guidance as: 'Assessment should be a dynamic process, which analyses and responds to the changing nature and level of need and/or risk faced by the child from within and outside their family. It is important that the impact of what is happening to a child is clearly identified and that information is gathered, recorded, and checked systematically, and discussed with the child and their parents where appropriate' [42, p.27].

Therefore, social workers and other professionals assessing a child who may be experiencing symptoms of PANS or PANDAS need to analyse the changes in their behaviour that have taken place, gaining information from parents, siblings, extended family, school staff, and anyone else who can provide helpful information.

It is not the role of a social worker or teacher to make a diagnosis, nor dispute a medical diagnosis, as this would be stepping outside of their professional remit. However, non-medical professionals can make changes for children and their families by taking decisive action to ensure effective liaison with other professionals, as well as assessing and monitoring. The key to good professional practice is 'relationship', where practitioners seek to forge a positive connection with the families they serve and providing a two-fold service where they facilitate interorganisational working, societal dynamism, and act as an ally to support families to find solutions, whilst also implementing appropriate levels of authority and control in their efforts to protect children from the risk of harm.

The essence of social work practice is to develop good agencies rather than to impede bad ones. Many difficulties of social control will be reduced if we can channel social control practices back into the mainstream of social helping '...the practitioner must always endeavour to look 'beyond' or 'through' the problem and its causes...to support actions directed towards solutions' [43, p. 271].

HOW TO WORK WITH THE FAMILY?

> *"I would like them to know how incredibly difficult it is. How it affects the entire family, friends, and wider relationships. PANS stole my happy little girl and turned her into an unrecognisable shadow of herself who sometimes hurts me physically and screams so loud she vomits before collapsing in a heap sobbing and begging me to make it stop. It's absolutely heart-breaking and until others have witnessed a PANS meltdown, they have no idea what hell the child and their family go through."*
>
> Parent of PANS or PANDAS child (PANS PANDAS UK, Parent survey 2022)

It is important that professionals start their assessment and information gathering with an open mind and non-bias. When a social worker is assigned to work with a family, including those where the child has been identified with PANS or PANDAS, it is their professional duty to listen to and analyse what is being said by other professionals, the child's parents, and other people who know the child well. The social work assessment must accurately 'reflect the unique characteristics of the child within their family and community context" [42, p. 30], and ensure their individual needs are assessed, including whether their parent(s) are meeting these.

Although PANS and PANDAS are medically diagnosed conditions associated with signficant changes in a child's behaviour [1-3, 11], in contrast, FII is an unevidenced list of behaviours which are not research based. No data have been identified on the ratio of parents investigated for possible FII and those where FII is confirmed. It is suspected that far more families are being investigated than are actually true cases. It has been theorised that there is a high rate of false positives in FII allegations [24]. In a BASW report, it was highlighted that 'social workers need to be aware of the lack of evidence for currently used indicators for FII and perplexing presentations and the high incidence of these indicators identifying children where illness is neither fabricated or induced' [26].

Whereas the Medical Model seeks to identify and treat (fix) an individual's difficulties, the Social Model considers how people are disabled by the barriers they experience in society, including the attitudes by professionals towards difference, which can lead to the knowledge and expertise of parents/ caregivers being quickly dismissed as invalid, exaggerated, or fabricated. Noticeably, reports alleging parental abuse of children who are medically fragile generally arise from one of three situations:

- Parental disagreement with a doctor,
- Emergency department visits, or
- Medical disagreements among doctors, when the physician whose opinion is not chosen raises a safeguarding concern [44, p. 108]

The questions professionals should consider when assessing a situation in which safeguarding or FII accusations have been made include: Are there previous or ongoing school/parental disputes? Does the child have a diagnosed condition and is there diagnostic corroboration? Have the parents raised a complaint against the school, doctor, or social care? If any of the answers to these questions is 'yes', then a careful consideration and assessment of the evidence and reasoning supporting the accusations is required.

When a social worker is involved in a situation where there are concerns about the welfare of a child with PANS or PANDAS, they have a duty to ensure that the child and family receive the assistance required to promote effective child development whilst not necessarily adopting a safeguarding approach. The safeguarding approach can further alienate parents who may already be struggling to meet the needs

of their child and to have these needs be fully appreciated by the professionals already involved.

