

**Master of Public Health** 

Master de Santé Publique

# Gender differences in the detection of neurodevelopmental disorders: a cross-sectional and exploratory study in Seine-Saint-Denis, France

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# List of acronyms

ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism spectrum disorder
CAMSP	Centre d'action médico-sociale précoce (center for early medico-social action)
CMP	Centre médico-psychologique (medico-psychological center)
CMP-IJ	Centre médico-psychologique de psychiatrie infanto-juvénile (pediatric
	medico-psychological center)
CMPP	Centre médico-psycho-pédagogique (medico-psycho-pedagological center)
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (5 <sup>th</sup> edition)
Elfe	Étude Longitudinale Française depuis l'Enfance
GP	General practitioner
HAS	Haute Autorité de Santé
HCSP	Haut Conseil de la santé publique
HRQoL	Health-related quality of life
ICD-10	International Statistical Classification of Diseases and Related Health Problems
	(10 <sup>th</sup> revision)
NDDs	Neurodevelopmental disorders
PMI	Protection Maternelle et Infantile
TDAH	Trouble du déficit de l'attention/hyperactivité
TSA	Troubles du spectre de l'autisme
TND	Troubles du neurodéveloppement

# Abstract

**Introduction**. Autism spectrum disorder (ASD) and attention deficit/hyperactivity disorder (ADHD) are neurodevelopmental disorders significantly more diagnosed in males. It is now suspected that cases in girls are under-detected. In France, the *Protection Maternelle et Infantile* (PMI) belongs to the first line of professionals for the early detection of neurodevelopmental disorders, particularly during health assessments in preschool. The aim of this study is to explore how child gender is accounted for in the detection of ASD and ADHD by PMI professionals.

**Methods**. A review of the scientific literature was carried out (Pubmed and Scopus) followed by semi-structured interviews (n=21) conducted with pediatric nurses, childcare assistants, psychologists, psychomotricity therapists and PMI doctors in Seine-Saint-Denis. The interviews aimed at understanding their perceptions, attitudes and practices regarding the identification of ASD and ADHD. The role of the child's gender was explored. The interview guide and analysis grid were informed by the review of the literature.

**Results**. The interviews revealed very low levels of familiarity with the topic of ASD in females. Most participants had never heard of it before the interview. A lack of training and experience working with autistic girls was identified as the main explanation. ADHD ended up being a secondary topic, as children seen in PMI were considered too young.

**Conclusion**. Our results strongly suggest that child gender is currently not accounted for by PMI professionals in the detection of ASD. By largely being ignored, gender-specific issues remain widely absent from most participants' representation of ASD. Recommendations are provided to improve the detection of ASD in girls.

**Keywords**: neurodevelopmental disorders, screening, gender, early childhood, first-line professionals.

#### Introduction

Health disparities between women and men are well-reported in adults. These disparities can be explained by factors linked to sex, gender, or the interaction between the two. Sex is a biological concept, while gender is a social construct that defines the "norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other" (1). Sex and gender are generally viewed as binary concepts. Both sex and gender impact health behaviours as well as exposure and vulnerability to risk factors, especially occupational and psychosocial (2). For instance, men tend to smoke more, while gender-based violence overwhelmingly affects women, negatively impacting their mental and physical health (3,4). We observe sex/gender disparities in many pathologies and disorders (5,6). Part of these disparities is explained by sex differences in biological systems. They play a role in the vulnerability to pathologies, their symptoms, severity, and the response to treatments (6). Often, gender is at play in generating disparities. In addition to the previously described differences in health behaviours and exposures, gender stereotypes about certain pathologies create biases in the detection of symptoms, the diagnostic process and the treatment implemented. Well-known examples include cardiovascular diseases, osteoporosis, and psychiatric conditions such as anxiety and depressive disorders (2,5,7).

In children and adolescents, the literature on sex/gender health disparities is sparse. Studies on health-related quality of life (HRQoL) do not report flagrant sex/gender disparities until the beginning of adolescence. From then, both physical and mental health tend to be poorer in girls (8-10). Nonetheless, neurodevelopmental disorders (NDDs) stand out: in this group of disorders, we observe sex/gender disparities starting in early childhood. Among NDDs, the prevalence of autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) is significantly higher in boys than in girls (11,12). While both of these conditions have long been considered as only affecting boys, there are increasing suspicions that these conditions are underdiagnosed in females. In both ASD and ADHD, a number of potential causes have been suggested: a different and/or less severe clinical presentation in girls; the current knowledge on the disorders being disproportionately influenced by male presentations; and gender stereotypes on the conditions (11,13–16). These elements are interconnected and are thought to explain the under-detection of the conditions in girls and down the line a bias in the referral, diagnosis and proposed interventions. The under-detection of ASD and ADHD is concerning because, for both, a late diagnosis is associated with higher rates of psychiatric comorbidities, substance use disorders, suicidality, and overall poor quality of life (17-20). In France, the National Health Strategy (2018-2022) highlights the importance of early detection, diagnosis and intervention for NDDs (21). But France still has sizeable progress to make. The country's delay in detecting autism and supporting autistic individuals has been heavily publicized. Between 2004 and 2014, the Council of Europe condemned France five times for discrimination against autistic<sup>1</sup> children (25). The field of psychiatry in France remains shaped by a long psychoanalytic tradition, which is believed to contribute to its delay in the field of autism, especially in women and girls (25,26). Another area of concern is that ASD is diagnosed too late. While precise epidemiological data on ASD does not exist in France, the Haute Autorité de Santé (HAS) estimates that children are diagnosed between 3-5 years old on average, while ASD can be diagnosed as early as 18 months (27,28). As for ADHD, the average age of diagnosis is around 9-10 years old in France (29). There is no consensus on the minimum age for diagnosis, with no age-related guidelines in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (30). Still, ADHD is thought to be largely underdiagnosed in adults, despite significant social and educational difficulties in childhood in many cases (31). It suggests that ADHD is under-detected in childhood and diagnosed too late. The delay in the detection and diagnosis of ADHD is significantly less publicized than ASD but remains a salient public health topic. In 2019, new recommendations for the diagnosis and support of individuals with ADHD have been requested to the HAS by the Direction Générale de la Santé (DGS) and patient associations (HyperSupers - TDAH France) but have not yet been published (32).

In this context, two priorities emerge: improving the detection of ASD and ADHD in girls and reducing the average age of diagnosis. At the intersection of these priorities, it is of interest to explore how the child's gender is accounted for in the early detection of ASD and ADHD in France. Before continuing, it is important to note that gender is not a binary concept but a spectrum with dozens of gender identities (e.g., transgender, non-binary, agender) (33). Gender incongruence – when one's gender identity does not align with their sex assigned at birth – can be experienced by children before 2-3 years old (34). An estimated 1-4.7% of children globally experience gender incongruence (35). While keeping this in mind, the lack of information on the gender identity of children in the current study forces us to make the simplifying assumption that sex is equivalent to gender and that gender is binary.

#### Current knowledge

The literature search was first carried out in English in PubMed and Scopus. To identify references specific to France, the search was then replicated in French<sup>2</sup>.

<sup>&</sup>lt;sup>1</sup> We will use the term 'autistic' rather than 'with autism' as this formulation is generally preferred by the autism community in France and abroad, despite the absence of consensus on the best terminology (22–24).

<sup>&</sup>lt;sup>2</sup> The list of keywords used in the literature search can be found in Appendix A.

#### 1. Sex/gender disparities in children's health

#### 1.1. Health status and HRQoL

If sex/gender disparities in health are well-documented in adults, data is limited in youths. The few published studies have primarily focused on HRQoL and health status. One study measured HRQoL in children aged 8-18 in Europe, including France (10). The authors observed that at 8 years, girls had poorer physical well-being and self-perception, while their scores remained close to boys. After 8, they noted a significant decline in HRQoL in both girls and boys, with a steeper decrease in girls starting at 12. Another study focused on HRQoL in children aged 5-17 in the Netherlands (8). It reported that starting in the 8-12 years old group, physical functioning was poorer in girls. In the 13-17 group, both physical and emotional functioning were lower in girls. To our knowledge, only one study included children younger than 5 years (0-19 years), measuring 44 health indicators in Asia (9). Before the beginning of adolescence, the authors observed no significant sex/gender differences in health status.

#### 1.2. Neurodevelopmental disorders

Neurodevelopmental disorders stand out in the children's health literature because sex ratios (boy:girl) are systematically high, starting during early childhood. 'Neurodevelopmental disorder' is an umbrella term for a group of conditions which affect the child's cognitive and/or affective development. NDDs impact intellectual, sensory, cognitive, motor, social and/or behavioural functioning (36,37). According to the DSM-5, NDDS include the following conditions: autism spectrum disorder (ASD); attention-deficit/hyperactivity disorder (ADHD); intellectual disabilities; communications disorders; specific learning disorder (dyslexia, dysgraphia, and dyscalculia); motor disorders; and other neurodevelopmental disorders (37).

ASD and ADHD are the disorders where sex/gender differences are the most documented. **ASD** is characterized by a dyad of impairment with a deficit in social interactions and communication as well as restrictive and repetitive behaviours, interests and activities (38). Symptom presentation varies greatly across individuals, hence the notion of the autism spectrum. In France, ASD affects 0.9 to 1.2% of children born in a given year, corresponding to around 100,000 youths and 600,000 adults living with ASD (39). The current estimated sex ratio for ASD is four boys for one girl (40). **ADHD** is defined by symptoms of inattention, hyperactivity and/or impulsivity (32). Three ADHD subtypes exist: impulsive/ hyperactive, inattentive, and combined. Symptoms can appear before 4 years old, and systematically before 12 (41). In France, its prevalence is estimated at 5% in youths and 2.5% in adults (39). The estimated sex ratio ranges between 2:1 and 10:1, with the DSM-5 reporting a 2:1 ratio (42). The global prevalence of both conditions has been increasing in the past decades. It is unclear whether this increase is caused by better identification or a real case surge (43).

#### 2. Why are neurodevelopmental disorders more prevalent in males?

#### 2.1. ASD

A combination of genetic, hormonal and environmental factors is believed to explain the male predominance in ASD (25,44). Though many hypotheses along these lines have been developed, none has received consistent empirical validation (44). Importantly, it remains uncertain whether such factors are protective for females or if they result in a different or more discreet presentation, leading to an under-detection and underdiagnosis (25). What these hypotheses have in common is that they overlook social and cultural factors (44). There is strong evidence that biological factors alone do not explain why the sex ratio is so high (45). As early as 1981, British psychiatrist Lorna Wing hypothesized that ASD is underdiagnosed in girls, especially those without intellectual deficiency (45). In epidemiological studies, sex ratios from community samples are lower than clinical samples, suggesting that some cases are missed in females outside of the clinical setting (46). If the ratio of four males for one female is most commonly cited, a 2017 meta-analysis estimated that the sex ratio is closer to 3:1 (40). Girls are also diagnosed on average later than boys, suggesting that some autistic girls are not identified by detection and diagnosis processes (46). Moreover, at similar levels of autistic traits, females are less likely to get diagnosed (47).

