There is something “extra” with my child

Parent’s lived experience in the process of obtaining an ADHD diagnosis for their child.

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Preface

Since undertaking my teacher education and subsequently working as both a Primary school teacher in England, a Kindergarten teacher, and a Special Educator in Norway, I have been interested in the ways ADHD impacts not only the child themselves, but also their family. On numerous occasions, I have experienced a lack of agreement between the parents of the child and the school regarding the appropriate treatment plan, and witnessed how this impacted the management of the child's symptoms. Moreover, it stood out to me that some parents and children saw the diagnosis as something neutral or even positive, whereas others would struggle with the ADHD label. Lastly, one of the reasons for choosing this area is because I received an ADHD-diagnosis at the age of 32. I am acutely aware that an ADHD-diagnosis is interpreted differently by those affected, but for me and my family, it was immensely positive. Thus, when deciding upon the theme of the current master thesis, the decision was an easy one.

There are many people who have helped me during this year, but a special thanks must still go to my dream-team of supervisors; Kari Hagatun and Ingunn Ness. Your combined wealth of knowledge and experience, as well as the open and direct relationship we have had since day one, has been of immense importance. I would also like to thank my fellow students for their supportive and critical feedback during the presentation round of our projects. Otherwise, I would of course like to thank all my informants who chose to share their experiences and views with me.

A master thesis is a demanding and time-consuming project, particularly when combined with a 4-year-old son at home, another child on the way, and a full-time job. The support and understanding from my wife has made this period infinitely more manageable.

Conor Healy

Summary

ADHD is one of the most commonly diagnosed conditions among children and adolescents in Norway, equating to approximately one in every school class (Surén et al., 2018). Individuals with ADHD can experience a host of additional difficulties resulting not only from the condition itself, but also from the common comorbidities, which tend to increase in terms of both quantity and intensity as one becomes older (Ghandour et al., 2019). As a result of these additional difficulties, and due to the children's age, parents are a crucial group to cater for during the diagnostic process. Yet, little attention has been paid to the parents and their experiences in the ADHD screening and diagnostic process (Moen et al., 2011).

The aim of the current study is thus to gain a deeper understanding of Norwegian parents' lived experiences throughout the ADHD diagnostic process for their child. Furthermore, the study examines health professionals experience working with the parents of the patient. In order to gain an insight into this research topic, seven semi-structured interviews across two informant groups were conducted. Informant group I consisted of four parents of children with ADHD. Informant group II consisted of three health professionals from the Child and adolescent psychiatric outpatient clinic (BUP) who are involved in the screening and diagnostic process of children and adolescents. An analysis of the audio recorded and transcribed interviews was carried out using Malteruds (2012) "Systematic text condensation".

Overall, the study showed that the parent participants experience in collaborating with kindergarten\school and PPT varied enormously. However, with regards to collaboration with BUP, the experience was unanimously positive. Both informant groups emphasised the need for increased knowledge of ADHD inattentive subtype by teachers in kindergartens and schools. A further important finding was that all participants in informant group I found the ADHD diagnosis for their child to be a relief. For those parents who experienced significant resistance from their spouse, the relief of receiving a diagnosis was notably greater than for the other parent informants. In addition, informant group II raised a number of concerns regarding inconsistent ADHD assessment practises carried out at BUP, as well as having high patient numbers leading to an overemphasis on medication as a recommended treatment.

Sammendrag

ADHD er en av de hyppigst diagnostiserte tilstandene blant barn og unge i Norge, og tilsvarer omtrent én i hver skoleklasse (Surén et al., 2018). Personer med ADHD kan oppleve en rekke tilleggsvansker som ikke bare skyldes selve diagnosen, men de vanlige komorbide tilstandene, som har en tendens til å øke både når det gjelder mengde og intensitet når man blir eldre (Ghandour et al., 2019). Som følge av disse tilleggsvanskene, samt barnas alder, er foreldre en avgjørende gruppe å ivareta under diagnoseprosessen. Likevel har det vært lite oppmerksomhet i litteraturen rettet mot foreldrene og deres erfaringer med ADHD-screening og diagnoseprosessen (Moen et al., 2011).

Det overordnede målet med denne studien er derfor å få en dypere forståelse av norske foreldres levde erfaringer gjennom ADHD-diagnoseprosessen for deres barn. Videre undersøker studien helsepersonells erfaring med å jobbe med foreldrene til pasientene. For å få et innblikk i dette forskningstemaet ble det gjennomført syv semistrukturerte intervjuer på tvers av to informantgrupper. Informantgruppe I bestod av fire foreldre til barn med ADHD. Informantgruppe II bestod av tre helsepersonell fra Barne- og ungdomspsykiatrisk poliklinikk (BUP) som er involvert i screening og diagnostikk av barn og unge. En analyse av lydopptak og transkriberte intervjuer ble utført ved bruk av Malteruds (2012) «Systematisk tekstkondensering».

Samlet viser studien at foreldredeltakernes erfaring i samarbeid med barnehage\skole og PPT varierte enormt. Men angående samarbeidet med BUP var erfaringen enstemmig positiv. Begge informantgruppene understreket behovet for økt kunnskap om ADHD uoppmerksom subtype hos ansatte i barnehage og skole. Et ytterligere viktig funn var at alle deltakerne i informantgruppe I opplevde ADHD-diagnosen for deres barn som en lettelse. For de foreldrene som opplevde betydelig motstand fra ektefellen, var lettelsen ved å få en diagnose betydelig større enn for de andre foreldreinformantene. I tillegg reiste informantgruppe II en rekke bekymringer angående inkonsekvent ADHD-utredningspraksis ved BUP, samt høye pasienttall som førte til en overvekt i fokus på medisinering som anbefalt behandling.

Contents

1.0 Introduction

In the past few decades, society has gone through major changes, and areas that were previously left to the family has now become a social responsibility. In Norway, we have a support system that is organised according to the principle that people who need it should receive help (Befring & Næss, 2019). Which support service\s that will be utilised depends upon the nature of the help that is pursued. One such type of support that families have the right to seek is for children with special needs (ibid). Appropriate supporting services regarding children with special needs can include, but are not limited to; The Health Clinic (Helsestasjon), The General Practitioner, Kindergarten, School, Educational Psychology Service (PPT), Department for kindergardens\schools (Fagavdeling barnehage\skole), Child and adolescent psychiatric outpatient clinic (BUP), The habilitation service for children and young people (HABU), Physiotherapists, Occupational therapists and State special education service (Stadped).

If the patient is under 16 years of age, it is the parents who give consent for health care, and who ultimately choose the methods of treatment on behalf of the patient (Samtykke til helsehjelp, 1999, § 4-4). Thus, a significant area of focus within child welfare and mental health care for children and young people is parent counselling (Øgrim & Hvalstad 2004; NOU 12: 2000). Among other things, parent counselling aims to provide the parents with both the necessary knowledge of their child's difficulties, as well as strategies in which to facilitate the child's development (Taylor & Antshel, 2021). However, despite a long tradition of these supporting services providing help where needed, a 2018 Evidence review carried out by the National Institute for Health and Care Excellence (NICE, 2018) found that a significant number of parents do not feel their family's needs are being adequately met (NICE, 2018). This was found particularly in the cases where the children of the parents had received an Attention Deficit Hyperactivity Disorder (ADHD) diagnosis.