Effective practice is created when professionals seek to build meaningful and productive relationships with families. Good relationships are established when the following principles are adhered to:

- Openness about the concerns raised and what is non-negotiable
- Eliciting the child and parent(s) views, as well as the wider family, when appropriate
- Proactively identifying the needs of the child and parent/caregiver
- Establishing collaboratively how these needs can be met
- Exploring the barriers to positive change
- Utilising a strengths-based approach whilst not diminishing the difficulties being expressed
- Treating all family members with dignity and respect.

Good professional practice involves attentively listening to parental concerns and seeking to understand their child's experiences by stepping into their shoes and seeing the world through their eyes. It is about gathering information and making an informed decision about what needs to happen, without alienating families who are reaching out for support. Effective and conscientious professionals make time and endeavour to do the right thing, to make a difference, whilst consciously realising every child matters, their welfare is paramount, and equally every parent/caregiver matters too.

> *"This is such an exhausting, terrifying experience having a child so acutely ill, both physically and mentally. It's such a battle to have our child (particularly when already have an autism diagnosis) be heard and believed. I struggled to access GP/CAMHS during the most acute times of my son flaring... I was fortunate to have an amazing Social Worker who put our son's mental health and wellbeing front and centre... Once our social worker supported our cause, it seemed everyone else listened. I was no longer desperately shouting out to the void and this is when the team around the child started to have its impact."*
> *Parent of a PANS or PANDAS child (PANS PANDAS UK, Parent survey 2022)*

Parental trauma and burden

Whilst there is a need for social workers to be fully committed to responsibly safeguard all children from any harm, they also have a duty to ensure parents are appropriately supported, rather than being subjected to unnecessary child protection proceedings when inappropriate and wrongful accusations of FII are made [26]. The clustered injustice that parents of children with disabilities experience has been described as "distressing, avoidable and shaming'" [45, p. 99]. When a need arises and it is met, the person can move onto the next experience. However, if this does not happen, and professionals do not accurately assess and quantify the needs of the child, trauma will occur, particularly when a parent must focus their fullest attention to access the right support for their child.

Due to the severe impacts of the PANS or PANDAS symptoms, their chronic nature when untreated, feelings of having no control, and difficulties surrounding medical treatment, parents of children with PANS have been identified as particularly vulnerable to experiencing high levels of psychological stress [19]. Notably, the impact of PANS or PANDAS on the emotional well-being of the family entails a higher level of suffering and caregiver burden than found for other chronic childhood illnesses [46, 47].

EDUCATION PROFESSIONALS

SUMMARY

- Teachers are in a uniquely privileged position of knowing children well, however lack of training about PANS and PANDAS and the symptom profile overlap with other, better-known, disorders make it unusual for PANS or PANDAS to be suspected as a potential reason for changes in a child's presentation at school.
- Symptoms and presentations can vary widely and many children mask their symptoms in school. This can cause confusion and misinterpretation of the reasons for change in a child.
- Schools have a key role to play in providing evidence of change in a child. This can be a vital part of building a complete picture of what is happening and securing support for the child and family from other professionals.
- Education professionals should understand that there is significant overlap between the symptoms of PANS and PANDAS and the alerting signs of safeguarding. Maintaining professional curiosity and an open mind is crucial.

Current levels of awareness about the PANS and PANDAS conditions are low amongst educational professionals, this is due to a number of reasons, including:

- Lack of training for educators, SEND professionals and educational psychologists about the conditions.
- Schools may have not known the child before they developed PANS or PANDAS. They will therefore not be in a position to recognise the extent of the change in the presentation of the child.
- Few SEND organisations and networks hold any information about the conditions.

It is undeniable that improved awareness of PANS and PANDAS within education settings is particularly important, given their privileged professional position of knowing children well.

Part of a school's role includes being responsive to any 'changes' in a child's typical presentation within the context of the family. Schools have a duty to identify concerns early, to provide help for children and to prevent concerns from escalating. Schools also have a responsibility to prevent impairment of children's mental or physical health and to take action to enable all children to have the best outcomes [48].

"I wish all teachers knew about PANS and PANDAS - None of them knew about it."

Millie, 15

WHAT MIGHT A TEACHER OBSERVE IN THE CLASSROOM?