A potential cause of underdiagnosis in females is that their symptoms tend to differ from the typical - predominantly male - clinical presentation. The fundamental symptoms remain the same for males and females, but their expression can vary across genders (45). Some authors consider that there is a 'female ASD phenotype' (18,48,49). Ample sex/gender differences have been described in terms of socio-communication deficits. Autistic females tend to have more social attention, social motivation, empathy and social-emotional reciprocity than autistic males (25). These differences could be explained by sex/gender differences in brain organization, stemming from both intrinsic (biological) and extrinsic (social, educational) factors (25). The DSM-5 notes that socio-communicational deficits may appear less severe in females, which could be in part explained by camouflaging (45). Camouflaging corresponds to strategies allowing autistic individuals to mask part or all of their autistic traits in social settings, making them appear closer to the norm than they truly are (50). Camouflaging in females has several causes, including an increased social pressure to hide autistic traits and behave according to gender roles, and a need to circumvent feelings of isolation stemming from the bullying and ostracism often experienced by autistic individuals (51). Camouflaging can be found in both autistic males and females but is significantly more frequent in females: at equal levels of autistic traits, females tend to use significantly more camouflaging strategies (50,52,53). Late-diagnosed individuals also tend to adopt more camouflaging behaviours, a group in which females are overrepresented (52). In terms of restrictive and repetitive

behaviours, sex/gender differences have been reported as well. Females' restricted interests might be more conventional and aligned with gender norms (e.g., dolls and animals), making them harder to identify (46). Females could also present with less visible stereotyped movements but have a stronger adherence to routines (25).

Historically, research on ASD has been dominated by male participants. Since the first descriptions of ASD in 1926, case descriptions were predominantly of boys (45). Today, scientific studies on ASD still mainly include male participants: a 4-5:1 ratio is most often used for sampling (49). A formal diagnosis is generally necessary to be recruited in studies, creating an ascertainment bias against females who are already less likely to get diagnosed (44). The use of 'gold standard' diagnostic instruments to ascertain the diagnosis (e.g., the Autism Diagnostic Observation Schedule, ADOS and the Autism Diagnostic Interview, ADI) has been shown to disproportionately exclude females from samples, despite them being diagnosed (54). The male predominance in ASD research creates a 'nosological bias', which refers to gender bias in the definition of ASD, causing a bias towards male presentations in the diagnostic criteria (DSM-5 and ICD-10) and instruments (11,49). For instance, the ADOS was developed with predominantly male samples and fails to detect camouflaging (54). As a result, diagnostic instruments are poorly adapted to the specificities of ASD in females, rendering them less likely to reach diagnostic cut-offs, and less likely to be included in studies - further perpetuating the nosological bias.

The male predominance participates in gender bias in the detection, referral and diagnosis. Expectancy bias refers to "a tendency to consider and/or diagnose a condition when it is more common in a particular sex/gender or has features more closely aligned with normative behaviours of this sex" (55). It may affect educators and healthcare professionals. Educators play a key role in detecting ASD and often act as gatekeepers for referrals. In an experimental study, researchers presented primary school educators with vignettes of children with a male or female phenotype and either a boy or girl name. Participants were significantly more likely to identify ASD in males (regardless of the phenotype) and in children with the male phenotype (regardless of gender). Girls with a female phenotype were significantly less likely to be identified, suggesting important gender bias (56). A similar study with experienced ASD diagnosticians did not find expectancy bias. It did show that participants were significantly more confident in assessing males for ASD than females. While encouraging, these results should be nuanced by potential selection bias: as convenience sampling was used, we cannot exclude the possibility that participants with heightened interest or sensitivity to the topic volunteered (55). Qualitative studies on autistic females show that among healthcare professionals, a maledominated perception of ASD is common (18,25,57). It often results in lengthy and complex diagnostic processes, dismissal and skepticism from professionals.

Having comorbid or secondary psychiatric disorders can increase the risk of a missed or delayed ASD diagnosis. It is frequent for disorders such as other NDDs, anxiety disorders, depression and eating disorders to overshadow an undiagnosed ASD (18,45,49). Other conditions, such as borderline personality disorder, might be misdiagnosed in place of ASD (49). Autistic individuals are at greater risk of developing a psychiatric disorder than their non-autistic counterparts, but certain studies suggest that autistic females, especially starting in adolescence, are even more at risk (45,48). Psychiatric disorders can be comorbid or secondary to their autism (18,58,58). Finally, externalizing problems are more frequent in autistic males, which can facilitate the identification of ASD (11). Externalizing problems are defined as "[occurring] in interaction with the social environment", while internalizing problems are "focused on the own self" (e.g., anxiety, withdrawal, depression) (59). Internalizing problems are harder to notice and are more prevalent in females (18). The weight of social expectations for females as well as the burden of camouflaging could explain the higher rates of internalizing problems in this group (25,48).

Figure 1 summarizes the determinants of under-detection and underdiagnosis of ASD in and will serve as an analytical framework for this study (see Materials and Methods section).



Fig. 1: Analytical framework (ASD) inferred from the review of the literature

# 2.2. ADHD

Similar to ASD, genetic and hormonal factors are believed to contribute to the sex ratio. The 'female protective effect' hypothesis holds that girls need a greater genetic load to experience

the same degree of impairment as boys (15). Yet, sex ratios are higher in clinic-referred samples than in community samples, pointing toward underdiagnosis in females (15). Girls are also, on average, older when they are first referred for diagnosis and diagnosed with ADHD (14). So, beyond biological factors, social, historical and clinical factors are believed to cause an under-detection and underdiagnosis of ADHD in girls.

The most commonly cited hypothesis is that girls tend to have a different ADHD symptomatology than boys, making them harder to detect. Girls with ADHD tend to have less hyperactive and impulsive symptoms while being more likely to have an inattentive subtype than boys (60,61). Boys with ADHD tend to have more externalizing problems such as behavioural issues and aggression, in addition to hyperactivity and impulsivity (62). The 'disruptiveness hypothesis' posits that boys with ADHD will be more easily detected because they tend to disrupt classroom activities, while predominantly inattentive girls will fly under the radar (63). Consequently, girls may remain undetected until school demands require organizational skills and independent work which will evidence their difficulties, typically around middle school (62). A large study found evidence supporting this hypothesis, showing that externalizing behaviours were stronger predictors of ADHD diagnosis in girls than in boys (60). It suggests that girls without externalizing symptoms – the majority of girls with ADHD – might be overlooked. These results, also found in other studies, also suggest that externalizing symptoms in girls derive from gender norms and prompt referrals and diagnoses (60,63). It has also been hypothesized that the later age of diagnosis in females is caused by a later onset of ADHD. Yet, studies have found little evidence of gender differences in the age of onset in children, nor of late-onset ADHD in adolescence or adulthood (64,65).

Psychiatric comorbidities have been pointed out as partly explaining the underdiagnosis in girls. Girls with ADHD tend to have more internalizing problems than boys, increasing the risk of misdiagnosis or diagnosis overshadowing (16). Along these lines, girls are more frequently prescribed antidepressants before an ADHD diagnosis than boys (14). Accordingly, in children later diagnosed with ADHD, emotional symptoms were significantly more often the reason for referral in girls than in boys, while neurodevelopmental concerns were more common in boys (14). The higher rates of comorbid psychiatric conditions in diagnosed girls compared to boys could be explained by the later ADHD diagnosis, which causes or worsens psychiatric disorders. Another possibility is that girls might need more severe emotional problems or symptom severity to reach the diagnosis threshold (14,60).

Similarly to ASD, we find a male predominance in ADHD research (16). Most of the research uses clinic-referred samples, in which boys are overrepresented (15). For instance, boys were

overrepresented in the DSM-5 field studies (15). Girls and boys in clinical samples tend to have similar symptoms, which suggests that clinic-referred girls are not representative of all girls with ADHD (13). It leads to the hypothesis that the DSM-5 criteria and clinical practice are biased toward the male presentation of ADHD (60,63,65).

Finally, we must note that some researchers have suggested that ADHD is over-diagnosed in boys because the typical ADHD symptomatology corresponds to stereotypically masculine behaviours such as impulsivity, aggressiveness and dominance (66). Overdiagnosis occurs when a person receives a clinical diagnosis which would not have otherwise caused symptoms or harm (67). An overdiagnosis fails to provide net benefits to the individual because of unnecessary pharmacotherapy, stress or stigmatization, for instance (68). A scoping review found evidence of overdiagnosis and overtreatment of ADHD in youths, with a large proportion of newly diagnosed cases having milder impairment (68). An experimental study did show that child gender was a significant predictor of overdiagnosis of ADHD, with boys only being overdiagnosed (69). Nevertheless, even if overdiagnosis of ADHD is possible, it does not prevent ADHD from being underdiagnosed in other patients simultaneously, especially in females (68).

Figure 2 summarizes the determinants of under-detection and underdiagnosis of ADHD.



Fig. 2: Analytical framework (ADHD) inferred from the review of the literature

# 3. Health-related quality of life

3.1. ASD

Early diagnosis of ASD allows for access to adapted interventions and services, a more positive sense of identity, and less judgment from others (18). On the other hand, a late diagnosis bears many negative consequences. As previously noted, autistic individuals are at increased risk of developing psychiatric disorders. A late diagnosis further inflates this risk, notably for depressive disorders, suicidality and self-harm (17,18,20). Camouflaging is more prevalent in late-diagnosed individuals and can be physically and mentally exhausting (18,25,52). It can increase the risk of severe stress, anxiety, depression and a poor sense of identity (50). Finally, despite not being directly related to early diagnosis, we cannot omit that autistic women are at a very high risk of experiencing sexual violence (18,48). Their difficulties in social communication are believed to make them more vulnerable to sexual victimization, with a 2-3 fold risk compared to non-autistic women (70). Along these lines, a study of French autistic women found that close to 90% had been victims of sexual violence (70). Overall, it is evident that early diagnosis and appropriate support are integral to the promotion of HRQoL in autistic individuals.

#### 3.2. ADHD

Similar to ASD, a late diagnosis of ADHD is associated with poor HRQoL. First and foremost, ADHD is frequently comorbid with psychiatric conditions, especially depression and anxiety disorders (12,14,32). Individuals with ADHD are also at increased risk of self-harm, suicidality and substance abuse (71,72). Females with ADHD report more severe anxiety and depression than men and are at higher risk for suicide attempts (12,72). Notably, late diagnosis appears to be associated with a higher lifetime prevalence of depressive and anxiety disorders (12,14). A late diagnosis has negative consequences spanning into adulthood: a study found that regardless of gender, adults not diagnosed as children reported higher scores on the Adult ADHD Self-Report Scale (ASRS) (12). Even when diagnosed, untreated ADHD has adverse consequences in many domains of life, notably: academic and professional achievements, finances (13,73,74), social functioning and peer difficulties (42,74). A systematic review found clear evidence that ADHD treatment (pharmacological, non-pharmacological or combined) offers net benefits related to academics, occupation, social relations, addictive behaviours and self-esteem, but not to the point of the normalization of symptoms (75). Overall, the current evidence strongly supports the need for timely ADHD diagnosis and appropriate treatment.

# 4. Qualitative studies on ASD and ADHD in females

A growing body of qualitative research has explored the lived experiences of autistic girls and women (see for ex. ,18,57,76,77) and girls and women with ADHD (see for ex. ,78–81). Other qualitative studies on the topic investigate the experiences of healthcare professionals. In France, the HAS differentiates three levels of professionals in the detection process for ASD

– a typology we can reasonably extend to ADHD (38)<sup>3</sup>. First-line professionals include primary care and early childhood professionals, teachers, school nurses and school doctors as well as the *Protection Maternelle et Infantile* (Maternal and Infant Welfare services, hereinafter referred to as 'PMI'). Second-line professionals are healthcare professionals specialized in NDDs who work in multidisciplinary teams<sup>4</sup>. They are responsible for diagnosing uncomplicated cases. Third-line professionals work in highly specialized structures and intervene in more complex cases. Qualitative studies with healthcare professionals have focused on the experience of second and third-line professionals diagnosing ASD in females (see for ex. ,82,83). To our knowledge, no studies have explored the role of first-line professionals in the detection of ASD. Similarly, no qualitative studies appear to have been conducted on healthcare professionals' experience detecting and diagnosing ADHD.