ADHD is one of the most commonly diagnosed conditions among children and adolescents in Norway, and is described as a neuro-developmental disorder which affects the brain's development (Surén et al., 2018). It is characterised by symptoms of inattention, hyperactivity, and impulsivity (Meerman et al., 2017; American Psychiatric Association, 2013). Based on these symptoms, the International Classification for

Disorders (ICD-11) state that there are three subgroups of ADHD; ADHD hyperactive\impulsive, ADHD Combination, and ADHD inattentive (World Health Organization, 2021).

1.1 Personal and Professional interest

When attempting to identify the theme for the current thesis, my personal and professional experience with ADHD did indeed impact my decision. I have both personal and professional knowledge of diagnosis, perhaps offering me the opportunity to see this theme from the perspective of both the family and the supporting institutions; that is to say, from both an individual perspective and system perspective.

On a personal level, I received an ADHD-diagnosis at the age of 32. I am acutely aware that receiving an ADHD-diagnosis is interpreted differently by those affected, but for me and my family, it was immensely positive. It helped answer questions I had been pondering for decades. By living undiagnosed for much of my life, and then suddenly having the knowledge and tools to mitigate the diagnoses' impact on my life has been an immense education into the ADHD. According to Dr Hannås, "Individuals receiving the ADHD diagnosis as an adolescent or an adult are a remarkable age group as they have lived with the condition for many years" (2015, p 1). It is an experience that I believe equips me with an additional perspective and a deeper insight into what children, adolescents and adults with ADHD, and their families *might* be experiencing. I emphasis the word *might*, because as the saying goes "If you've met one person with ADHD, you've met one person with ADHD" (ADHD Norge, 2022).

Professionally as a teacher in England, I have taught children both undergoing the assessment of ADHD and children who had received the diagnosis. In addition, after moving to Norway in 2017, I worked as a Kindergarten teacher, and now currently as a Special Educator for the Department of kindergartens\schools. A number of the children I have responsibility for have either received an ADHD diagnosis, or are currently undergoing an ADHD screening at BUP. My work with these three children the last year has been in collaboration with the Kindergartens, PPT and BUP. This interdisciplinary collaboration is something which has furthered my understanding as to how the diagnostic process; from raised concerns by the parents, to an ADHD assessment, is carried out. Perhaps unsurprisingly, I have learnt how the ADHD diagnostic process is far more nuanced than the perception of most who are not directly

working within the support system. In addition, I have regular contact and meetings with the child's parents. This experience has offered me some practical insight into how having a child with ADHD *can* impact a family. That which has stood out most was just how vastly different this experience can be between different families.

1.2 Project theme and research question

Once an ADHD diagnosis is given, decisions around accepting or rejecting the diagnosis, as well as the selection of appropriate treatments must be made. Decisions regarding personal matters of a child must adhere to the human rights laws mandated in; The Norwegian Constitution (Grunnloven, 2014, § 104), the UN Convention on the Rights of the Child (Barnekonvensjonen, 1989, artikkel 12), and the Children's Act (Barneloven, 1981, § 31-33). These laws aim to ensure that decisions affecting the child are made in their best interests. Furthermore, the laws emphasise that the child's views must not only be acknowledged, but should also have a degree of influence on the decisions in question.

If the patient is under 16 years of age however, it is the parents who give consent for health care, and who choose the methods of treatment on behalf of the patient (Samtykke til helsehjelp, 1999, § 4-4). The treatment selection, as well as treatment adherence and effectiveness have been shown to be influenced by a number of factors which are largely concerned with the quality of psychoeducation the parents have acquired, and their experience throughout the diagnostic process (Taylor & Antshel, 2021). Psychoeducation can be described as the provision of information and guidance about a psychological condition, in this case ADHD (Ibid). In obtaining both a comprehensive psychoeducation, *and* a satisfactory experience throughout the diagnostic process, the goal is for parents to be equipped to make informed decisions that are optimal for their child (Ibid).

Despite the large evidence base on ADHD associated treatments in the scientific literature, there exists widespread misunderstandings about the condition, and resistance to ADHD treatment among the public (Brown 2009; Meerman et al., 2017). Parents are effectively gatekeepers to evidence-based treatments for their children (Taylor & Antshel, 2021), and misconceptions of the condition has been associated with negative attitudes towards ADHD treatments (Bussing et al., 2012). Conversely, strong parental knowledge of ADHD, experiencing low levels of stigma, and positive experiences with

past providers have been reported as the strongest predictors of positive attitudes about ADHD treatment (Taylor & Antshel, 2021). Thus, in order to decrease barriers to ADHD treatments, health care providers have a determinative role in providing information to families that correct misconceptions, reduce stigma, and increase knowledge (Helsedirektoratet, 2018). Due to the children's age, parents are a crucial group to cater for during the diagnostic process. The aim of the study is therefore to gain a better insight into how parents experience the process of receiving an ADHD diagnosis for their child. Furthermore, the thesis aims to better understand the health professionals overall experience working with the parents of the patient. In order to achieve these aims, the study will include interviews with two informant groups; parents of children with an ADHD diagnosis (Informant group I), and health professionals involved in the ADHD diagnostic process (Informant group II).

As previously mentioned, ADHD is one of the most commonly diagnosed disorders among children and adolescents in Norway. In Norway, 3.8 per cent of all children have received an ADHD diagnosis by twelve years of age, meaning that, on average, there is one child in each school class with ADHD (Surén et al., 2018). With this in mind, the significance of parents making informed decisions regarding their child's ADHD diagnosis is further highlighted when looking at the host of negative consequences one can experience as a result of having the diagnosis. Perhaps even more concerning, these negative consequences have been shown to increase in terms of both quantity and intensity as one becomes older (Ghandour et al., 2019).

Due to the age of the patient, a pre-requisite to early identification and treatment of ADHD requires a level of agreement on the child's difficulties by both the support system and the parents. If the parents understanding of their child's problem is not consistent with the views of the support system, the diagnostic disagreement will likely hinder the collaborative relationship (Storhaug & Ulfseth, 2018; Ødegård & Bjørkly, 2012). This can influence the choice of measures and treatment adherence, as well as the treatment's effectiveness for the child (Yeh et al., 2004). In addition, it could significantly affect the long-term parent-child relationship (Storhaug & Ulfseth, 2018). In light of these issues, it is of great importance that the parents of the child obtain both comprehensive psychoeducation, *and* a satisfactory experience throughout the diagnostic process (Taylor & Antshel, 2021). In doing so, the parents will likely be equipped to make informed decisions that are optimal for their child.

In recognition of the determinative role that parents play in their child's ADHD diagnosis and treatment, a 2018 Evidence review was carried out by the National Institute for Health and Care Excellence (NICE, 2018). The rapport highlighted that a number of parent's felt that their concerns were not being listened to by the health professionals. Moreover, a number of parents claimed that they were not provided with adequate information of the condition by the health professionals upon request. Equally worrying, ADHD assessment practice was found to vary significantly across different clinics and regions in Norway, once again impacting the parents experience and thus their decisions (Surén et al., 2018). It is important to note that these findings are not exclusive to Norway. Indeed, several studies have shown varying practises concerning the screening, diagnostic and treatment processes of ADHD across countries (Conrad & Bergey, 2014; Polanczyk, 2007).

In response to these findings, the Ministry of Health and Care Services commissioned the Norwegian Directorate of Health in 2019 to prepare a package for the assessment of ADHD in children and young people (Helsedirektoratet, 2021). The Norwegian Directorate of Health produced a new chapter in the "pakkeforløp for psykiske lidelser blant barn og unge". The chapter entered into force from March 2022, and aims to give the health professionals clear recommendations for both the assessment and management of ADHD. Moreover, the chapter aims to provide the health professionals general principles for feedback to the child and parents after assessment:

In summary, due to the high (and increasing) prevalence of ADHD, the importance of early intervention, and the limitations concerning the screening process in Norway, the role of the parents in their child's ADHD management arguably represents a highly important area of research. Much of the research on ADHD concentrates on the school and the child's perspective. There is, however, less research on the parental perspective, and consequently, this will be the focus on the current thesis.