If a child presents in the classroom and/or home with multiple unexplained behavioural and mental health changes then educational professionals should be aware of the potential for PANS and PANDAS to be the cause. These medical conditions have unusual characteristics that can easily lead to the child's altered behaviours being misconstrued, and crucial symptoms either dismissed or not regarded as being related to each other **(Table 3).**

Furthermore, symptoms can lead to bullying, trauma and social isolation which can cause secondary mental health issues. The observable symptoms in the classroom can range from nothing at all, to the total unravelling of a child's previous level of functioning. A child living with PANS or PANDAS can also go from requiring no support in school to requiring intensive accommodations within a very short period of time **(Figure 4).**

Figure 4. Educational Supports. Children require increased educational support or adjustments following onset of PANS or PANDAS symptoms. Data from PANS PANDAS UK parent survey 2022: parents indicated whether or not their children were receiving each educational support type before and after onset of PANS or PANDAS, and whether (in the parents opinion) the child required a specific type of support but was not currently receiving it.

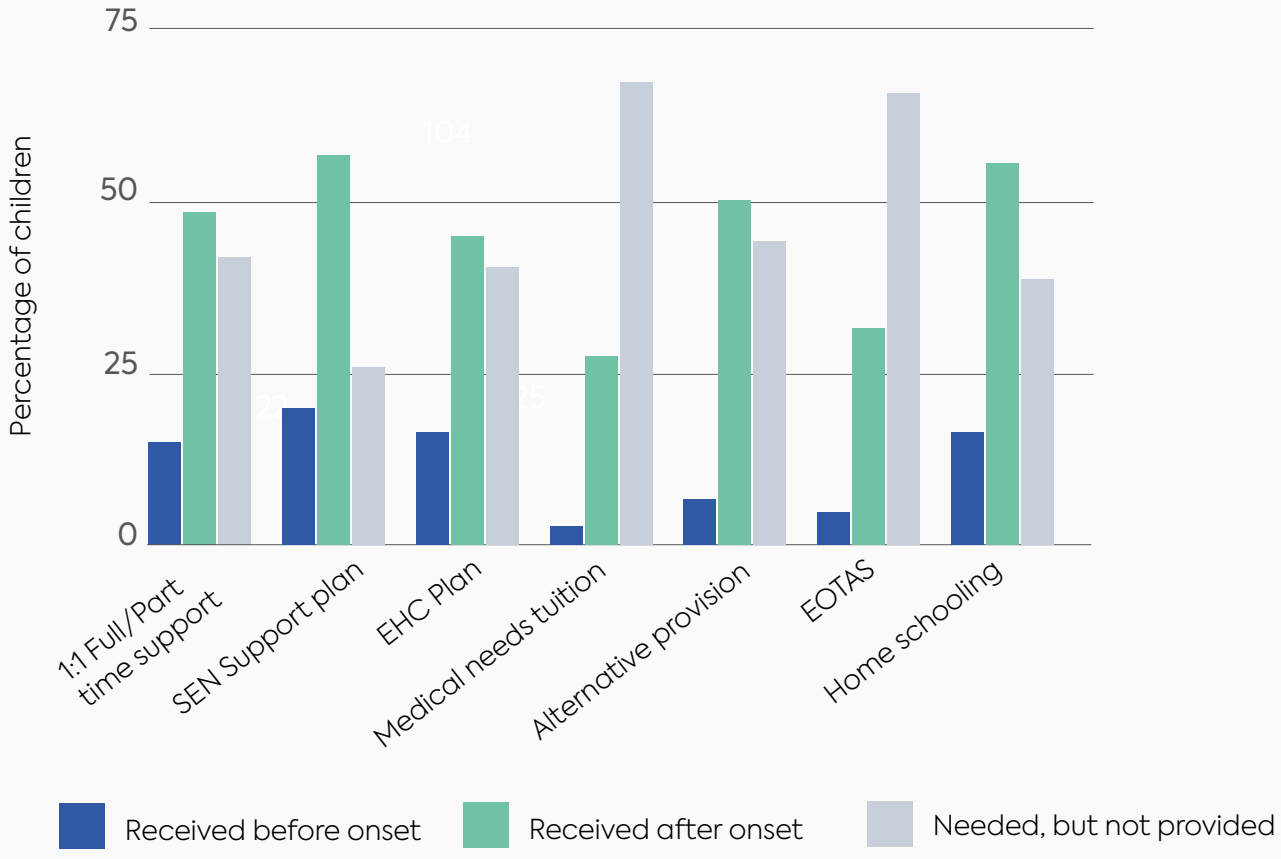


Table 3. Examples of the unusual characteristics of PANS and PANDAS as specifically relevant to Educational Professionals