# Research question and objectives

This study aimed to contribute to the current body of research on the role of child gender in the detection of ASD and ADHD by first-line professionals by answering the following question: how is child gender accounted for in the detection of autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) by first-line professionals?

More specifically, our objectives were to:

- Provide an overview of the detection and referral practices for ASD and ADHD by firstline professionals, in particular, PMI professionals in the context of health assessments in preschool.
- Understand PMI professionals' perceptions, attitudes and practices on ASD and ADHD according to child gender.
- Formulate recommendations for a better consideration of child gender in the detection of ASD and ADHD, especially in girls, by PMI professionals.

In the longer term, our results may inform upcoming training on the detection of neurodevelopmental disorders for PMI professionals in Seine-Saint-Denis.

<sup>&</sup>lt;sup>3</sup> For a visual representation, see the HAS's figure: "Pathway of the child and his/her family from the identification of warning signs to the implementation of the personalised intervention plan" in Appendix B.

<sup>&</sup>lt;sup>4</sup> Centre médico-psychologique (CMP), Centre médico-psychologique infanto juvénile (CMP-IJ), Centre médico-psycho-pédagogique (CMPP), Centre d'action médico-sociale précoce (CAMSP), pediatrics departement.

#### Materials and Methods

# 1. The French case: *Protection Maternelle et Infantile* and health assessments in preschool

#### 1.1. Overview

The PMI is a public service managed by the *Conseils départementaux*<sup>5</sup>. Its missions are articulated around children's health, maternal protection and sexual and reproductive health. It plays a role in the prevention and early detection of pathologies and disorders, including NDDs. According to the *Code de la santé publique*, the PMI must organize pre- and post-natal consultations for pregnant women; consultations for children under age six; sexual health promotion interventions; medico-social prevention interventions for pregnant women and children under age six; and the collection and treatment of epidemiological data (84).

In France, the medical follow-up of children includes 17 mandatory medical assessments between 0 and 6 years old. They can be carried out in PMI or community medicine<sup>6</sup>. In addition, children benefit from two health assessments at school: a health assessment in preschool (bilan de santé en école maternelle), organized by PMI professionals for children at 3-4 years; and an assessment before starting primary school, organized by the educational health services. This study uses the health assessment in preschool as a framework, as we will describe below. The objective of health assessments in preschool is the early detection of health-related difficulties that could hinder the child's development and learning. According to the Code de la Santé Publique, this assessment is mandatory (84). During the assessment, professionals are attentive to signs of psychological or neurodevelopmental difficulties. If a caregiver is present, topics such as screen use, sleep and nutrition can be discussed. If an abnormality is detected, the child is referred to adequate healthcare professionals to initiate treatment or interventions as early as possible. The child can be referred to PMI professionals (doctor, psychologist, psychomotricity therapist) or outside of the PMI (dentist, ophthalmologist, otolaryngologist, speech and language therapist, general practitioner (GP), and various public child psychiatry services<sup>7</sup>). Referrals depend on the local healthcare offering. At the national level, there is no framework defining the specific content of the assessment nor the screening tools to be used. It creates a significant heterogeneity in

<sup>&</sup>lt;sup>5</sup> In France, a *département* is a territorial unit larger than a municipality but smaller than a region. It is the equivalent of a county. The *Conseil départemental* is the governmental body of a *département*.
<sup>6</sup> We use 'community medicine' as a translation for '*médecine de ville*'.

<sup>&</sup>lt;sup>7</sup> CMP, CMP-IJ, CMPP, CAMSP or local child and adolescent psychiatry structures.

practices between territories, and in some cases between the municipalities of the same territory (85).

# 1.2. The PMI in Seine-Saint-Denis

The present study was carried out in the context of a 6-month internship in the PMI services in Seine-Saint-Denis. Seine-Saint-Denis is a territory located in the north of Paris. In 2019, its population reached 1.6 million. It is characterized by a large immigrant population and unfavourable socio-economic indicators: 27.9% of the population lives under the poverty line (14.6% nationally), and the unemployment rate is higher than the national average (11.8% vs. 8.3%). Demographically, its population is younger, with 42.6% under 29, vs. 35.1% nationally (86,87). Immigrants made up 30% of its population in 2015 - a proportion three times higher than that of France. The PMI in Seine-Saint-Denis has a strong local anchoring, with 100 PMI centers in 38 of the 40 municipalities. The territory is divided into 22 PMI districts managed by district supervisors. 1,200 professionals work in PMI services in Seine-Saint-Denis (~700 are employed by the *Conseil départemental*, 500 by municipalities): doctors, midwives, pediatric nurses (*puériculteur.rice*), childcare assistants (*auxiliaires de puériculture*), clinical psychologists, psychomotricity therapists, relationship counsellors, early childhood educators, medical secretaries and administrative staff. Significant means are dedicated to the Seine-Saint-Denis PMI, with its budget being 50 times the national average (88).

In Seine-Saint-Denis, health assessments in preschool are conducted by a pediatric nurse and a childcare assistant. Practices vary between municipalities and teams, in particular, related to the presence of a caregiver, the screening tools used, and the location of the assessment (preschool or PMI center). The assessments systematically include a vision test; a hearing test; a short language test; a psychomotricity test; height and weight measurements; and a vaccination status check. The detection of NDDs, including ASD, is one of the objectives of the health assessments, as outlined in the PMI's Public Health Project (89). Health data is collected through a standardized medical form<sup>8</sup> filled out by professionals on the day of the assessment. It contains socio-demographic information; medical history (vaccinations, birth-related information); the tests carried out; test results; and recommended referrals. The data is entered by professionals in dedicated software. Despite health assessments being mandatory, the coverage rate is far from 100%. In the 2021-2022 school year, 6,341 children benefited from a health assessment, corresponding to a coverage rate of 26.4%. 26

<sup>&</sup>lt;sup>8</sup> An example of the medical form used can be found in Appendix C.

municipalities organized health assessments with a coverage rate between 1 and 93%<sup>9</sup>. Availability of human resources and proper organization of professionals are the main determinants of the coverage rate.

# 2. Participants and procedures

# 2.1. Study design

Because no previous studies have, to our knowledge, explored the role of child gender in the detection of ASD and ADHD by first-line professionals, this study was exploratory. Qualitative methods were selected, as they can produce in-depth and rich insights into the studied topic (90). The researcher conducted semi-structured interviews between April 18<sup>th</sup> and May 31<sup>st</sup>, 2023. In semi-structured interviews, the researcher intervenes to direct the interview while allowing flexibility in the themes explored (91). More precisely, the interviewer "sets the agenda in terms of the topics covered, but the interviewee's responses determine the kinds of information produced about those topics, and the relative importance of each of them" (91). The flexibility of the semi-structured interview allows the interviewer to ask follow-up questions, change the order of the questions or skip questions altogether, depending on the participant's answers. To increase trust and facilitate building rapport, interviews were conducted in person in PMI centers whenever possible. Alternatively, they were conducted on the phone.

# 2.2. Participants

Participants were PMI professionals in Seine-Saint-Denis working in PMI centers which organized health assessments in 2021-2022. Different healthcare professions were represented: pediatric nurses and childcare assistants who conduct the health assessments, and psychologists, doctors and psychomotricity therapists who can see children referred after assessments if ASD or ADHD is suspected. Psychomotricity therapists were included after interviews had begun, as they were spontaneously recommended by most of the participants.

Different methods were used to recruit participants, depending on their profession. For doctors, nurses and childcare assistants, the director of the PMI first presented the study during a weekly meeting with the 22 district supervisors in March 2023 and asked them to provide contacts of professionals participating in health assessments in preschool. Additional participants were identified through a working group on health assessments the researcher attended. This working group aimed at elaborating a new reference framework to harmonize

<sup>&</sup>lt;sup>9</sup> The table with the coverage rate in each municipality is in Appendix D.

practices across Seine-Saint-Denis. It brought together around 20 nurses, childcare assistants and secretaries who volunteered to attend the five sessions held between February and June 2023. Finally, suggestions from the researcher's coworkers helped identify two additional professionals. To recruit psychologists, the researcher's supervisor emailed all PMI psychologists, presenting the study and asking for volunteers to contact the researcher directly. Psychomotricity therapists were recruited through snowball sampling: during interviews, participants recommended two psychomotricity therapists interested in autism. The main reason for the refusal to participate was not currently contributing to health assessments. Potential participants were contacted by email by the researcher. The email contained a brief presentation of the study, the expected length of the interview, and explained that participation was voluntary and anonymous. On the day of the interview, the researcher presented the study again and answered any questions the participant had. The interviewee's verbal consent to participate and record the interview was obtained. If the participant did not consent to the recording, the interviewer took detailed notes during the interview.

#### 2.3. Interview guide

Two versions of the interview guide were developed<sup>10</sup>: 1) nurse and childcare assistant and 2) psychologist and doctor. The second version was used with psychomotricity therapists. The core questions remained the same, but each version was adapted to the role of each professional in health assessments. The interview guide was developed based on the review of the literature presented in the Current Knowledge section. It started with a brief introductory section about the participant's career, their activities in PMI and their role in health assessments. The second section aimed at understanding detection and referral practices for ASD and ADHD, irrespective of gender. Themes included the warning signs identified, which referrals professionals made, and the difficulties experienced with referrals. The third section addressed the professional's observations, perceptions and attitudes on the interaction between ASD/ADHD and child gender. Participants first shared their observations. They were then asked to formulate potential explanations for the current sex ratio in ASD/ADHD. Their perceptions of the main hypotheses on the underdiagnosis of ASD and ADHD were explored. The last part of the interview guide was meant to open up the conversation on the role of PMI professionals in the early detection of NDDs. Participants were asked what they believed their role was in the detection of NDDs and what could help them fulfill this mission better.

<sup>&</sup>lt;sup>10</sup> An example of interview guide is in Appendix E.

Several steps were undertaken to check the validity of the interview guide. First, exchanges with child and adolescent psychiatrists specialized in ASD and ADHD ensured that the questions were medically accurate. Then, a graduate student in clinical psychology with expertise working with children with NDDs, including ASD, provided feedback on the psychologist/doctor version. To make the questions as reflective of the reality of the field as possible, the researcher spent a morning observing health assessments in a preschool in Aulnay-sous-Bois. She also attended three sessions of the aforementioned working group on health assessments. Finally, two pilot interviews were conducted with a pediatric nurse and a childcare assistant with experience conducting health assessments in Seine-Saint-Denis. Their feedback was used to adjust the interview guide as needed and reach a finalized version. These interviews were not included in the final sample.

#### 3. Analyses

Interviews were transcribed verbatim and anonymized. First, all the transcripts were read to identify emerging themes. The interviews were then coded in the qualitative research software NVivo (QSR International, Release 1.7.1) based on a pre-defined codebook. Descriptive codes followed the interview guide and were developed before the interviews were conducted. Interpretive codes reflected emerging themes identified after reading the transcripts. The codebook was adjusted iteratively throughout the coding process, with modifications made to the granularity of the codes. To structure the analysis and the reporting of results, two analytical frameworks were developed based on the review of the literature (Fig. 1 and 2). The frameworks respectively describe the main determinants of under-detection and underdiagnosis of ASD and ADHD in females. Each determinant in bold represented an axis for the analysis and reporting of results. While these frameworks served as guides, emerging themes which did not strictly fit into them were still explored.