Based on the importance of effective collaboration between health professionals and parents in ADHD assessment and treatment, as well as the mentioned current goals from both the Norwegian Directorate of Health and the Ministry of Education, my overarching research question is the following:

How do parents experience the process of getting an ADHD diagnosis for their child and how do health professionals experience supporting the parents in this process?

As interviews were conducted on two informant groups; parents and health professionals, this question is broken up into the following:

How do parents experience the process of getting an ADHD diagnosis on their child?

How do health professionals experience supporting the parents in this process?

1.3 Thesis structure

Chapter 1 contains the introduction, and a description of the project's theme and research question. Chapter 2 provides relevant background information including the history, characteristics and associated difficulties of ADHD, it's prevalence, comorbidities, and it's aetiology. Focus is then turned to the screening and treatment process of ADHD in Norway. Here, an overview of the screening process is provided, followed by the legal framework that directs the supporting service's actions in regards to children with ADHD. Next, limitations in the screening of ADHD as well as various disputed themes around ADHD are described. Finally, an overview of the empirical research from my literature search deemed relevant to the research questions of the thesis will be presented.

Chapter 3 provides the theoretical framework for parent counselling which will later be used in the discussion of current findings. Here, counselling tradition is viewed from the humanistic perspective where particular focus is placed on Antonovsky's "Sense of Coherence" (SoC) counselling model.

In chapter 4, the method of the study is presented, that is, an introduction to qualitative methodology and semi-structured interviews, a presentation of the participant groups, the procedure and ethical considerations. Next, the way in which the data was analysed is accounted for, as well as ethical considerations. In chapter 5, the findings from the semi-structured interviews are presented individually for both informant groups, and then patterns between the two groups are explored. The discussion section in chapter 6

looks at the most important findings in light of the current literature. Finally, in chapter 7, the main findings and their implications are summarised in the conclusion, where possible future studies are accounted for.

2.0 Background

2.1 Attention Deficit Hyperactive Disorder (ADHD)

Attention Deficit Hyperactivity Disorder (ADHD) is a neuro-developmental disorder which affects the brain's development, and is characterized by symptoms of inattention, hyperactivity, and impulsivity (Meerman et al., 2017; American Psychiatric Association, 2013). Although the European ICD-10 (International Classification of Diseases and Related Health Problems, tenth edition) is used in Norway, screening for ADHD uses the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, fifth edition) diagnostic criteria (Helsedirektoratet, 2021). The symptoms must be present before the child turns twelve, appear in several different contexts, have a duration of more than six months, and must cause significant difficulties in social or school functions. Moreover, the condition must not be better explained by another disorder, such as affective disorders (American Psychiatric Association, 2013). Based on these symptoms, the International Classification for Disorders (ICD-11) state that there are three subgroups of ADHD; Predominantly inattentive, Predominantly hyperactive\impulsive, and Combination (World Health Organization, 2021).

Despite the symptomology of ADHD, as well as the common comorbidities, there are some individuals with ADHD who report that the condition is integral part of their personality, and can in fact be a positive in their life, for example with increased creativity (Hoogman et al., 2020). According to Kooij et al. (2019), some individuals with the condition are able to find a job that is suitable to their symptom profile, thus minimising its impact on one's professional life. Fleischmann and Fleischmann (2012) take this a step further by suggesting that some adults with ADHD may actually be able to use their ADHD idiosyncrasies to their advantage. There are, for example, a number of studies showing a positive link between typical ADHD behaviours and being self-employed\entrepreneurship (Lerner et al. 2016).

2.1.1 The aetiology of ADHD

When addressing the causes of ADHD, Larsson et al. (2014) explain that the genetic component has been shown to play a large part. Two studies are of particular interest here. The first is a study on twins in Sweden, where researchers found the mean heritability of ADHD among twins to be 76% (Larsson et al., 2014). The second study looked at children and adolescents with ADHD that were adopted within the first year of their life in the US. It was revealed that ADHD prevalence was considerable higher in biological parents and siblings compared to adoptive parents and siblings (Sprich et al., 2000). Taken together, the findings indicate that ADHD has a strong genetic component. However, there has also been identified a number of environmental factors that can increase the risk of an individual having ADHD. These factors are broken down into three areas; Pregnancy or early childhood risk factors (Galéra et al., 2011), Socioeconomic risk factors (Hjern et al., 2010) and Environmental contaminant risk factors (Froehlich et al., 2009).

2.1.2 Prevalence of ADHD

ADHD was originally thought to be a condition of childhood and early adolescence (Hill & Schoener, 1996; Nigg, 2013), but current evidence implies persistence into adulthood is common (Biederman et al., 2010). In an epidemiological study of 20 countries from the World Health Organization World Mental Health Surveys (Fayyad et al., 2016), it is estimated a mean worldwide prevalence of ADHD of 2.2% in school children and adolescents (see Figure 1). As already mentioned, in Norway, 3.8 per cent of all children have received an ADHD diagnosis by twelve years of age (Surén et al., 2018). These statistics are broken down in to 1.9% in pre-school children (Wichstrøm et al., 2012), and 5.4 % in boys and 2.1 % in girls for school children (Surén et al., 2018). While the overall prevalence in the population is relatively small, ADHD is among the most frequently used psychiatric diagnoses in children and young people in Norway (Surén et al., 2018), and a primary ADHD diagnosis is given in 31% of all cases referred to BUP on a national basis (Bræmnes & Indergård, 2020).

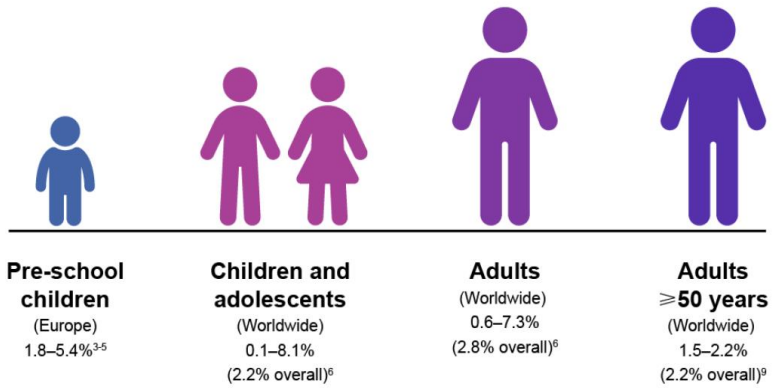

Figure 1: Summary of ADHD prevalence rates in different age groups (Fayyad et al., 2016).

2.1.3 Rising prevalence of ADHD

Amidst the dramatic expansion of ADHD prevalence rates and medication practises, various critics begun to question both the validity of the diagnosis and the increasing drug treatment of children. These viewpoints became prominent in the late nineties by both the media and a number of authors. Popular books that developed these perspectives include; "Talking back to Ritalin" (Breggin, 1998), "Ritalin Nation" (DeGrandpre, 1999), "Running on Ritalin" (Diller, 1998), "Ritalin is not the answer" (Stein, 1999), and "The totality of the ADD/ADHD fraud" (Baughman, 1998). Some query the existence of ADHD and claim that it is a culturally created disorder designed to address behavioural problems in school, or a means to make the parents' everyday life easier (Carey, 2002; Breggin, 1998). Others argue that medication as treatment is offered to families as a simple, quick-fix strategy, and one which benefits the large pharma companies from drug sales (Neufeld & Foy, 2006).