The conditions can cause the unexpected development of SEN across all four areas of the code of practice.
Children can regress in their functioning across all areas.
The PANS PANDAS conditions relapse and remit so that symptoms that would more typically be chronically present, such as handwriting difficulties, may just 'appear' and then 'disappear'.
Symptoms/signs that can appear unrelated (for example regression in maths skills, disordered eating and urinary urgency) can all be part of the symptom spectrum of PANS or PANDAS.
Developed skills that would not be expected to suddenly become impaired for certain age groups, for example fine motor skills in older children, can suddenly and unexpectedly deteriorate.
The wide potential range of symptoms (Table 1) can easily be confused as poor behaviour, attachment disorders, parenting issues, neurodevelopmental conditions or solely mental health conditions.

Observations at school may include the onset of new behaviours across all four areas of SEN:

COGNITION AND LEARNING

- Difficulties in executive functioning skills including attention, prediction, planning and organising skills
- Deterioration in handwriting
- Visual or auditory processing difficulties
- Short term, long term and/or working memory difficulties

SOCIAL EMOTIONAL AND MENTAL HEALTH

- Outbursts of aggression
- Lack of impulse control
- Emotional regulation issues
- Severe intrusive thoughts affecting the ability to focus and concentrate
- Disabling anxiety including separation anxiety
- Seeing, hearing or feeling things that are not there
- Paranoia (for example, thoughts of being in danger or being followed)

COMMUNICATION AND INTERACTION

- Difficulties with friendships (can include aggression)
- Withdrawal
- Overreliance on adults
- Speech and language difficulties
- Difficulties with co-operative group tasks

PHYSICAL AND SENSORY NEEDS

- Disordered eating patterns
- Sleeping difficulties /exhaustion
- Messy clothes
- Sensory hyper/hypo sensitivity to sounds, touch, taste, smell or movement
- Tics
- Toileting issues (usually urinary urgency, frequency and wiping behaviours)

Cognitive and academic abilities can fluctuate as part of the relapsing and remitting nature of PANS and PANDAS [1, 49]. An otherwise unexplained decline in the academic abilities of children with PANS or PANDAS may be observed by educational professionals [50, 51]. In a 2022 survey, PANS PANDAS UK found that parents reported a significant decline in their childs academic achievement levels following the onset of PANS or PANDAS symptoms **(Figure 5).** The decline in academic progress is likely caused by multiple factors, including primary impacts on the brain, as well as secondary causes such as low attendance, educational gaps, and trauma, among others.

Reduced visiospatial recall, sustained attention, response suppression and processing speed in children with PANDAS have all been evidenced [49, 52, 53]. Lewin et al. [52] found that PANDAS children experiencing a period of relapse (a flare) had greater difficulty with graphomotor function, inhibitory control, and dexterity, as well as greater OCD symptoms. Studies in patients with PANDAS have found weaknesses in executive functions and fine motor skills which may interfere with academic functioning, particulary expressed via difficulties being experienced in writing [54]. Further research is needed to fully understand the complex nature of these causes.

PANS, PANDAS AND SAFEGUARDING CONCERNS (INCLUDING FII)

The RCPCH have suggested that professionals across the board including paediatricians, GP's, psychiatrists, psychologists, health visitors, public health school nurses, dieticians, physiotherapists, speech and language therapists and occupational therapists should all have the knowledge and skills to make competent judgements on recognising FII (childprotection.rcpch.ac.uk).

More recent guidance centres schools within the safeguarding process [23]. There is, however, little information and guidance for schools specifically about FII. Although not referenced in the main body of Keeping Children Safe in Education 2022, all staff should be aware of FII under the category of physical abuse: 'Physical harm may also be caused when a parent or carer fabricates the symptoms of, or deliberately induces, illness in a child.' [48, p. 10]

Many of the signs and symptoms of PANS and PANDAS are the same as red flags in safeguarding **(Figure 6).**

Figure 5. Decline in academic achievement of children following the onset of PANS or PANDAS symptoms.