#### Results

Twenty-one interviews were conducted, covering 16 municipalities as shown in Figure 3 (92 modified): Aulnay-sous-Bois (2), Bobigny (1), Bondy (1), Clichy-sous-Bois (1), Dugny (1), Epinay-sur-Seine (1), La Courneuve (1), Livry-Gargan (2), Montreuil (7), Pantin (2), Pavillons-sous-Bois (1), Saint-Denis (1), Saint-Ouen (2), Stains (1), Vaujours (1), Villetaneuse (1)<sup>11</sup>.

<sup>&</sup>lt;sup>11</sup> Doctors, psychologists and psychomotricity therapists usually work in more than one municipality, so the total exceeds the number of participants.



Fig. 3: Map of Seine-Saint-Denis with municipalities covered by interviews

Nineteen interviews were conducted in person, and two over the phone. All but one participant consented to the recording. Participants included seven pediatric nurses, five childcare assistants, five psychologists, two doctors and two psychomotricity therapists, with on average 10 years of work experience in PMI in Seine-Saint-Denis. Two participants were men. Interviews lasted 50 minutes on average and data saturation was reached. Quotes were left in French to maintain authenticity. An English translation is available in Appendix F, with hyperlinks to the corresponding quotes in the text. For quotes, the following participant IDs are used: PDE refers to nurses, AP to childcare assistants, PSY to psychologists, MD to doctors, and PMT to psychomotricity therapists.

# 1. Detection of ASD and ADHD and referrals practices

# 1.1. Detection

All nurses and childcare assistants noted that health assessments are not a key moment to detect ASD, as most children are detected and/or diagnosed earlier than 4 years old. But they can be useful to identify children who had remained undetected or are not receiving support. They can also allow to touch base with parents in denial of their child's difficulties. Four participants (PDE06, AP07, AP14, AP15), mainly childcare assistants, pointed out that health assessments are not meant to detect ASD, referring to the absence of a formalized test:

« Maintenant l'autisme (...) pour les bilans, je suis pas chargée de ça. Je suis chargé des yeux, du visuel, de l'audio. C'est déjà des trucs fondamentaux. Après quand déjà ça je peux pas le faire, c'est [qu'il] y a un autre problème donc je passe le relai à la puéricultrice et au médecin. Ça dépasse mes compétences (...) » (AP15, <u>Quote1</u>)

Nearly all nurses and childcare assistants still frequently detect signs suggestive of ASD in health assessments. Both doctors reported systematically screening for ASD in consultations with children under age two but rarely saw children referred after health assessments. Psychologists and psychomotricity therapists all reported seeing many children with signs of ASD, but they are generally referred to them at younger ages. Referrals after health assessments for ASD-related concerns still occur occasionally.

Conversely, it was significantly less frequent for participants to detect signs of ADHD, be it during assessments or in follow-up consultations. Several reasons could explain this. As seven participants from all professions except psychomotricity therapists noted, 4 is rather young to detect ADHD symptoms. The health assessments last a short time (usually ~30min), which three professionals (PDE05, PDE08, AP11) believed was too brief to properly detect signs of ADHD. Finally, four professionals (MD02, MD04, PDE13, AP17) noted that it was not unusual for children to be agitated or hyperactive in preschool, as pointed out by this participant:

« [Le] TDAH, je suis étonnée que vous en parliez dans le cadre de bilan de santé en école maternelle. Parce qu'on pose jamais ce diagnostic avant 6 ans, c'est plutôt un diagnostic d'école élémentaire. Parce que c'est quand même assez habituel d'être hyperactif. » (MD02, Q2)

All nurses and three out of five childcare assistants still reported occasionally seeing agitation, fidgeting and difficulty concentrating. These can all be signs of ADHD but also remain non-specific and could be explained by many factors other than ADHD. Overall, ADHD was significantly less talked about in interviews, despite the same number of questions planned in the interview guide. In eight out of 21 interviews, ADHD was not talked about at all, either because the children were considered too young (MD02, PSY16, PSY19), the children were not seen long enough (AP11), the participant never saw children with ADHD (PMT20, PMT21), or we ran out of interview time (PSY01, PSY03). In most ADHD-related questions, participants tended to provide much briefer answers and probing generally failed to bring out more information. It quickly became apparent that participants had significantly less experience with ADHD than with ASD. The topic was usually rapidly forsaken. Due to the scarcity of results, we will not expand on ADHD further.

#### 1.2. Referrals

If ASD is suspected, professionals juggle a variety of referrals within or outside of the PMI. Nurses tend to make referrals to the PMI doctor and/or psychomotricity therapist first. Nurses appeared to favour referrals to other PMI professionals, while doctors, psychologists and psychomotricity therapists all systematically referred outside of the PMI, sometimes in addition to internal referrals. External referrals can be made to public child psychiatry services (CMP, CMPP, CAMSP, hospitals in Seine-Saint-Denis or Paris) or other healthcare professionals, mainly speech and language therapists. PMI psychologists can be solicited in second intention, as a few professionals (MD04, PDE06, PDE12, PDE13) noted that parents more easily accepted consultations with psychomotricity therapists than psychologists. This sentiment was echoed by two psychologists (PSY03, PSY16). Nonetheless, the lack of doctors and psychomotricity therapists in PMI complicates internal referrals, as spontaneously mentioned by 12 participants across all professions. A common thread in interviews is that professionals face significant difficulties with referrals, with all but two participants (AP11, PMT20) expressing struggles. Public child psychiatry services have very long wait times, sometimes up to 3 years. Supply-related factors, including the growing proportion of unfilled positions were mentioned by 11 participants across all professions except psychomotricity therapists. Two participants (PDE08, AP15) also pointed out that the increasing prevalence of neurodevelopmental and mental disorders in youths contributed to the difficulties experienced. This participant summarized these difficulties: « Toutes les difficultés, bien sûr qu'on les cumule. On n'a pas suffisamment de professionnels, on n'a pas forcément les moyens. Je trouve qu'en plus, on est dans une explosion de ce type de trouble et que on est hyper frustrés parce qu'on n'a pas les orientations pour.» (PDE08, Q3).

Given the lack of healthcare services downhill, the PMI frequently fills the gap while children wait for more appropriate care. Psychologists and psychomotricity therapists, in particular, tend to work with children regularly before handing over the reins, often for extended periods. While fulfilling the children's need for immediate support, it goes way beyond the PMI's original missions. Two psychologists pointed out the conflict between what they end up doing out of necessity, and what their work in PMI should be:

« Par contre, on n'est pas un lieu de soins. Donc on a vraiment besoin qu'il y ait des prises en charge qui puissent se mettre en place à l'extérieur, et actuellement c'est très difficile. » (PSY16, Q4)

« Donc nous, psychologues de PMI, on se retrouve à faire des suivis d'enfants. (...) Je me souviens avoir dit, "on se voit le temps qu'il a besoin parce que je te laisse pas dans

*la nature". On appelle le CMP et le psychologue quand on téléphone, "Ah non, mais vous commencez ?" (…) Mais on se retrouve à accompagner les enfants et c'est les limites de notre intervention. » (PSY03, Q5)* 

It is apparent that professionals make do with what they can, which can be taxing on a professional and personal level. Nearly half of the participants (nurses, psychologists and doctors) reported considerable frustration and helplessness with the lack of options for referrals. These feelings are well expressed by this psychologist:

« Et ça, ça nous atteint au niveau personnel. Parce que on se demande quel sens ça a finalement notre travail, si on a pas les moyens d'aller au bout. Et donc on a l'impression des fois d'être un pansement sur une jambe de bois. On essaie de continuer de voir les familles, mais on peut pas palier, remplacer le CMP. » (PSY16, <u>Q6</u>)

#### 1.3. The PMI's role in the detection of neurodevelopmental disorders

The great majority of participants, from all professions, confirmed that the PMI contributes to the detection of NDDs. They pointed out a number of enabling factors. First and foremost, early prevention is one of the PMI's core missions, as pointed out by nearly all participants. Four professionals (PSY03, PDE08, AP15, PMT20) underlined that the Seine-Saint-Denis PMI has strong multidisciplinary teams, which aids in the detection process. As such, it takes a holistic approach to the child's health and well-being, as described by this doctor « La chance et l'avantage qu'on a en PMI, c'est qu'on peut balayer assez large quand même. Donc on parle un peu de tous les domaines de la vie avec les parents. » (MD02, Q7). Along these lines, several participants contrasted the work in PMI with pediatricians and GPs outside of the PMI. Two participants (PDE10, AP11) explained that PMI professionals see children when they are not sick, which gives them a better idea of what the child is usually like. Five participants (MD04, PDE05, PDE08, PDE10, PSY19) also pointed out that pediatricians and GPs do not have time to detect NDDs. On the contrary, taking the time to observe the child, especially in the waiting room, is central to the work of PMI professionals. As noted by five participants (PSY03, MD04, PDE05, PDE13, AP17), child observation is a great help in detecting signs of abnormal development:

« Et je trouve qu'on prend plus le temps en PMI, alors les médecins peut-être prennent pas le temps.(...) On est des professionnels dans la salle d'attente, on va avoir plus de temps d'observer les enfants et je pense que c'est grâce à cette observation-là qu'on peut plus déceler. Parce qu'en cabinet de ville, il y a personne pour observer dans la salle d'attente, donc personne va dire au médecin... » (PDE13, <u>Q8</u>) Finally, compared to other community medicine services, a nurse (PDE10) pointed out that the PMI offers unconditional and free services, which ensures that all children can be seen by professionals.

These enabling factors need to be contrasted with a generalized feeling that professionals lack the appropriate training to fulfill those missions, with clear patterns depending on the profession. None of the nurses and childcare assistants reported receiving initial training on detecting NDDs. Opportunities for continuous education appeared to be rare and hard to access. Similarly, psychologists, doctors and psychomotricity therapists generally reported low levels of initial training on the topic. Nevertheless, nearly all of them have sought continuous education, either by attending conferences or training days/programs or by documenting themselves.

# 2. Gender and ASD

# 2.1. Male predominance in ASD field / Experiences with autistic girls

To introduce the topic of gender and ASD, participants were asked whether they had noticed more autistic girls, boys or similar proportions. Most participants reported noticing more autistic boys than girls, but several patterns emerged. Six participants (PDE05, PDE08, PDE09, PDE13, PSY18, PMT21) expressed that while they did see more boys, they had never thought about it before the interview. For instance, a nurse noted:

« Parce que j'avoue, je sais même pas si on a décelé une fille. J'avoue que les garçons, oui, mais j'y avais pas pensé, mais dès que vous avez annoncé le sujet que je me suis dit, "ah ouais, on a surtout des garçons"». (PDE13, <u>Q9</u>)

Another eight participants, across all professions except doctors, had noticed a male predominance but were uncertain whether it was a generalizable observation. Expressions such as « *C'est mon ressenti personnel* » (PDE10, PDE06, Q10), « *j'ai l'impression* » (PDE05, PDE06, PDE10, PSY16, AP17, Q11), « *comme ça, de tête* » (PDE12, Q12), « *c'est que mon avis* » (AP15, Q13) expressed a significant level of uncertainty and a feeling of subjectivity. Six participants did confidently note that ASD was more common in males and knew it to be true. This observation only held true for doctors, psychologists and one psychomotricity therapist. It appears that most professionals have had much less experience with autistic girls than boys, as suggested by this psychologist: « *Mais à vrai dire, j'ai beau penser, je me souviens, pas d'avoir vu tellement de filles avec ce syndrome* » (PSY18, Q14).