Even for those who accept the validity of the diagnosis and see the benefits of pharmacholgical treatment often are concerned with the rising statistics of children receiving an ADHD diagnosis and using medication as a treatment (Döpfner et al., 2004; Remschmidt, 2005). Folkehelseinstituttet (2007), for example, found that in children and adolescents in Norway using medicine for ADHD rose from 13000 in 2006, to 18000 in 2016. In countries with large populations such as the USA, the rise is even greater:

> From 1990 to 1995, the number of children and adolescents diagnosed in the United States rose from 950,000 to over 2.3 million, and doubled over the

following five years. In the last fifteen years of the twentieth century, the production of Ritalin in the United States increased 1700 percent. (Mazza, 2014, p1)

2.1.4 Variation in prevalence rates of ADHD

An area of concern in the ADHD literature involves not only the rising ADHD prevalence rates, but also the wide variation of ADHD prevalence rates both globally and nationally (Fayyad et al., 2017). Indeed, even within Norway, a country claimed to have a modest inequality and a universal healthcare system, a study by Surén et al. (2018) found substantial regional differences in ADHD diagnosis and medication. The main issues found in the research are twofold. Firstly, 51% of the assessed ADHD diagnoses were not documented correctly, and often lacked an assessment of alternative explanations for the symptoms. Secondly, numbers of individuals diagnosed with the condition varied significantly from county to county. For instance, county-rates of ADHD diagnosis for children aged between 6–12 vary between 1.7 % and 4.8 % for boys and between 0.4 % and 2.0 % for girls. Important to note is that these similar variations have been found for medication rates (see figure 2) (Surén et al., 2018). As already mentioned, these findings led to the Ministry of Health and Care Services commissioning the Norwegian Directorate of Health in 2019 to prepare a package for the assessment of ADHD in children and young people (Helsedirektoratet, 2021).

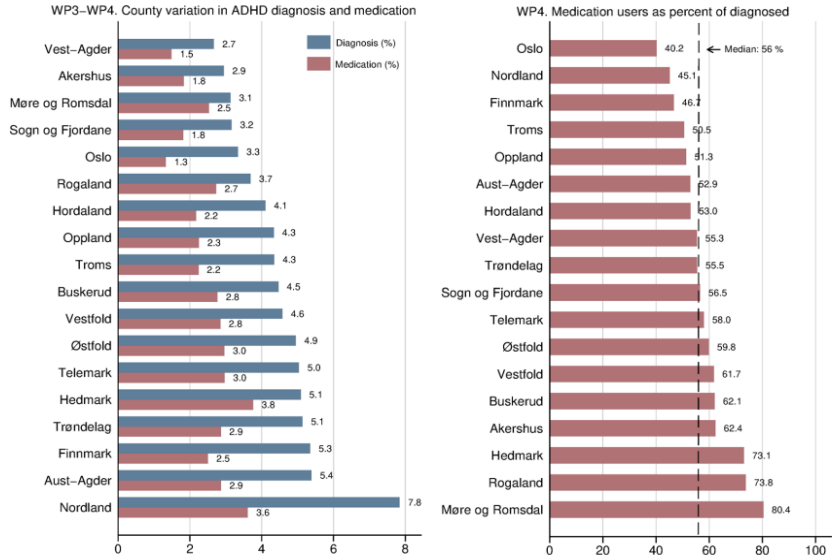

Figure 3 County variation in ADHD diagnosis and medication percent for children and adolescents between 10 and 19 years in Norway. ADHD as main diagnosis registered once or more times during 2009–2011. Registered diagnosis in NPR 2009–2011 and registered filled ADHD prescription NorPD 2012. ADHD, attention-deficit/hyperactivity disorder; NorPD, Norwegian Prescription Database; NPR, Norwegian Patient Register; WP, work package.

Figure 2: County ADHD diagnosis and medication variation (Mykletun et al., 2020)

2.1.5 The skewed sex-ratio\prevalence

Another issue concerning the reliability of ADHD prevalence rates is the large discrepancy between boys and girls. There is much research and debate around the topic of ADHD and its prevalence in gender. Data from the Attention-Deficit Hyperactivity Disorder Observational Research in Europe (ADORE) suggest that ADHD is more prevalent in males (Nøvik et al., 2006). However, it has also been suggested that ADHD is over-diagnosed in boys, and that this could be due to gender stereotype and clinicians not following the DSM requirements fully (Fresson et al., 2018). Furthermore, it is believed that girls could be under-diagnosed (Biederman et al., 2002). For example, Young et al. (2020) points out that the original diagnostic criteria for ADHD was based on hyperactive boys. This can cause gender-based biases in teachers and parents, leading to fewer referrals to healthcare professionals for girls. Moreover, in a Norwegian study, Hannås (2015) found that even when girls are referred to their General Practitioner, some faced hesitancy from them for a further referral due to differing opinions on the cause of the problem.

Some studies also reveal that girls are more likely to have the inattentive ADHD sub type, often referred to as ADD, characterised by internalising symptoms which can be less noticeable to both teachers and parents (Biederman et al., 2002). In addition, due to societies expectations on girls, Young et al. (2020) explain that girls may be more effective than boys at masking their symptoms. In contrast, the hyperactive\impulsive and combination subtypes that boys are more likely to have can present more external and noticeable hyperactive and aggressive symptoms (Biederman et al., 2002). These studies and theories are, however, contested as the large European ADORE study of clinically referred children found no evidence to suggest that core ADHD symptomatology differed between genders (Nøvik et al., 2006). Nevertheless, something that has been well established in the literature is that the ADHD male-dominant prevalence becomes weaker in adulthood (Willcutt, 2012). According to Young et al. (2020), greater self-referrals from women as they become older could underly this more balanced gender ratio.

2.2 Screening and diagnosing ADHD in children and adolescents in Norway

All diagnoses in mental health today, whether it is depression, anxiety, behavioural disorders, autism, psychosis or ADHD are based on behaviour that can be observed (adhdnorge, 2021). Thus, there currently exists no objective diagnostic test (such as a blood test or an examination with CT or MRI) to identify the pathology believed to cause ADHD type behaviours (Furman, 2009; Helsedirektoratet, 2021). Instead, an ADHD diagnosis is based on a multi-test battery, which can consist of a comprehensive clinical history, testimonies from teachers and parents, neuropsychological testing, and direct behavioural observations (Helsedirektoret, 2021; Gualtieri & Johnson, 2005). A combination of these screening tools is generally necessary for an accurate ADHD diagnosis as each tool has limitations in terms of reliability and validity (Zulueta et al., 2018).

In the context of Norway, The Norwegian Directorate of Health's national professional guidelines recommends that parents who want an ADHD examination for their child to take up the matter with the Educational Psychology Service (PPT) via the school and with their General Practitioner (Helsedirektoratet, 2021). If these parties come to the conclusion that ADHD is a possible diagnosis, the case is referred to the child and adolescent psychiatric outpatient clinic (BUP). It is at BUP that an ADHD diagnosis is provided by the expert opinions of health professionals (such as doctors, psychologists and special educators) based on a multi-test battery (Klem & Hagtvet, 2019). The multi-test battery involves observations, questionaires, and neuropsychological testing, and aims to be carried out within 6 weeks (Helsedirektoratet, 2021).