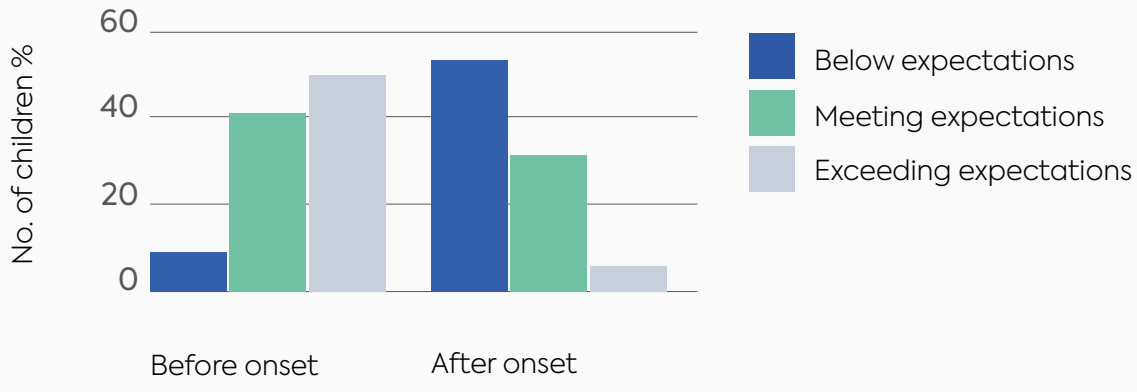
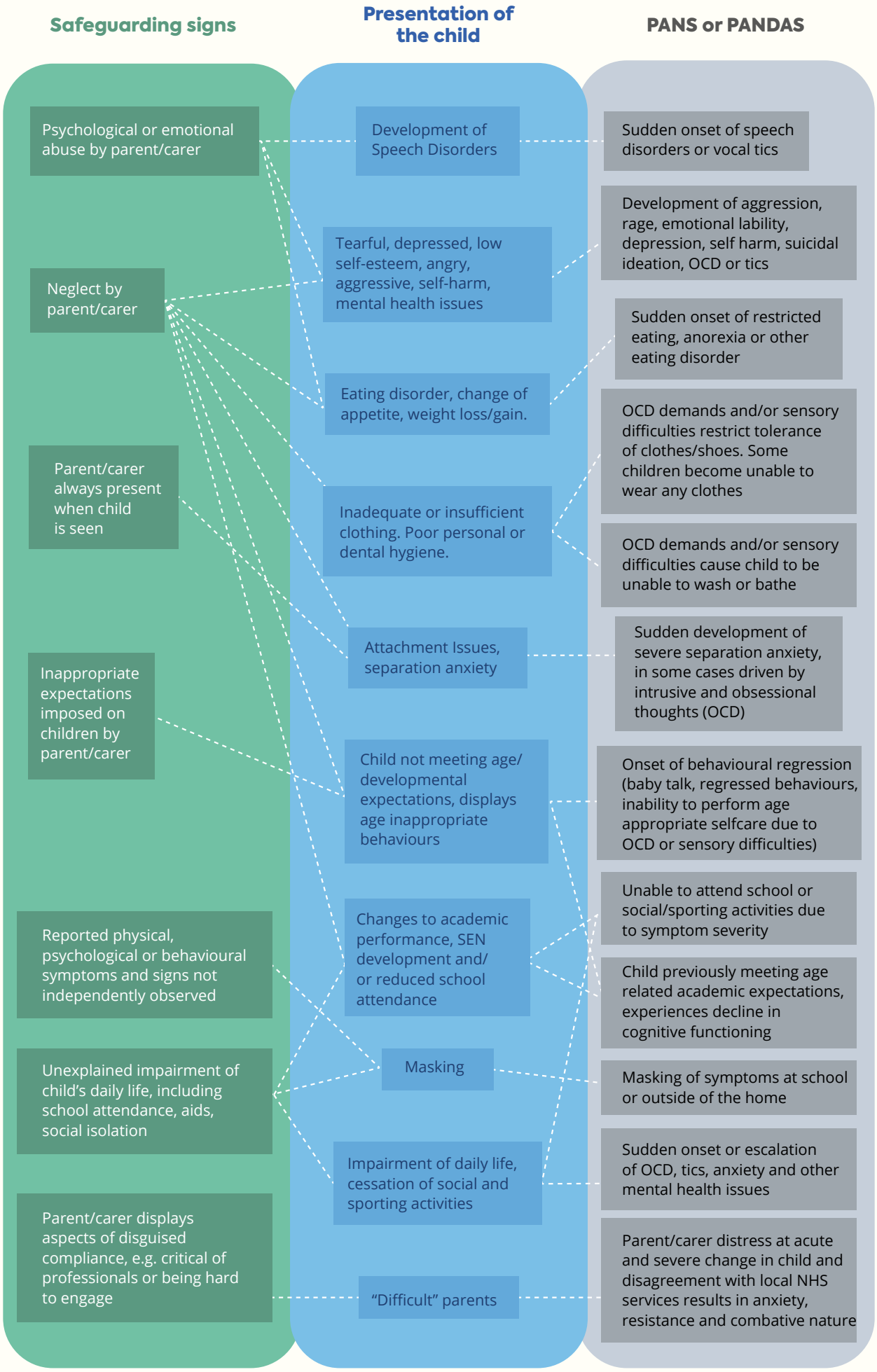