For participants who were unsure that ASD was truly more prevalent in males, the researcher confirmed it. Participants where then asked to reflect on why it might be the case. Only one participant (PMT20) had a clear idea of the answer, having received training on ASD in females. Others were uncertain, along a spectrum. They ranged from never having heard of

or thought about it, to being familiar with hypotheses but not knowing their level of veracity. The following quotes demonstrate the varying levels of familiarity: *« Bonne question... [réfléchit]. Non, c'est une question [que] je me suis jamais posée. »* (PSY16, Q15); *« Je trouve que c'est vraiment très mystérieux le TSA. Moi, c'est quelque chose qui me pose question, et je me demande si y a pas quand même un gène quelque part qui fait que. »* (PDE12, Q16); *« Mais je me suis toujours posé la question, pourquoi plus les garçons ? »* (AP15, Q17); *« Je ne sais pas, il y a des études qui sont faites sur le plan génétique sur cette question.là. »* (PSY19, Q18). While the first participant (PSY16) had never considered the question, the last one (PSY19) was aware of published studies, nonetheless without having a clear understanding of the topic. Participants were then encouraged to formulate hypotheses. Biological causes, spanning genetic, hormonal and neurological factors were the most frequently cited across all professions. Social and cultural factors, such as underdiagnosis and gender bias, remained largely absent from responses. A doctor even expressed skepticism about the role of social factors:

« La carte sociale, sociétale je l'accroche pas trop. Ça doit jouer peut-être pour le timing du repérage. Si on regarde ceux qui sont dépistés à un moment donné, peut-être que ça le sera plus tard, mais pas 10 ans plus tard. Enfin, je ne pense pas. » (MD04, Q19)

#### 2.2. Female autism phenotype

When asked whether they had noticed different symptomatology in autistic children based on gender, most professionals said no. The five participants (PDE08, PDE12, AP15, PSY16, PMT21) who said they did perhaps notice differences were careful to underline that it was specific to their experience and not generalizable. The lack of experience working with autistic children, especially girls, appeared to render the comparison difficult. Nonetheless, a common observation pointed out by five participants (PSY01, PDE09, PDE10, PDE12, PSY18) was that the symptomatology varied significantly between children, irrespective of the child's gender: *« Puis après je pense que c'est le degré de TSA, c'est pas forcément une différence filles-garçons. Parce qu'il y a aussi plusieurs degrés. »* (PDE10, Q20).

While answers on potentially observed differences between girls and boys are inconclusive, we can explore which symptoms participants mentioned when thinking about ASD in general. Early in the interview, professionals were asked which potential signs of ASD they usually identified in children. The signs reported most often were language disorders or absence (14 participants; all professions); shouting (PDE08, PDE09, PDE12, AP15, AP17); agitation or behavioural problems (8 participants; nurses, childcare assistants and a psychomotricity therapist); a lack of social interaction or withdrawal (8 participants; all professions); and lack of eye contact (MD04, AP14, PSY16, PSY18). Referring back to the autistic dyad of impairment,

these symptoms are more characteristic of a deficit in social interactions and communication, which are known to be less severe or visible in autistic females.

The concept of camouflaging was foreign to the great majority of participants. After the interviewer explained what camouflaging entailed, two types of reactions occurred. A third of participants across all professionals except doctors, found the concept interesting and possible. The fact that women are generally expected to handle large burdens reinforced the impression that camouflaging was probable in females; a sentiment a psychologist (PSY19) and a nurse (PDE12) shared, and that the latter described well:

« le rapport que j'ai par rapport à ça, c'est que dans les décennies précédentes, une femme qui montrait ses faiblesses c'était pas bien parce qu'il fallait vraiment qu'elle porte : qu'elle porte le foyer, qu'elle porte les enfants, qu'elle porte le mari, qu'elle porte la famille. Et je pense que malheureusement, comme c'est quelque chose qui est inscrit depuis des générations, on a un peu cette tendance à vouloir un peu tout porter. Et je pense sincèrement, même quand on a des difficultés qui sont visibles, on essaie de les garder et de porter les choses. » (PDE12, Q21)

Yet, three participants (PSY01, PDE05, PDE08) were more skeptical, as they doubted that camouflaging could be present in children as young as those seen in PMI:

« Enfin 'camouflage', ce terme convient pas si on parle d'autisme. (...) Enfin, y a pas de démarche de camouflage propre dans ce syndrome-là, c'est pas possible. » (PSY01, <u>Q22</u>)

« J'y crois pas, parce que les enfants qu'on voit ici sont tellement petits, comment ils peuvent camoufler ? Je sais pas, je pense pas, j'ai pas l'impression qu'une fille puisse camoufler. » (PDE05, <u>Q23</u>)

A final consideration pointed out by two psychologists (PSY16, PSY19) is that they tend to see children with more significant impairments, hence who could not have gone undetected. One of them noted that children with lower levels of impairment or higher levels of compensating behaviours - where girls are overrepresented - could then be missed:

« Nous, les enfants qu'on rencontre, c'est des autismes plutôt sévères, donc c'est difficile de passer à côté, filles et garçons. Alors effectivement, peut-être que ça sera les chiffres qui concerneraient les autismes qu'on dit de haut-niveau, où là, peut-être que les filles compensent et puis qu'on passe à côté. Mais dans ce cas-là, l'hypothèse pour moi elle pourrait se confirmer, mais moins pour les situations que nous on rencontre en PMI. » (PSY16, <u>Q24</u>)

#### 2.3. Secondary/comorbid psychiatric conditions

Diagnosis overshadowing/misdiagnosis was spontaneously mentioned by one participant only (PMT20), who had significant knowledge of ASD in females. Her answer links camouflaging behaviours and secondary psychiatric conditions, resulting in diagnosis overshadowing or misdiagnosis:

« Et donc elles ont tendance à avoir un niveau de compensation qui est plus important, et où il va y avoir des troubles qui vont apparaître qui seront liés à l'autisme mais qui vont passer un peu dans la population standard pour des choses [que] la société associe plutôt aux femmes, qui vont être l'anxiété et puis des symptômes un peu comme ça, qui seront pas forcément rattachés tout de suite à l'autisme. » (PMT20, <u>Q25</u>)

Overall, the role of secondary or comorbid psychiatric conditions was difficult to assess in interviews since first-line professionals do not diagnose psychiatric conditions. For this reason, we had not planned questions on the topic in the interview guide.

#### 2.4. Possibilities of underdiagnosis

During the interview, the researcher presented the possibility that ASD was underdiagnosed in females communicating the results of the 2017 meta-analysis that estimated a 3:1 sex ratio rather than 4:1 (40). Participants were asked to reflect on the underdiagnosis of ASD in females. Fourteen participants (nurses, childcare assistants and psychologists) heard about this topic for the first time during the interview. The rest were aware that ASD could be underdiagnosed in females, but their level of familiarity and understanding of the phenomenon was generally low. For instance, they may have vaguely heard of the concept without having a concrete understanding, such as a psychomotricity therapist (PMT21) who noted having read that ASD was under-detected in girls in the « Plan Autisme » (National Strategy for Neurodevelopmental Disorders) but did not know more. In four occurrences, the notion of underdiagnosis made the participants think of women diagnosed in adolescence or adulthood, which illustrates the possibility of 'slipping through the cracks' of detection and diagnostic procedures. Participants recalled hearing these stories from a variety of sources, including the specialized press (PDE10), magazines (PMT21), acquaintances (PSY01), or past professional experiences (PSY19). One participant only (PMT20) had a clear understanding of the topic and underlined the risks associated with underdiagnosis, including poor self-esteem, mental health issues and suicidality.

Five participants (MD02, MD04, PDE06, AP11, PSY18) formulated that if professionals are familiar with the semiology of ASD, it is not possible to overlook autistic girls. This notion is described by this nurse:

« Pourquoi il y aurait un [sous-] diagnostic si on s'en tient au comportement de l'enfant ? Fille ou garçon, si le comportement est similaire, le diagnostic peut être fait de la même façon, ou alors ça montrerait que les symptômes sont pas les mêmes. Et que du coup, on les voit moins, ils sont moins évidents et on diagnostique moins. Je sais pas [pause]. C'est une hypothèse réelle ? » (PDE06, <u>Q26</u>)

The participant intuitively formulates that this notion only holds if the symptomatology is the same regardless of child gender, which they appear to hold as true. Along these lines, when presented with the concept of underdiagnosis in girls, 12 participants of all professions intuitively hypothesized that girls might have a different presentation, rendering them less likely to be detected. Some of them mentioned potential differences which could explain this phenomenon, including a more discreet presentation (PSY18, PMT21), compensation strategies (PSY01, MD02), better language abilities (PSY19), or fewer externalizing behaviours (PDE13). Interestingly, all but two (PDE08, PDE12) of these 12 participants failed to notice any actual gender differences in symptoms in their practice.

#### 3. Overexposure to screens and 'autistic like' children

While it was not in the interview guide, the theme of overexposure to screens was spontaneously mentioned in 15 interviews, across all professions. Overexposure to screens has exploded since the Covid-19 pandemic and appears to be associated with significant damage to children's language, social communication, attention, learning and behaviours. A recurrent observation, in 15 interviews, was that the symptoms of overexposure to screens and ASD overlapped. A participant talked about "autistic like" children (MD04) in those cases. Another clearly described this phenomenon: *« je suis beaucoup confrontée à des enfants en PMI qui ont eu beaucoup d'écrans dès tout petits, et qui vont présenter une symptomatologie qui ressemble beaucoup à l'autisme dans ses manifestations »* (PMT20, Q27). It can be difficult to tease apart which children have 'real' signs of ASD and which are overexposed to screens. Six participants (PSY01, MD04, PDE10, PSY16, PSY19, PMT20) noted that reducing screen usage could lead to significant progress, while the absence of progress constituted a red flag for ASD:

« La première chose que je demande, c'est d'arrêter les écrans. Comme ça je vois quelles sont les ressources de l'enfant et quand c'est pas un TSA, les ressources sont visibles tout de suite. C'est-à-dire quand on se revoit par exemple un mois après, l'enfant a changé. Son attitude, son comportement, il a récupéré des compétences, et cetera. Quand c'est un trouble du spectre autistique, c'est beaucoup plus nuancé, voire ça a pas vraiment eu beaucoup d'effet. » (PSY19, Q28)

Three participants (MD04, PDE06, PDE13) made links between gender, ASD symptoms and screen overexposure. When reflecting on why ASD is more prevalent in males, they hypothesized that as boys tend to be more agitated, they might be more exposed to screens to manage their behaviour, which could cause autistic traits.

#### Discussion

This study's main objective was to explore how child gender is accounted for in the detection of autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) by firstline professionals. Health assessments in preschool were used as a framework for the study. Twenty-one semi-structured interviews were carried out with PMI professionals in Seine-Saint-Denis. While health assessments do not appear to act as a key detection mechanism for ASD, they can be a 'catch-up' mechanism for children who had remained undetected until then. Conversely, 4 years old is slightly too young to detect signs of ADHD. Participants had significantly less experience with ADHD, and this disorder ended up being a secondary topic.