2.2.1 Limitations in the screening process and the debate of over\misdiagnosis

In respect to the prevalence figures given above, it is vital to be aware that significant limitations in the screening process of ADHD have been found internationally; the rising prevalence of ADHD, variation in prevalence rates of ADHD, the skewed sex-ratio\prevalence, as well as ADHD comorbidities hindering the screening process. These limitations have contributed to a debate internationally with two opposing perspectives. On the one hand, there is a restrictive perspective characterised by concerns about potential overdiagnosis of ADHD, leading to medicalisation of normal behaviour, unnecessary stigma, and side effects of pharmacological treatment that might not even be helpful in the presence of true ADHD. On the other hand, there is a liberal

perspective distinguished by concerns about underdiagnosis and undertreatment, which argues that increased rates of ADHD diagnosis and medication are due to improved recognition and understanding by professionals, broadened diagnostic definitions and methodological problems in the literature (Bisset et al., 2021). Differing views on the causes of ADHD are of importance to address in the current thesis. This is because these are views that are often held by parents, and the parent's beliefs in the cause of their child's ADHD has been proven to heavily influence the selected treatment options for their child (Storhaug & Ulfseth, (2018).

2.2.2 Teacher's role in referring children for an ADHD screening

The combined and hyperactive subtypes types of ADHD typically include children thought to be overemotional, immature, aggressive, and impulsive. Those with ADHD-inattentive subtype lack these characteristics and can be classified by a more passive, quiet, easily bored and introspective nature (Meerman et al., 2017). As previously mentioned, it is often the parents and teachers that first consider referring the child for an ADHD screening. Arguably, the behaviours related to the combined and hyperactive ADHD subtype *could* pose problems for teachers as well as parents (McCarthy et al., 2012). Moreover, findings from previous studies indicate that overall, teachers have little and\or inaccurate knowledge of ADHD (Lasisi et al., 2017; Kos et al., 2004), and often possess negative attitudes towards children with the condition (Lasisi et al., 2017). According to Walter et al. (2006 as cited in Meerman, 2017), this lack of knowledge can cause teachers to seek the screening for an ADHD diagnosis with less caution than necessary, potentially leading to mis\overdiagnosis of the condition. With this in mind, combined with the findings that the youngest children in class are twice as likely as their classmates to receive a diagnosis of ADHD and medication (Meerman et al., 2017), and that not only teachers, but also health professionals are unaware of this association (ibid); one can understand that many are sceptical towards both the diagnosis and the use of medication (Folkehelseinstituttet, 2017; Elder, 2010; Evans et al., 2010; Halldner et al., 2014; Morrow et al., 2012; Zoëga, Valdimarsdóttir, & Hernández-Díaz, 2012).

Furthermore, even in cases of a correct diagnoses, there exists a host of potential issues around an ADHD classification. Most of these potential issues concern labelling and low teacher and parent expectations that may become a self-fulfilling prophecy, and stigmatisation leading to a lack of inclusion (Batstra et al., 2012; Mueller et al., 2012).

Thus, several researchers believe that only those with severe diagnosis symptoms seem to benefit from diagnosis and medication, while those with mild diagnosis symptoms have worse outcomes compared with undiagnosed matches (Döpfner et al., 2004; Remschmidt, 2005). With this in mind however, Haugan and Vorkinn (2009) found that the go-to treatment in practice in Norway is that an ADHD diagnosis requires drug treatment, regardless of type and background. They highlighted that this finding was frightening as relatively little is known about the long-term effects these drugs have on a developing brain.

2.2.3 ADHD comorbidities and the screening process

Typical comorbidities that often accompany an ADHD diagnosis have already been mentioned in regards to the individual additional challenges they can bring. However, findings also highlight them as a factor which can hinder the ADHD diagnosis process. According to Katzman et al. (2017), comorbidities can make it harder to diagnose the ADHD as the symptoms of the condition can be disguised as symptoms of another disorder, such as depression, generalised anxiety disorder, or bipolar disorder. This is particularly the case if one has the ADHD inattentive subtype as it can be particularly challenging to determine whether inattention is a result of anxiety or from difficulty regulating attention due to ADHD (Katzman et al., 2017). To complicate this matter further, those with ADHD are at a higher risk for almost all anxiety disorders, where some studies place co-occurrence of anxiety with ADHD as high as 50% (Mancini et al., 1999; Katzman et al., 2017). Not only do people with ADHD have higher risk of anxiety disorders such as; agoraphobia, simple phobias, separation anxiety disorders, social phobia, and OCD (Spencer et al., 1999), but in cases where anxiety is present, this can cause ADHD symptoms to be exacerbated (Tsang, et al., 2015). Thus, early identification and treatment of ADHD may provide a better prognosis for the patient (Katzman et al., 2017), and is a current focus area by the Norwegian Government (Meld. St. 6 Kunnskapsdepartementet 2019).

2.3 ADHD treatment

After the child, adolescent or adult has received the diagnosis, there are a number of measures and treatment options that can be considered. Figure 3 illustrates the typical treatment options for ADHD in children. These treatment options are consistent with the recommended options in Norway, and are typically conducted by, or supported by BUP

(Helsedirektoratet, 2021). It is important to note that this is not an exhaustive overview of all recommendations, and that treatment can differ internationally.

Figure 3 ADHD pharmacological and non-pharmacological treatment (NICE guidelines, 2018).

A number of meta-studies have shown that a combination of both non-pharmacological and pharmacological treatments is typically most effective for individuals with ADHD (Fabiano et al., 2009; Kooij et al., 2019). The clinical recommendations for ADHD treatment however, are not a *one-size fits all* approach. Instead, clinicians, together with the patient and\or parents aim to tailor the treatment options to the individual to provide optimal management of ADHD (Helsedirektoratet, 2018). The aim of optimal management of ADHD, whether it be non-pharmacological and\or pharmacological options, is to reduce core symptoms, improve functioning in everyday life and prevent or reduce the development of additional difficulties (HelseNorge, 2020; Taylor et al., 2004). Put another way, the goal of treatment is to ensure that the benefits outweigh any unwanted adverse effects (Remschmidt, 2005).

2.3.1 Non-Pharmacological treatment

The most common forms of non-pharmacological treatment for ADHD in children and adolescents in Norway include psychoeducation, classroom interventions at kindergarten\school, and in cases where there exist behavioural difficulties from the child; Parent Management Training (HelseNorge, 2020).

Psychoeducation

The treatment selection, as well as treatment adherence and effectiveness, have been shown to be influenced by a number of factors (see Table 1). The majority of these factors concern the quality of *psychoeducation* that parents have acquired, and their experience throughout the diagnostic process (Taylor & Antshel, 2021).

Table 1: Key factors found to influence a parent's decisions regarding their child's recent ADHD diagnosis (Dillon, 2011; Harborne et al., 2004; Moen et al., 2011; Mueller et al., 2012; Taylor & Antshel, 2021).

Key factors found to influence a parent's decisions regarding their child's recent ADHD diagnosis
- How effectively the health professionals educate the parents on the condition - The parent's views of health professionals - The parent's attitude of medication and concerns around the side affects - Whether the parent perceives stigma attached to the diagnosis and\or medication - Whether the parent believes that ADHD is a medical or a psychosocial condition - Whether the parent has concerns in regards to the child's peer relations - Whether the ADHD diagnosis is seen as a relief for the parent - The parent's own research - The level of expectations at the school - The level of concern from the parent about their child's future - Whether the parent attaches their child's behaviour to their parenting competency - Whether a parent also has ADHD

According to The Directorate of Health's 'National professional guidelines for the investigation and treatment of ADHD', the first step in the treatment process is providing the patient and their family with information about the diagnosis and recommended treatment (Helsedirektoratet, 2018). Moreover, health professionals are advised to direct the parents of the child to organisations that can provide further reliable information on the condition, such as ADHD Norge. The parents must also be made aware of the rights that the child obtains when receiving the diagnosis, including the right to adapted education (Section 1-3 of the Education Act). Strong parental knowledge of ADHD has been found to alleviate misconceptions of the diagnosis and medication, reduce levels of stigma, and increase the efficacy of the patient's treatment outcomes (Taylor & Antshel, 2021).