Figure 6. Overlap in signs of safeguarding and symptoms of PANS or PANDAS



Almost all children with PANS or PANDAS will have some of these signs of FII (Figure 6). Some children will have all of them. They include:

- Interrupted attendance and education as the child is too unwell to attend school.
- Social isolation for the child too unwell to attend school or participate in other activities.
- Siblings who are also struggling, due to the impact on the entire family of the PANS or PANDAS symptoms.
- Parents being perceived to be 'inappropriately' seeking multiple medical opinions.
- Parents focus on medical investigation instead of on the management of individual symptoms, for example, being unwilling to give only psychotropic medications to their child who they suspect has PANS or PANDAS.
- The child masks the range and severity of symptoms in school so that parents and schools have a very different picture of the child's level of need and, therefore, the parental description of the child and their condition does not fit with the child seen in school.

Clearly it is a difficult situation.

How can it be ensured that children with PANS or PANDAS are correctly supported and families are not subject to mistaken safeguarding or FII accusations whilst also ensuring that a child is not missed who does require protection? There is not an easy answer given the number of vulnerability factors for families supporting children with PANS or PANDAS.

Robust and informed practice should include all professionals being aware that *'no single practitioner can have a full picture of a child's needs and circumstances'* and that *'If children and families are to receive the right help at the right time, everyone who comes into contact with them has a role to play in identifying concern, sharing concerns and taking prompt action"* [48, p. 6].

MOVING FORWARD: SUPPORTING GOOD PRACTICE

All educational professionals should have a working knowledge of PANS and PANDAS. This should include a knowledge of the diagnostic criteria (Table 1) and also a wider understanding of the current medical context around the diagnosis and treatment of these conditions (and the potential for interprofessional differences). It is already quite rightly not acceptable for any educational professional to be unaware of how to effectively support a child with Autistic Spectrum Condition or ADHD, and this should be the same with both PANS and PANDAS.

Schools should collate and share information about both a child's current and pre-onset functioning and use this evidence to contribute to professional interpretations, safeguarding questions and observations. It is important to ensure that a complete historical picture of the child is also captured rather than just a snapshot of the child at the current time. Collated information should include current and prior school attendance, progress, attainments, emotional and behavioural states and peer relationships. Medical diagnosis is outside the remit of the school, but it is the educational professionals' responsibility to ensure that all impacts on the child in school have been accurately assessed and documented. This assessment may be used to provide an evidence base that will best help the child by evidencing changed behaviours and presentation to other professionals.

All professionals should be aware of the complexity of situation-specific difficulties and of masking. It is oversimplistic to generalise that difficulties 'only' occurring at home after the end of the school day are unlikely to indicate a problem with the child, or that the problem is being 'caused' by the environment in which the child feels safe enough to express their distress/difficulties.

PANS and PANDAS are medical conditions. If initial concerns about the possibility of PANS or PANDAS come from school, then school should recommend a referral to a health professional for assessment. With consent from parents/carers, school can contact relevant health professionals to provide assessment information and to then gather further information.

Educators should be aware of how many signs and symptoms of PANS and PANDAS are the same as red flags in Safeguarding. It is important to ensure that a complete review of every child's situation is performed, with an open, curious and clear mind as to the reasons driving the observed or reported changes in a child. Educational professionals should be curious and vigilant about the high incidence of accusations of fabricated or induced illness (FII) and safeguarding concerns within families of children with special educational needs.