The main finding of the study is that a large majority of participants discovered the topic of ASD in females during the interview. These results contrast with qualitative studies carried out with second and third-line professionals, where participants were familiar with the topic (82,83). Bothereau-Mariau (82) conducted semi-structured interviews with second-line speech and language therapists who participate in autism assessments in France (n = 8). Participants demonstrated a good awareness of the topic of ASD in females without intellectual deficiency, especially on the differences in symptomatology, camouflaging, the potential for diagnostic overshadowing/misdiagnosis by psychiatric conditions, and possible gender bias from professionals. Muggleton et al.'s (83) study focused on clinical psychologists and psychiatrists who conduct autism assessments in the United Kingdom (n = 14). They found that while participants believed autistic girls and boys have the same core impairments, significant differences in presentation exist. Participants were also aware that girls were underdiagnosed and referred later for assessments, with a role played by psychiatric conditions. The second and third-line professionals in these two studies were used to working with autistic females and were aware of a number of the issues at hand. On the other hand, participants in our study were largely unfamiliar and inexperienced with them. Training and experience with autistic females thus appear to be the main explanation for the discrepancy between our results and other studies. It was reflected to some extent in our data. One of the participants (PMT20) stood out as she had extensive experience working with autistic children and had received indepth training, including on ASD in females. She was the only participant with excellent knowledge on the topic, spontaneously mentioning late diagnoses in females, the role of psychiatric conditions and camouflaging to name a few. On the other hand, none of the other

participants recalled gender being mentioned in any of the - albeit scarce - training they had received on ASD.

#### The interview as a space of awareness-raising: from a non-topic to action

Participants were overwhelmingly unfamiliar with the topics on ASD in females explored in interviews. For many, it was a non-topic - something they had never considered -, as shown in the following quotes: « Je me suis jamais vraiment représenté comme ça. » (PSY01, Q29) ; « J'accueille des enfants, pas des filles et des garçons. » (AP11, Q30) ; « Je le vois pas lié au sexe, je le vois lié à l'enfant. » (PDE09, Q31). In these quotes, gender is absent from the participants' representations of ASD. As a result, the researcher ended up explaining why ASD is believed to be more prevalent in males and the potential mechanisms leading to underdetection and underdiagnosis in nearly all the interviews. Though it was not the initial goal of the study, the interview became a space of awareness-raising where participants became conscious of an issue they had not known until then. It was, for many, a moment of conscientization where a new facet of ASD came to light. An interesting dynamic emerged in two third of the interviews, where of participants frequently asked questions or placed the interviewer in a role of information-provider, for instance: « Et ca, c'est vous qui allez me l'expliquer. Ca je peux pas vous en parler [rires]. » (PSY01, Q32); « Je sais pas, peut-être que vous avez la réponse vous dans vos recherches ? » (PDE08, Q33). In an interview, the researcher "uses their skills in social interaction to get others to disclose particular kinds of information" (91). In our study, this dynamic was reversed in some instances. The researcher could have decided that the interview was not the right place and time to provide information and answer questions. Nonetheless, this study was not conducted within a research laboratory but within a local governmental body. Knowledge production was not the only aim, and our results were meant to be operationalized as they may inform future training materials for PMI professionals. For those reasons, it felt appropriate to use the interview to explain concepts and share information, as it might raise the participants' awareness of the issue, spur conversations within teams, and overall improve the reception of future training materials. The transition from knowledge to action came about in some of the interviews. A few participants voiced they would try to modify their practices to be more careful with girls in the future. For instance, this nurse reflected at the end of the interview:

« C'est top parce que ça ouvre des visions différentes [rires], de faire attention à différentes choses. C'est chouette et c'est vrai que même si on savait qu'il y avait plus de garçons, enfin concrètement on le voit vraiment, c'est vrai que faire attention aux filles c'est bien. Non c'est pas mal, on va réfléchir à tout ça. » (PDE13, Q34)

More than half of the participants, across all professions, also asked for resources to educate themselves on ASD in girls after the interview<sup>12</sup>. Informal exchanges with some participants a few weeks after interviews suggested the interview had increased their awareness of the topic and that they had explored the resources sent.

# Overexposure to screens

Overexposure to screens was the main emerging theme in interviews. Two notions are at play: the potential causal link between overexposure to screens and ASD symptoms, and genderrelated differences in screen overexposure. The deleterious impact of screen exposure on children's health and development is well-documented. There is strong evidence that screen overexposure is associated with overweight, obesity, issues with sleep latency and duration, and poor language development (93–95). However, studies on children younger than 6 tend to be of low to moderate quality, and longitudinal studies are lacking (94). In France, the *Haut Conseil de la Santé Publique* (HCSP) recommends no screen exposure before 3 years old. At all ages, they recommend no screens in the bedroom, one hour before bed and during meals (94). In a study evaluating screen exposure of 2-year-old children in the Elfe cohort (*Étude Longitudinale Française depuis l'Enfance*), Poncet et al. (95) found that only 13.5% of families adhered to 'no-screen' guidelines and 63% of children were exposed to screens daily. Another study from the Elfe cohort showed that as expected, the average screen time increases with age: it was 49 min at 2 years old, 1h09 min at 3 ½ and 1h23 at 5 ½ years old (96).

The majority of participants in our study noted that screen overexposure could lead to symptoms similar to ASD, which is consistent with the literature. Clinicians have reported this phenomenon in France and abroad (97,98). A number of epidemiological studies have confirmed an association between early intensive screen exposure and ASD-like symptoms (99–101). Several potential explanations have been put forward, with the basis that screens provide poor learning opportunities and impair parent-child interactions (100). The 'displacement hypothesis' posits that screen usage displaces "developmentally appropriate learning opportunities (e.g., imaginative play) with an attention-grabbing stimulus with little developmental value" (102). Similarly, the 'social withdrawal hypothesis' suggests that screens reduce opportunities for social interactions, which play an integral role in the development of socio-emotional skills, language and communication (102). Nonetheless, Melchior et al. (103)

<sup>&</sup>lt;sup>12</sup> The list of the resources the researcher most frequently shared can be found in Appendix G.

uncovered a non-linear relationship between the two. Using data from the Elfe cohort, they aimed at evaluating the relationship between early screen exposure and the risk of ASD as measured by the M-CHAT (Modified Checklist for Autism in Toddlers, a questionnaire which evaluates the risk of ASD in toddlers aged 16-30 months). They assessed screen exposure and M-CHAT scores at 2 years old. They found that compared to children never or infrequently exposed to screens, children exposed daily or weekly had a greater likelihood of being at intermediate risk of ASD, but a decreased likelihood of being high-risk. They point out that the cross-sectional design could explain the complex relationship observed. It is also important to note that reverse causality is possible. It has been suggested that autistic children might be more exposed to screens by their parents to manage behavioural difficulties (100). Autistic children have also been shown to be drawn to screens more than non-autistic children (102), which was pointed out by a participant:

« Là aussi y a pas mal d'hypothèses, est-ce que l'exposition aux écrans déclenche les troubles, c'est très controversé. Parce qu'en même temps, on peut penser ça, mais on peut penser qu'il y a un terrain vulnérable qui fait que l'enfant va être attiré par les écrans parce que ça vient répondre à un besoin. » (PSY16, <u>Q35</u>)

Overall, evidence still points towards an association between screen exposure and ASD-*like* symptoms, but there is no evidence of screens as a *causative agent* of ASD.

A notable difference between ASD and ASD-like symptoms is the potential for evolution. Six participants described that in children with ASD-like symptoms due to screen overexposure, the reduction or complete elimination of screens tend to be associated with a decrease in symptoms and a positive developmental trajectory. Their answers compared the immutability of the 'real' ASD symptomatology: *« il y a quand même quelque chose autour de l'enfant qui bouge pas, donc on est pas forcément dans la question de l'exposition précoce aux écrans »* (PSY01, Q36) to the fast progress observed when screens are stopped: *« en arrêtant les écrans, c'est un enfant qui est revenu au bout de plusieurs mois à un comportement et une attention tout à fait adaptée »* (PDE10, Q37). In their case study of children overexposed to screens with ASD-like symptoms, Bossière et al. (97) - two of the authors who practice in Seine-Saint-Denis - had the same observations. Two out of three children had a significantly positive evolution within 2 months of reduced screen exposure.

Three participants hypothesized that boys were more exposed to screens than girls, which could partly explain the ASD sex ratio. Beyond the fact that screens have not been established as a causative agent for ASD, this hypothesis is not backed by the literature. In France, studies from the Elfe cohort found no gender differences in screen exposure in children aged 2 to 3 ½

years (95,96). At 5 ½, boys were only exposed for an additional 10 min compared to girls (96). The literature indeed suggests that gender disparities in screen exposure start around age 5 and persist into adolescence (104). Overall, existing studies fail to demonstrate gender differences in screen exposure in children at the age of health assessments in preschool.

# Changes from the initial protocol

We originally intended to use mixed methods in this study, as we also wanted to assess the gender-specific rates of referrals for ASD and ADHD after health assessments. Upon examination of the medical form and the quantitative data available, it appeared that the data did not allow this analysis to be completed. We were able to calculate referral rates to healthcare professionals typically solicited for suspicions of NDDs (e.g., PMI psychologist, psychomotricity therapist and doctor, CMP), but we did not have access to the cause of the referral. Because these referrals are far from being specific to NDDs, the data was not granular enough to draw conclusions. The number of referrals was also too low to hope of finding statistically significant gender differences.

In the initial protocol, when deciding which professions would be eligible for inclusion, psychomotricity therapists were not chosen. After a few interviews where most participants said they frequently referred children with signs of NDDS to psychomotricity therapists, it appeared necessary to conduct interviews with them too. Due to time constraints, we were only able to include two psychomotricity therapists in the study. Future studies may consider including more psychomotricity therapists in their sample.

# Strengths & weaknesses

The present findings should be considered in light of some limitations. We had to adopt a binary and cisgender conception of gender, which is a simplifying assumption. Interestingly, transgender and gender-diverse individuals have been found to have higher rates of autism and other NDDs, including ADHD (105). A hypothesis is that autistic individuals are less likely to conform to social norms, making them freer to express their gender identity (106).

In terms of our sample, only two participants were men, which might induce bias. Nonetheless, the large majority of PMI professionals are women, so our sample is representative of the gender distribution in our population. To our knowledge, there are no studies on the role of the professional's gender in detecting ASD. Other qualitative, quantitative and mixed-methods studies on the topic have included a large majority of female participants (55,56,82,83), so our sample mirrors other studies. There could also be recruitment bias since we relied on convenience and snowball sampling. Nonetheless, since most professionals did not know much about the topic, it is unlikely that volunteers differed from non-volunteers in terms of their knowledge of the topic. Social desirability bias is also unlikely, again because most participants

were greatly unfamiliar with the topic, so would likely not know which answers would be positively viewed by the researcher.

Finally, the researcher conducted, coded and analyzed interviews alone, and also wrote the manuscript on her own. It would have been preferable for another researcher to be available to cross-check the work. Since the results were written in English (and will be translated later for restitution to professionals), this significantly limited the opportunities for feedback that the researcher's French-speaking co-workers could have provided.

This study also had strengths. It fills a gap in the literature on the role of child gender in the detection of ASD by first-line professionals. Data saturation was reached, which suggests that our sample size (n = 21) was large enough. It also included a variety of professional backgrounds, which provides a more nuanced view of the way gender is approached in PMI.

#### Conclusion

Our results strongly suggest that child gender is currently not accounted for by PMI professionals in the detection of ASD. By largely being ignored, gender-specific issues remain widely absent from many participants' representations of ASD. Due to age constraints, we were unable to draw conclusions on ADHD. We identified the lack of experience and training on gender and ASD as the main driver of our results. The lack of training reported by participants is particularly concerning since all PMI professionals are officially recognized as part of the first line by the HAS (38).