Classroom interventions at kindergarten\school

Although the majority of students with ADHD attend mainstream schools, rather than special schools, individually adapted classroom interventions in kindergartens and school will often be necessary to help the child to function better both academically and socially (HelseNorge, 2020). Examples of such interventions could be to take frequent breaks, allowing for extra outdoor activities when necessary, providing support during transitions, a high degree of structure and predictability, allowing for extra outdoor activities and minimising visual overstimulation on the walls of the classroom (Statped, 2022).

Parent Management Training

As a result of the symptomology of ADHD, children and adolescents frequently have difficulties across multiple behavioural domains. Behavioural disorders in the form of opposition, outbursts of anger, protests, and provocation are the additional difficulties that occur most often with ADHD in children and adolescents (Helsedirektoratet, 2019). In such cases, treatment programs such as Parent Management Training (PMT) and Multisystemic therapy (MST) to reduce behavioural difficulties are offered to families.

Many studies have found positive results of such programmes, where providing guidance to parents on how to handle their own child's behaviour has been shown to improve the interaction between child and parents (Furlong et al, 2013; Modesto-Lowe et al., 2008). Moreover, Russell Barkley's study of behavioural difficulties in children with ADHD in Norway showed clear reductions in both symptoms of ADHD and other

behavioural difficulties as a result of such programs (Meltzer et al., 2006). These positive effects however, have been questioned in recent years by a number of overview analyses. For example, Sonuga-Barke et al. (2013) found a large variation in the effects of Parent Management Training.

2.3.2 Pharmacological treatment

In the cases where medication treatment is utilised in combination with arrangements at home and at school, it is a specialist doctor at BUP who is responsible for organising a systematic trial with varied doses and assessments of the side effects. This process usually takes multiple weeks, where the most commonly used medication is so-called central stimulant medication, such as Ritalin and Concerta (Helsedirektoratet, 2022). Once this process is complete, and all parties are satisfied, a treatment plan is then written up by the clinicians at BUP and sent to the appropriate parties. The child's GP is then responsible for further follow-up meetings with the child and their parents, where there will be regular re-evaluating of the individual's ADHD treatment (Helsedirektoratet, 2022). Regular re-evaluation of the treatment plan and the ongoing impact of ADHD is considered important (NICE guidelines, 2018). This is because the symptoms and comorbidities can differ in their impact on the individual over time, both in terms of personal, educational, occupational and social functioning. Some examples of typical re-evaluating of the treatment plan could be in the transition from child to adult mental health services, from school to university, and from university to full-employment (NICE guidelines, 2018).

2.4 Relevant previous research

In exploring previous research relevant to the topic of the current thesis, block searches were conducted within the two most commonly used sources for citation analysis; Web of Science and Google Scholar. In order to gain an overview of ADHD screening and treatment practices here in Norway, Directorate of Education (Utdanningsdirektoratet), The Directorate of Health (Helsedirektoratet) and ADHD Norge websites were utilized. See table 2 in Appendix 1 for a list of the key areas within the field, as well as some of the most prominent authors and researchers that were used.

In the investigation of the screening and treatment process by BUP in Norway, search words included; "ADHD", "attention deficit hyperactivity disorder", "obtaining an ADHD diagnosis in Norway" and "ADHD diagnostic process in Norway". In the

investigation of parents' experiences of having a child with an ADHD diagnosis and collaborating with supporting services, search words included; "parents of children with ADHD", "Parents' experience collaborating with ADHD health services", and "parental ADHD treatment-seeking attitudes". Truncation of some words were used to include different endings and singular and plural variants of the words. In total, the initial searches resulted in 158 hits, of which 27 were considered to be potentially relevant to the current thesis topic. Next, the abstracts and conclusions of these articles were read. Following this screening process, 19 articles were downloaded and read in full. Furthermore, the "snowball effect" was used, in which relevant articles led to further sources that were deemed relevant for the current thesis. To avoid the incision of out-of-date research findings, only articles published after 2003 were included. Moreover, to ensure quality and reliability, only articles published in peer reviewed journals were included, and it was ensured that a number of the studies were carried out in Scandinavia. In the following paragraphs, summaries of eight previous research findings considered relevant to the current thesis will be provided.

One study by Surén et al. (2018) investigated the quality of the screening and treatment process of ADHD in children\adolescents by BUP. Patient data from the Norwegian Patient Registry and population data from the Norwegian Population Registry was used to estimate the proportion of children with ADHD for both Norway as a whole and by county. The authors reviewed 549 medical records from BUP and assessed whether the diagnoses met the research criteria for ADHD. Two important findings concerning BUP's screening and treatment process of ADHD were highlighted. The first was that the proportion of children diagnosed and treated for the condition varied significantly between counties in Norway, ranging from 1.4 % and 5.5 %. Secondly, they found that only 49 % of the diagnoses were reliably documented in the records. Here, discrepancies were highlighted between the information in the medical record and diagnostic criteria and inadequate differential diagnostic assessment. Due to these findings, Surén et al. 2018 called for the guideline for evaluation, diagnostics and medical recordkeeping to be reviewed.

In 2018, the evidence-based guidelines for the diagnosis and management of ADHD were published by the National Institute for Health and Care Excellence (NICE), with new and updated recommendations that built upon the guidelines originally released in 2008. The recommendations were aimed at healthcare professionals, people with

ADHD, and their families and carers. Among other findings, the report highlighted that a number of parent's felt that their concerns were not being listened to by the health professionals. Moreover, a number of parents claimed that they were not provided with adequate information of the condition by the health professionals upon request.

A Norwegian study by Moen et al., (2011) aimed to gain a deeper understanding of Norwegian parents' lived experiences of having a child with an ADHD diagnosis. Nine qualitative interviews with parents who were members of the ADHD Association were carried out, and the interviews were analysed according to Colaizzi's method. The lived experience of the challenges of being a parent to a child with ADHD emerged as the fundamental essential structure. Here, it was shown that the unpredictability of the condition required additional energy from the parents to meet the daily challenges and the needs of their child. This additional energy often required the parents putting their individual needs aside to focus on their role as parents. Furthermore, the interaction with the parent's network and the health professionals played a significant role in either renewing the parent's strength, or diminishing it. Thus, Moen et al's. (2011) study highlighted the importance of the health professionals maintaining a dialogue with the parents, being aware of the parents' situation, as well as being sensitive to their individual needs.

A study from Bussing et al. (2012) explored factors that influence willingness to engage in treatment for ADHD. The longitudinal study in the USA obtained ADHD treatment perceptions from four stakeholder groups: 148 adolescents, 161 parents, 90 ADHD health professionals, and 122 teachers. There were significant discrepancies found among US adolescents, parents', teachers' and health professionals' willingness to use ADHD interventions. Information on the condition was highlighted as being highly influential in willingness to engage in ADHD treatment. Strong knowledge of the condition and treatment options led to higher perceptions of treatment effectiveness and lower expectations of side effects and embarrassment.