FINAL COMMENTS

The trend in the UK towards an increased focus on early identification of cases of FII puts both families living with complex medical conditions and the professionals surrounding them in an impossibly difficult situation. Understandably desperate not to miss a true occurrence of FII, little emphasis in the existing literature is placed on the impacts of false accusations on a family. Inappropriate safeguarding referrals not only damage families' reputations (and sometimes livelihoods), and the functioning and quality of life of those involved, but they may also hamper a medically fragile child's access to healthcare causing further trauma and lasting harm.

PANS and PANDAS are disorders commonly subject to a clinical prejudice. As such they are rarely identified or treated. Any professional involved with a child or family living with PANS or PANDAS, where one of these disorders is either a possiblity or is confirmed, should reflect on whether safeguarding or FII concerns have been raised primarily due to previous controversies in the field or differing clinical views on diagnosis and treatment approach.

> *"Being a parent of a child with PANDAS is like being trapped in a double whammy of trauma ... the trauma of your child being ill and then the trauma of not being believed or accused of neglect ... being told our child could be removed from our care. It is hard to make sense of that".*
> *Parent of a child with PANDAS*

Much work remains to be done to improve the support and care available to families and children living with PANS or PANDAS. Open minds, better awareness and genuine professional interest and curiosity are crucial if health, social work and educational professionals are to avoid adding further trauma to ordinary parents and families dealing with extraordinary circumstances who seek help to improve their child's health and wellbeing. Careful consideration should be given to the language used to describe the symptoms and needs witnessed by professionals in order that their interpretation of symptoms and behaviours does not draw conclusions but rather sheds light on the child's presentation.

Collaboration is needed between the different parts of the educational, health and social care systems that the child and family find themselves within. A recognition that historical prejudices and bias surrounding the PANS and PANDAS conditions should not cloud decision making by the professionals involved with a child and their family is vital in order to achieve good outcomes and support for the child. We do not advocate that professionals should hesitate to make a safeguarding or FII referral if they are concerned about a child, but rather that they should make these referrals in a trauma-informed manner. Referrals should include any information that may relate to a medical reason for the child's presentation, such as PANS or PANDAS.

We hope this guide has added a new perspective to the ongoing conversations around safeguarding, FII and complex medical conditions such as PANS and PANDAS, and that it encourages all professionals to ensure that they are diligent in reviewing the whole picture of a child and family's presentation with a open mind.

GLOSSARY

ADHD Attention deficit hyperactivity disorder.

CYPMHS Children and young people's mental health services (CYPMHS) is used as a term for all services that work with children and young people who have difficulties with their mental health or wellbeing. The term children and adolescent mental health services (CAMHS) is an older term for the main specialist NHS community service within the wider CYPMHS that may be available locally.

EHCP Education and Health Care plan - a plan for children and young people up to 25 who require more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out additional support to meet those needs.

FII Fabricated or Induced Illness.

OCD Obsessive-Compulsive Disorder.

PANS Paediatric Acute-onset Neuropsychiatric Syndrome.

PANDAS Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections.

PPWG PANS PANDAS Working Group. Established in 2022. Made up of representatives from the British Paediatric Neurology Association, PANS PANDAS UK, the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the Royal College of Occupational Therapy, the British Paediatric Allergy, Infection and Immunology Group, the British Association of Social Workers and the Royal College of General Practitioners.

SEN Special Educational Needs - used to describe learning difficulties or disabilities that make it harder for a child to learn than most children of the same age.

SEND Special Educational Needs and Disabilities, Four Areas of Need - four broad areas of need in the Code of Practice that include a range of difficulties. The areas are Communication and Interaction (CI), Cognition and Learning (CL), Social, emotional, and mental health (SEMH) and Physical and/ or Sensory Needs (PSN). A child with PANS PANDAS may have needs across all four areas. A detailed assessment of need should ensure that the full range of their needs are identified.

Professional profiles of contributors

Cathleen Long is an award-winning independent social worker with an MA in Autism. With almost 30 years of post-qualifying experience, Cathleen has worked within local authorities in both England and Wales. She is an expert witness and provides reports for 'disabled' children, young people and adults for Special Educational Needs and Disability Tribunals, Judicial Review, the Court of Protection, and Family Court.