To conclude, we will formulate a few recommendations for the better consideration of child gender in the detection of neurodevelopmental disorders. In PMI, a 'suspicion of neurodevelopmental disorder' box could be included in the medical form. It would be quick for professionals to tick and would significantly improve the quality and usability of the data. When developing training materials for professionals, we recommend including a short section on gender, including the current sex ratios, notions of under-detection and underdiagnosis and clinical particularities found in girls and boys. Given the breadth of content to cover on neurodevelopmental disorders, gender should not embolize training materials under any circumstances, but it should still be mentioned. As was done in this study, further resources may be provided to professionals who wish to dig deeper into the topic. Finally, more research should be conducted to further explore first-line professionals' knowledge, conceptions and attitudes on gender and NDDs. Researchers should keep in mind that PMI professionals do not appear to be the right population to study ADHD due to age limitations. It would also be informative to conduct studies on non-PMI first-line professionals, including pediatricians, GPs, early childhood professionals, teachers, and school nurses/doctors.

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# Appendices

# Appendix A

# Keywords used in the literature search

# <u>English</u>

- sex OR gender
- disparit\* OR inequalit\* OR differenc\* OR gap
- child\* OR kid OR pediatr\* OR paediatr\*
- health OR "health status"
- "neurodevelopmental disorders" OR "neuro-developmental disorders"
- "attention deficit disorder" OR "attention deficit hyperactivity disorder" OR ADHD OR ADD
- Autis\* OR ASD OR "autism spectrum disorder"
- referr\* OR orientation OR identif\* OR assess\* OR diagnos\* OR screen\* NOT "screen"
- early OR preschool OR kindergarten

# French

- sexe OU genre
- santé
- « troubles du neuro-développement » OU « troubles du neuro-développement » OU « troubles neurodéveloppementaux »
- « trouble déficit de l'attention/hyperactivité » OU « trouble du déficit de l'attention avec ou sans hyperactivité » OU TDA/H OU TDAH
- « troubles du spectre de l'autisme » OU « troubles du spectre autistique » OU TSA OU autis\*
- « bilan de santé en école maternelle » OU « bilan de santé à 3-4 ans » OU « bilan de santé PMI » OU « bilan de santé protection maternelle et infantile »

# Appendix B

Fig. B: "Pathway of the child and his/her family from the identification of warning signs to the implementation of the personalised intervention plan" (38)



\*Paediatric psychiatry teams (children's psychiatry departments including medico-psychological centres - CMP), paediatrics departments, centres for early medico-social action (CAMSP), medico-psycho-pedagogical centres (CMPP), networks of specialised care in the diagnosis and assessment of autism or private practitioners coordinated by a doctor. † Professionals practising at autism resource centres (CRA) or at hospital centres for additional specialised opinions, namely in paediatric neurology, clinical genetics and medical imaging.

# Appendix C

# Fig. C: medical form used for health assessments

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# Appendix D

Municipality	Nber of children to see	Nber of health	% of children
	1.045	assessments carried out	seen
Aubervilliers	1 045	100	10%
Aulnay-sous-Bois	1 355	675	50%
Bagnolet	467	-	-
Bobigny	833	38	5%
Bondy	853	303	36%
Clichy-sous-Bois	495	135	21%
Coubron	83	-	-
Drancy	1 145	189	17%
Dugny	192	140	73%
Epinay-sur-Seine	765	113	15%
Gagny	500	208	42%
Gournay-sur-Marne	86	-	-
Ile-Saint-Denis	116	43	31%
La Courneuve	637	35	5%
Le Blanc Mesnil	920	-	-
Le Bourget	240	-	-
Le Pré-Saint-Gervais	194	-	-
Le Raincy	191	-	-
Les Lilas	239	-	-
Les Pavillons-sous- Bois	389	120	31%
Livry-Gargan	718	418	58%
Montfermeil	373	136	36%
Montreuil	1 413	19	1%
Neuilly-Plaisance	226	150	66%
Neuilly-sur-Marne	528	203	38%
Noisy-le-Grand	1 017	-	-
Noisy-le-Sec	670	-	-
Pantin	771	95	12%
Pierrefitte	476	276	58%
Romainville	500	-	-
Rosny-sous-Bois	722	-	-
Saint-Denis	1 725	1 608	93%
Saint-Ouen	687	272	40%
Sevran	818	428	52%
Stains	665	111	17%
Tremblay-en-France	565	-	-
Vaujours	121	70	58%
Villemomble	433	-	-
Villepinte	643	331	51%
Villetaneuse	208	125	60%

Table D: Health assessment coverage by municipality in 2021-2022

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 $\ensuremath{\textbf{Bold}}\xspace$  : municipalities eligible for inclusion in the study.

# Appendix E

Table E1: C	Driginal interview guide (nurse/childcare assistant version)
Introduction	1. Pouvez-vous vous présenter en quelques mots ?
	2. Depuis combien de temps participez-vous aux bilans de santé en école maternelle ?
	3. Pouvez-vous me raconter comment sont organisés les bilans de santé dans votre commune ?
	4. Combien de demi-journées par semaine y consacrez-vous ?
	5. Est-ce que les bilans sont réalisés à l'école ou en centre de PMI ?
	6. Est-ce que les parents sont invités à être présents ?
Repérage des TSA et TDAH en	7. Lorsque vous faites passer des bilans, est-ce qu'il vous arrive de repérer des signes évocateurs d'autisme ? <u>Si oui</u> , est-ce que vous pouvez me décrire les signes qui attirent votre attention ?
bilan	8. Lorsque vous faites passer des bilans, est-ce qu'il vous arrive de repérer des signes évocateurs de TDAH ? <u>Si oui</u> , est-ce que vous pouvez me décrire les signes qui attirent votre attention ?
	9. S'il vous arrive de soupçonner un autisme ou un TDAH, quelle démarche suivez- vous ?
	<ul> <li>Orientez-vous l'enfant vers un e professionnel.le ? <u>Si oui</u>, quel.le professionnel.le ?</li> </ul>
	<ul> <li>Est-ce-que vous échangez avec des collègues sur vos observations ? <u>Si oui</u>, quel.les collègues ? Qu'est-ce que ces échanges vous apportent ?</li> </ul>
	10. Quelles difficultés rencontrez-vous dans l'orientation, si vous en rencontrez ?
	11. Y a-t-il un échange avec les enseignant.es en amont des bilans de santé ? <u>Si oui</u> , comment est-ce-que vos échanges contribuent - ou non - dans le repérage de signes d'autisme ou TDAH ?
	12. Y a-t-il un échange avec les parents en amont ? <u>Si oui</u> , par quel moyen ? Comment est-ce-que vos échanges contribuent - ou non - dans le repérage d'autisme ou TDAH ?
Genre & TSA	13. Dans votre travail, avez-vous remarqué plus de cas d'autisme chez les filles, les garçons ou équivalent ?
	14. Quand vous pensez à l'autisme, quels symptômes vous viennent spontanément à l'esprit ?

Table E1: Original interview guide (nurse/childcare assistant version)

	15. Maintenant quand vous pensez à l'autisme spécifiquement chez une petite fille, est- ce-que vous pouvez me décrire les symptômes auxquels vous pensez ?
	16. Dans votre travail, avez-vous remarqué des symptômes différents entre les filles et les garçons ? <u>Si oui</u> , quelles différences ?
	17. Avez-vous constaté d'autres différences entre les filles et les garçons autistes ?
	18. De manière générale, il est admis qu'il y a beaucoup plus de cas d'autisme chez les garçons que chez les filles. D'après vous, qu'est-ce qui peut expliquer qu'il y a plus de cas chez les garçons ?
	<ul> <li>Que pensez-vous de l'hypothèse que les filles camouflent leurs difficultés ?</li> <li>Est-ce que vous pensez qu'il y a un sous-diagnostic des filles ? <u>Si oui</u>, pour quelles raisons ?</li> </ul>
	19. Est-ce-que vous aviez déjà entendu parler du sujet de l'autisme chez les filles ? <u>Si</u> oui, qu'est-ce qu'il en ressortait ?
	<ul> <li>Est-ce-que c'est un sujet dont vous avez déjà parlé avec des collègues ?</li> <li>Avez-vu déjà lu ou entendu des éléments sur le sujet ?</li> <li>Dans votre expérience personnelle ?</li> </ul>
	20. Est-ce-que vous avez été formé.e au repérage de l'autisme ? <u>Si oui</u> , les questions de genre ont-elles été abordées ? Quelles informations avaient été communiquées ?
Genre & TDAH	21. Dans votre travail, avez-vous remarqué plus de cas de TDAH chez les filles, les garçons ou équivalent ?
	<b>22.</b> Quand vous pensez au trouble du déficit de l'attention/TDAH, quels symptômes vous viennent spontanément à l'esprit ?
	23. Maintenant quand vous pensez au TDAH spécifiquement chez une petite fille, pouvez-vous me décrire à quels symptômes vous pensez ?
	<ul> <li>24. D'après vous, quels signes font qu'un.e enfant avec un TDAH va facilement être repéré.e ?</li> <li>Par les parents ?</li> <li>Par les enseignant.es ?</li> </ul>
	<ul> <li>25. Dans votre travail, est-ce-que vous avez remarqué des différences de symptômes entre les filles et les garçons ? <u>Si oui</u>, quelles différences ?</li> </ul>
	<b>26.</b> Certains considèrent qu'il y a un sous-diagnostic de TDAH chez les filles. Qu'est-ce que vous en pensez ?
	27. Est-ce-que vous aviez déjà entendu parler du sujet des TDAH chez les filles ? <u>Si</u> <u>oui</u> , qu'est-ce qu'il en ressortait ?

	<ul> <li>Est-ce-que c'est un sujet dont vous avez déjà parlé avec des collègues ?</li> <li>Avez-vu déjà lu ou entendu des éléments sur le sujet ?</li> <li>Dans votre expérience personnelle ?</li> </ul>
	28. Est-ce-que vous avez été formé.e au repérage du TDAH ? <u>Si oui</u> , les questions de genre ont-elles été abordées ? Quelles informations avaient été communiquées ?
Rôle de la PMI dans le repérage des	29. D'après vous, quel rôle est-ce-que la PMI a à jouer - ou non - dans le repérage des TSA et TDAH ?
TND	<b>30.</b> Qu'est-ce qui vous aiderait à mieux repérer les TND dans votre travail en PMI ? Quelles modalités ?

# Table E2: Translation

Introduction	1. Can you briefly introduce yourself?
	2. How long have you been participating in health assessments?
	3. Can you explain how health assessments are organized in your municipality?
	4. How much time each week do you dedicate to health assessments?
	5. Are the health assessments conducted in schools or in PMI?
	<b>6.</b> Are parents invited to be present?
Detection of ASD and ADHD during	7. When you conduct health assessments, do you ever detect signs of autism? <u>If yes</u> , can you describe the signs that catch your attention?
health assessments	8. When you conduct health assessments, do you ever detect signs ADHD? <u>If yes</u> , can you describe the signs that catch your attention?
	9. If you suspect autism or ADHD, which procedure do you follow?
	<ul> <li>Do you refer the child to another professional? <u>If yes</u>, which one(s)?</li> <li>Do you share your observations with colleagues? If yes, which one(s)? What do these exchanges bring you?</li> </ul>
	10. Which difficulties do you experience with referrals, if any?
	11. Do you communicate with teachers ahead of health assessments? <u>If yes</u> , how do these exchanges contribute - or not - in detecting autism or ADHD?
	12. Do you communicate with parents ahead of health assessments? <u>If yes</u> , in which ways? How do these exchanges contribute - or not - in detecting autism or ADHD?