Taylor & Antshel's (2021) study in the USA aimed to establish a cause for the significant delay to ADHD treatment for many children after receiving the diagnosis despite the well-recognised association between childhood ADHD and long-term negative outcomes. The study's results aimed to highlight ways in which to decrease barriers to treatment in the cases of ADHD in children and adolescents. This objective

was carried out by examining (a) variables associated with parental treatment-seeking attitudes and information-seeking behaviours and (b) the relationship between these attitudes and behaviours in 87 non–treatment-seeking parents whose children had elevated ADHD symptoms. The study found that the strongest predictors of positive attitudes towards ADHD treatment concerned parental knowledge of ADHD, low levels of stigma, and positive experiences with past providers. Of these predictors, experience with past providers was the only factor related to treatment-seeking behaviour.

Harborne et al. (2004) recognised that although a large amount of research has been undertaken on the aetiology of ADHD, little is known about how parents of the child make sense of the variety of different aetiological models. Ten parents of nine boys, aged between eight and 11 years, were interviewed in order to investigate this issue. A key finding from the study was that a number of the parents experienced that the genetic explanation of ADHD gave them a feeling of relief. However, the data analysis from the study also showed that an issue for parents was the discrepancy in the way in which they themselves understood the causes of ADHD compared with the views from those in their network, as well as the views from the health professionals they collaborated with. The implications of these differing perspectives were as follows: (i) parents battled with professionals and family members to encourage them to share their views of the condition; (ii) parents felt blamed by professionals and family members for their children's difficulties; and (iii) parents reported experiencing significant emotional distress as a result of the differing views.

A study by Kvist et al (2013) aimed to explore the relationship between ADHD in children and parental outcomes. They used Danish register-based data on children born from 1990 to 1997 to investigate the significance of children's ADHD for parents' outcomes. They observed 172,299 pairs of parents from 1990 to 2007 of which 2457 have a firstborn child diagnosed with ADHD and 169,842 have a firstborn child without ADHD. The study found that the parents of children diagnosed with ADHD have a 75% higher probability of divorce, as well as a 7–13% lower labour supply.

In a similar study, Wymbs (2008) aimed to establish whether parents of youths with ADHD are more at risk for divorce than are parents of children without ADHD. The authors compared the rate of marital dissolution between parents of adolescents and young adults with and without ADHD by the use of survival analyses. The results from

Wymbs (2008) study also found that parents of children\adolescents diagnosed with ADHD in childhood were more likely to divorce, and the divorce process happened faster compared with parents of children without ADHD.

3.0 Theoretical framework - Parent counselling

At one point or another, parents can find themselves in situations where it is challenging to see potential opportunities and solutions, and will thus require help from an outsider. One such instance can be when the parent's child is being screened for, and\or has received a diagnosis, such as ADHD. Having children with special needs can be a source of stress for the family, and ADHD is no exception (Idan et al., 2022; Kvist et al., 2013; Wymbs et al., 2008). In such cases, the parent\s can often require help to better manage the situation. Theories related to counselling are deemed appropriate to explore in the current thesis in an attempt to better interpret and understand the experiences expressed by the parent informants. The counselling theories will also be used to better comprehend the descriptions given by the health professional informants regarding their experience of collaborating with the parents. Although it is at BUP that family counselling usually takes place, kindergartens, schools and PPT are also crucial partners in the supporting process. Thus, the fundamentals of the counselling tradition that will be explored in this section can be seen to apply not only to health professionals at BUP, but also to PPT advisors, as well as to kindergarten and school teachers.

3.1 The concept of counselling

There exists no universal definition of the special educator counsellor's role, and what the counselling process involves in practise (Tveitness & Simonsen, 2019). It can however, be understood in relation to individuals, and/or in relation to groups and organisations, that is to say at a system level. How one defines counselling will also be characterised by which tradition one chooses to view the term from. The various traditions, such as psychodynamic tradition, behavioural therapy tradition, cognitive tradition and humanistic tradition, will have different ways of defining the counsellor's role in relation to the advice seeker. In the current thesis, emphasis will be placed on the solution-focused humanistic tradition, from the works of among others; Rogers (1965), Lassen et al., (2014) and Johannessen et al., (2010). One main reason for this choice is that the humanistic counselling perspective is arguably well suited for a critical

examination of the experiences of power and powerlessness that can arise in an assessment process.

3.1.1 Empowerment

According to Lassen (2014), if one is to say that the counselling process has been successful, one should see a movement from crisis, hopelessness, and despair, towards improved functioning, hope and faith in one's own coping skills. From the perspective of the humanistic tradition of counselling however, this success is realised through supporting the advice seeker to be able to better help themselves (Johannessen et al., 2010). Thus, a central theme in counselling from a humanistic tradition perspective involves the advisor avoiding to give all the *correct answers* to the advice seeker in the process (Rogers, 1975). Instead, emphasis is placed on carrying out conversations with the advice seeker and trying to help the advice seeker to find out for themselves what is important (Johannessen et al., 2015; Lassen, 2014).

Antonovsky (1979) explains that supporting advice seekers to become self-reliant and independent is possible because all people have the inherent powers and opportunities to make their own choices and realise their potential, providing that their basic needs are met. This approach is viewed as a partnership-model, which is characterised by equality and recognition of each other's knowledge and experiences (Cunningham & Davis, 1985). This can be seen as opposed to the expert-model, where the perception is that the advisor knows best, and should tell the advice seeker what to do. The partnership-model is in line with the empowerment principle which is rooted in the belief that people are not only capable of understanding their own problems, but with support, they are also capable of finding appropriate solutions (Befring, 2019). Indeed, empowerment and ownership of the solution have been highlighted as building blocks to the success of the counselling process (Carkhuff, 2000; Befring, 2019; Mjelve 2017).

> Empowerment is an active process that reduces powerlessness and strengthens the individual's opportunities to make their own decisions about matters that relate to their own existential everyday conditions. The empowerment process creates personal growth, increased control over one's own life and changes in everyday life through the achievement of coping skills that are acquired by

> actively promoting participation and influence in common causes, organizations and the surrounding society. (Faureholm et al. 1999, 52)[1]

According to the humanistic perspective, the pillars of a successful counselling process are supported by literature regarding power dynamics. Power is a difficult phenomenon to understand. Power is both visible and invisible, something which can be used to realise both positive and negative outcomes. In general, power can be understood as the ability to achieve the goals one sets, even if they are against the interests and will of others (Elster, 1989). In a counselling perspective, the dynamics of power refers to how the professionals, be that BUP or PPT advisors, or kindergarden\school teachers, inherently have more influence and control over the clients they work with (Nordahl, 2007).

Despite the desire for equality, it is largely recognised in the literature that power imbalances are present in collaboration processes between parents and the relevant supporting institutions (Thornquist, 2009; Nordahl, 2007; Lassen, 2014). It is often the parents who have a feeling that it is the institutions they collaborate with who have the most power when it comes to making decisions concerning their child (Drugli & Nordahl, 2016). Consequently, according to Nordahl (2007), collaboration problems between parents and such institutions are often rooted in problems of the power dynamic. For example, such collaboration problems can occur when the kindergarten\school appears to have maintained their *institutional power*, leading the parents to feel that they are in a situation characterised by powerlessness. Institutional power refers to the power that resides in the kindergarten\school (or other institustion) and those who work there (Engelstad, 2004). Indeed, Thornquist (2009) cautions that in the collaboration process, the stronger party must be conscious of symmetrical and asymmetrical power-relationships. This is because there exists a risk of the parents, as a weaker party, perceiving a power imbalance and a lack of control. In such situations, conflicts can easily arise about who has the correct perception of reality, and the teachers can use their power to decide that they understand the situation at that school best (Nordahl, 2007). According to Lassen (2014), such an attitude may lead to the parent's self-esteem being undermined, as well as feeling detached from the process, thus reducing the chance of success. These perspectives are again echoed by

[1] This quote has been translated from Danish to English.