Tina Coope is an experienced teacher with an MA in education. With over two decades of teaching experience including across mainstream, alternative provision and special schools, Tina has for the last two years been the educational lead at PANS PANDAS UK. This role has included supporting many families living with PANS or PANDAS through their educational journey. Tina has written multiple educational resources alongside creating and delivering the first CPD accredited teacher training on PANS and PANDAS in the UK.

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Original artwork by a child with PANDAS, age 10. *The Waves are Crashing, 2020.*

All the parents, carers and children living with PANS and PANDAS who shared their experiences with the authors

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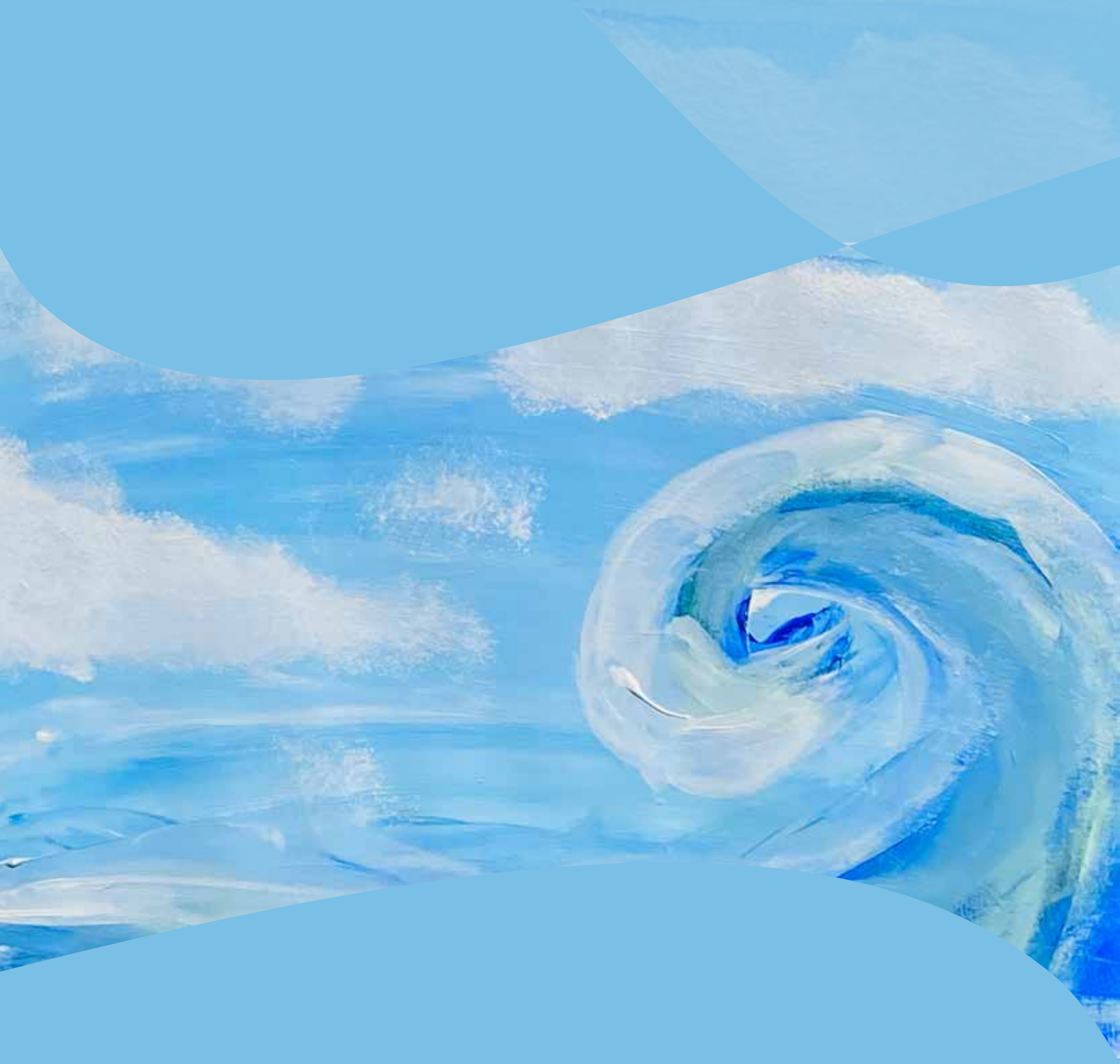

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