Gender &	<b>13.</b> In practice, have you noticed more cases of autism in girls, boys or equivalent?
ASD	
	<b>14.</b> When you think about autism, which symptoms do you spontaneously think about?
	15. Now when you specifically think about autism in a little girl, can you describe the symptoms that come to mind?
	16. In your work, have you noticed different symptoms between girls and boys? <u>If yes</u> , which differences?
	17. Have you noticed any other differences between autistic girls and boys? <u>If yes</u> , which differences?
	<ul> <li>18. It is generally accepted that there are more autistic boys than girls. According to you, what could explain that there are more cases in boys?</li> <li>What do you think about the hypothesis that girls hide/mask their difficulties?</li> </ul>
	<ul> <li>Do you believe there is an underdiagnosis in girls? <u>If yes</u>, for which reasons?</li> </ul>
	<ul> <li>19. Had you ever heard of the topic of autism in girls? <u>If yes</u>, what came out of it?</li> <li>Have you ever talked about this topic with colleagues?</li> <li>Have you ever heard or read elements on the topic?</li> <li>What about your personal experience?</li> </ul>
	20. Have you received training on the detection of autism? <u>If yes</u> , was gender mentioned? Which information on it was communicated?
Gender &	21. In practice, have you noticed more cases in girls, boys or equivalent?
IDAH	22. When you think about ADHD, which symptoms do you spontaneously think about?
	<b>23.</b> Now when you specifically think about ADHD in a little girl, can you describe the symptoms that come to mind?
	<ul> <li>24. According to you, which signs will make a child with ADHD easier to detect?</li> <li>By parents?</li> <li>By teachers?</li> </ul>
	25. In your work, have you noticed different symptoms between girls and boys? <u>If yes</u> , which differences?
	26. Some consider that girls with ADHD are underdiagnosed. What do you think?
	<ul> <li>27. Had you ever heard of the topic of ADHD in girls? <u>If yes</u>, what came out of it?</li> <li>Have you ever talked about this topic with colleagues?</li> <li>Have you ever heard or read elements on the topic?</li> <li>What about your personal experience?</li> </ul>

	28. Have you received training on the detection of ADHD? <u>If yes</u> , was gender mentioned? Which information on it was communicated?
PMI's role	<b>29.</b> According to you, which role does the PMI play - or not - in the detection of ASD and ADHD?
	30. What would help you better detect neurodevelopmental disorders in PMI?

# Appendix F

# Translation of quotes

Quote 1: "Now autism (...) for the health assessments, I'm not in charge of that. I'm in charge of the eyes, the vision, the hearing. These are already fundamental things. After that, when I can't do that, it's [because] there's another problem, so I pass it on to the nurse and the doctor. It's beyond my competences (...)" (AP15)

Q2: "I'm surprised that you're talking about ADHD as part of a health in preschool. Because it's never diagnosed before the age of 6, it's rather an elementary school diagnosis. Because it's quite common to be hyperactive." (MD02)

Q3: "All the difficulties, of course we cumulate them. We don't have enough professionals, we don't necessarily have the means. What's more, I think we're seeing an explosion in this type of disorder and we're extremely frustrated because we don't have the referrals we need." (PDE08)

Q4: "Nevertheless, we're not a care centre. So, we really need care to be provided outside [of the PMI], and that's very difficult at the moment." (PSY16)

Q5: "The advantage we have in PMI is that we can cover a lot of ground. So, we talk to parents about all areas of life." (MD02)

Q6: "We, PMI psychologists, find ourselves following up children. (...) I remember saying, "We'll see each other for as long as he needs, because I'm not leaving you without support". We call the CMP and the psychologist on the phone, "Oh no, but you're starting..." (...) But we end up accompanying the children and that's the limit of our intervention." (PSY03)

Q7: "And that affects us on a personal level. Because we wonder what the point of our work is, if we don't have the means to see it through. So sometimes we feel like a band-aid on a wooden leg. We try to continue to see the families, but we can't replace the CMP." (PSY16)

Q8: "And I find that we take more time in PMI, whereas doctors perhaps don't take the time. (...) we have professionals in the waiting room, we have more time to observe the children and I think it's thanks to this observation that we can detect more [disorders]. Because in a GP/pediatrician office, there's no one to observe in the waiting room, so no one's going to tell the doctor..." (PDE13) Q9: "Because I admit, I don't even know if we've detected a girl. I admit that boys, yes, but I hadn't thought of that, but as soon as you announced the subject I thought, "oh yeah, we've got mostly boys"." (PDE13)

Q10: "It's my personal feeling" (PDE10, PDE06)

Q11: "I'm under the impression" (PDE05, PDE06, PDE10, PSY16, AP17)

Q12: "like that, off the top of my head" (PDE12)

Q13: "it's only my opinion" (AP15)

Q14: "But to tell the truth, no matter how much I think about it, I don't remember seeing so many girls with this syndrome" (PSY18)

Q15: "Good question... [thinks]. No, it's not a question I've ever asked myself." (PSY16)

Q16: "I find ASD really very mysterious. It's something I wonder about, and I wonder if there isn't a gene somewhere that makes it so." (PDE12)

Q17: "But I've always wondered, why more boys?" (AP15)

Q18: "I don't know, there are genetic studies being carried out on this issue." (PSY19)

Q19: "I don't really believe in the social card. Perhaps it has something to do with the timing of detection. If you look at the people who are detected at a given time, maybe they'll be detected later, but not 10 years later. I don't think so." (MD04)

Q20: "And then I think it's the degree of ASD, it's not necessarily a difference between boys and girls. Because there are also several degrees." (PDE10)

Q21: "the relationship I have with this is that in previous decades, a woman who showed her weaknesses was not good because she really had to carry: she had to carry the home, she had to carry the children, she had to carry the husband, she had to carry the family. And I think that unfortunately, because it's something that's been ingrained for generations, we tend to want to carry everything. And I sincerely believe that, even when we have visible difficulties, we try to hold on to them and carry things." (PDE12)

Q22: "I don't think the term 'camouflage' is not appropriate when we're talking about autism. (...) I mean, there's no such thing as camouflage in this syndrome, it's not possible." (PSY01)

Q23: "I don't believe it, because the children we see here are so small, how can they camouflage? I don't know, I don't think so, I don't think a girl can camouflage." (PDE05)

Q24: "The children see tend to have severe autism, so it's hard to miss, girls and boys alike. So maybe the numbers will be for what's called high-functioning autism, where maybe the girls compensate and we miss them. But in that case, the hypothesis for me could be confirmed, but less so for the situations we see in PMI." (PSY16)

Q25: "And so, they tend to have a greater level of compensation, and there will be disorders that will appear that are linked to autism but that will be overlooked a little in the standard population, for things society associates more with women, which will be anxiety and symptoms a little like that, which will not necessarily be immediately linked to autism." (PMT20)

Q26: "Why would there be an [under] diagnosis if we just look at the child's behaviour? Girl or boy, if the behaviour is similar, the diagnosis can be made in the same way, or else it would show that the symptoms are not the same. And that as a result, they are less visible, less obvious and less diagnosed. I don't know [pause]. Is this a real hypothesis?" (PDE06)

Q27: "In PMI, I'm often confronted with children who have be exposed to a lot of screens from a very early age, and who will present symptoms that are very similar to autism in their manifestations". (PMT20)

Q28: "The first thing I ask is that they stop using screens. That way I can see what resources the child has and when it's not ASD, the resources are visible straight away. In other words, when we see each other again, for example a month later, the child has changed. Their attitude, their behaviour, their skills have recovered, and so on. When it's ASD, it's much more nuanced, and may not really have had much effect." (PSY19)

Q29: "I've never really thought of it like that" (PSY01)

Q30: "I welcome children, not girls and boys." (AP11)

Q31: "I don't see it linked to sex, I see it linked to the child." (PDE09)

Q32: "And you'll have to explain that to me. I can't tell you about that [laughs]." (PSY01)

Q33: "I don't know, maybe you have the answer in your research?" (PDE08)

Q34: "It's great because it opens up different visions [laughs], to pay attention to different things. It's great and it's true that even if we knew there were more boys, well we can really see it, it's true that paying attention to the girls is good. We're going to think about it." (PDE13)

Q35: "There are also quite a few hypotheses about whether exposure to screens triggers disorders, which is highly controversial. Because, at the same time, you can think that, but you can also think that there is a vulnerability which means that the child will be attracted to screens because they meet a need." (PSY16)

Q36: "there's something about the child that doesn't change, so we're not necessarily talking about early exposure to screens" (PSY01)

Q37: "by giving up screens, after several months the child's behaviour and attention patterns have returned to normal." (PDE10)

# Appendix G

# List of resources shared with participants

# Scientific articles / books

Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. J Autism Dev Disord. 2016;46(10):3281–94.

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# <u>Other</u>

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Groupe d'Actions Autisme au Féminin. L'autisme au féminin: brochure à destination des professionnels de santé ; 2020. Available from: https://www.autisme-cq.com/wp-content/uploads/2020/08/Brochure\_autisme-femmes-Graaf-1.pdf

Stras &ND. Webinaire: « Le camouflage autistique : Le comprendre et le mesurer » (enregistré le 14/04/2023) ; 2023. Available from: https://www.youtube.com/watch?v=f-shvpPnK6A

# Résumé

**Titre** : Le repérage de troubles du neurodéveloppement en Protection Maternelle et Infantile : biais de genre ? Une étude exploratoire et transversale en Seine-Saint-Denis.

**Introduction**. Faisant partie des troubles du neurodéveloppement (TND), les troubles du spectre de l'autisme (TSA) et le trouble du déficit de l'attention/hyperactivité (TDAH) sont caractérisés par une prédominance masculine. Il est aujourd'hui soupçonné que ces troubles sont sous-repérés chez les filles. La Protection Maternelle et Infantile (PMI) fait partie de la première ligne pour le repérage précoce des TND, notamment durant la réalisation des bilans de santé en école maternelle (BSEM). Cette étude a pour objectif d'explorer la place du genre de l'enfant dans le repérage de signes de TSA et TDAH par les professionnel.le.s de PMI dans le cadre des BSEM.

**Méthodologie**. Une revue de la littérature scientifique a été réalisée (Pubmed et Scopus) suivie d'entretiens semi-dirigés (n=21) menés auprès de puériculteur.rices, auxiliaires de puériculture, psychologues, psychomotricien.nes et médecins de PMI en Seine-Saint-Denis. Ces entretiens visaient à comprendre leurs perceptions, attitudes et pratiques autour du repérage des TSA et TDAH. Le rôle du genre de l'enfant a été exploré. La grille d'entretien et d'analyse des données s'appuyaient sur la revue de littérature.

**Résultats.** Les entretiens ont révélé un très faible niveau de familiarité avec le sujet des TSA chez les filles. La plupart des personnes interrogées n'en avaient jamais entendu parler avant l'entretien. Le manque de formation et d'expérience avec des filles autistes a été identifié comme la principale explication. Le TDAH était un sujet secondaire dans les entretiens, les enfants vu.es en PMI étant considéré.es comme trop jeunes par les participant.es.

**Conclusion.** Nos résultats suggèrent fortement que le sexe de l'enfant n'est actuellement pas pris en compte par les professionnel.les de la PMI dans la détection des TSA. En étant largement un "non-sujet", les questions spécifiques au genre restent largement absentes de la représentation des TSA chez de nombreux.ses participant.es. Des recommandations sont formulées pour améliorer le repérage des TSA chez les filles.

**Mots clés** : troubles du neurodéveloppement, genre, professionnel.les de première ligne, Protection Maternelle et Infantile.