Antonovsky (1979) were he emphasised the importance of having influence over one's own life is a universal human need.

On the other hand, when parents feel that they have a real involvement in the kindergarten\school through their opinions being taken into account and having a level of influence over the decisions, *communicative power* is often realised (Habermas, 1991). This is power that arises when two or more parties agree on something, and it is in many ways a stronger and more significant power than the institutional power. This often can benefit the child in question because they will then experience that parents and teachers\advisors stand together (Habermas, 1991). Moreover, the communicative power corresponds closely to the national guidelines for collaboration between home and school (Kunnskapsdepartementet, 2006).

3.2 Counselling models

In the field of humanistic counselling, there are many different counselling models. According to Lassen et al., (2014), the models can function as frames of understanding, or navigation maps, for the process. Examples of these models include Robert Carkhuff's problem-solving model presented by Lassen et al., (2014), The Skilled Helper Model by Egan (2010), The Special Education counselling model presented by Johannessen et al. (2010), and Aron Antonovsky's "Sense of Coherence" (SoC) counselling model. An in-depth discussion of all counselling models goes beyond the scope of the current thesis. Instead, focus will be placed on Aron Antonovsky's "Sense of Coherence" (SoC) counselling model. This model has been chosen as a foundation to better understand the experiences expressed by both informant groups due to its practical utility in supporting families in effectively coping with stress associated with having children who have special needs.

Aron Antonovsky's "Sense of Coherence" (SoC)

During the last couple of decades, the concept of *resilience* has been increasingly put into focus in the field of counselling (Hansson et al., 2008). One notion in this domain is "salutogenesis," a term coined by Antonovsky (Hansson et al., 2008). Salutogenesis can be described as an approach to human health that considers the factors contributing to the promotion and preservation of physical and mental well-being, rather than disease. Importantly, this approach places particular weight on the coping mechanisms of individuals which help preserve health despite stressful conditions (Lindström &

Eriksson, 2005). Within salutogenic theory, Antonovsky developed a theoretical model of stress management called “Sense of Coherence” (SoC), which he argued was different from previous stress theories. Antonovsky believed that the decisive factor in how we cope with stressors is our experience of connection, something he called “Sense of Coherence”. A strong sense of coherence helps one to mobilise resources to cope with stressors and manage tension successfully. Therefore, emphasis is placed on factors that dampen, facilitate or remove the stressors (Idan et al., 2022). The model presents three necessary elements that must be realised in order to achieve a strong sense of coherence. You must first understand the situation (comprehensibility). Next you have to have faith that you can find solutions (manageability). Finally, you must find good sense in attempting the solutions (meaningfulness).

Previous studies have found that people that possess a strong SoC tended to manage stress better, where they were able to transform their potential resources into actuality. On the other hand, people with a poor SoC tended to be more easily overwhelmed, experienced lower levels of positive mood, were more likely to give up, and had more health challenges. Furthermore, the levels of SoC reported by parents impact not only their approach to the situation, but has also been shown to be meaningful for the development of their children (Oelofsen & Richardson, 2006; Pisula & Kossakowska, 2010).

Strategies supporting a strong SoC

Counselling models which adhere to a salutogenic perspective acknowledge that all parent’s situations are nuanced. Indeed, the parents are not a homogeneous group with the same set of needs. Some will require significant support, while others will require minimal support (LaRocque & Kleiman, 2011). Thus, there exists no “recipe” that the advisor can follow in order to facilitate a satisfactory experience for all parents in need. It is, however, highlighted in the literature that the parent counselling process often involve a number of common elements that can contribute to parents obtaining a healthier way of handling life’s stress factors. Put in another way; elements that could contribute to a stronger SoC for the parents. In order for these elements to be present in the process, the parties involved need to first and foremost come to a common understanding of what a positive collaboration means for them. Here, roles and expectations from each party can be laid out. This process is described by Nordahl et al.,

(2017, p 32) as *formulisation*, that is "the extent to which there are formal rules for the collaboration". Moreover, it is necessary that the advisor has a deep knowledge of the area, and that this specialist knowledge is continually updated according to the recent literature. Moreover, solid communication skills are essential to the success of such processes. Specifically, it is recommended that the advisor utilises techniques such as active listening, nonverbal responses and clarifying questions in order to facilitate open communication perceived as a safe environment by the parent (Carkhuff, 2000; Tveitness & Simonsen, 2019).

Regarded as one of the key personalities in the development of humanistic counselling tradition, Carl Rogers explained that the communication tools described above should be utilised by the advisor in order to ensure three characteristics that together form the core part of the therapeutic relationship; congruence, unconditional positive regard (UPR) and accurate empathic understanding (Rogers, 1975). Congruence implies that the advisor is being him\herself in a genuine and authentic way throughout the process. Unconditional positive regard (UPR) involves the advisor deeply and genuinely caring for the client, whereby the advisor may not approve of some of the client's actions, but the advisor does approve of the client. Lastly, accurate empathic understanding implies that the advisor has the ability to understand sensitively, accurately and empathically, although not sympathetically, the client's experience and feelings in the here-and-now (Rogers, 1975). It is important to note that one cannot fully understand another's experience, and it is important to distinguish empathy from sympathy. With empathy, the other person's feeling is the starting point for understanding. However, in the case of sympathy, it is one's own feelings that are the basis; we understand the other because we have experienced something similar and comparable. Within counselling, it is important to keep a clear distinction. Empathy will enable you to stay focused on the person seeking advice, and thus avoid using your own feelings and experiences to understand. Empathy is thus a way of tuning in emotionally to the person seeking advice (Lassen, 2014).

Of these three characteristics, Rogers emphasised the ability to be congruent, that is to be genuine, as the primary characteristic of the advisor in the process. Thus, although there are numerous communication tools recommended in the counselling process, Rogers (1975) tells us that it is not sufficient to learn methods and procedures if these are not expressed in the counselling relationship in a genuine manner. Lassen (2014)

further adds to this point by highlighting that the when the adviser is congruent, it can create security and predictability for the client\parent. The client will have a better opportunity to feel relaxed, and will thus also be able to present the “problem” more easily. Moreover, perhaps the person seeking advice discovers strength in themselves, and increased self-realisation is made possible (Lassen, 2014). Furthermore, Lassen (2014) explains that it is equally important that the advisor assists the parents in identifying and executing the solution to the problem themselves in order for the parents to gain ownership and responsibility for their situation.

4.0 Method

In this section, the methodological considerations and approach to gathering data will be explained. First, the choice of a qualitative method (i.e., the epistemological position and the use of qualitative semi-structured interviews) will be described. Next, the frame and design of the interviews will be presented. Here, a description of how the participants were selected and recruited, the preparation carried out before conducting the interviews, as well as justifications for changes made during the process will be given. Next, an account of the analytical strategy and the analysis will be given. Finally, this will be followed by a description of reliability, validity, and ethical considerations.

4.1 Research paradigms

Within research there are two scientific method traditions; quantitative and qualitative methods (King & Horrocks, 2010). The desired outcome of a quanitative study is to “establish, confirm, or validate relationships and to develop generalizations that contribute to theory” (Leedy & Ormrod, 2001, p. 102). Conversely, qualitative research involves asking participants about their experiences of things that happen in their lives in order to get deeper insights (Creswell, 2014). As the nature of the current study is to gain an insight into both the parents' experience of the ADHD diagnostic process for their child, and the health professionals experience of advising the parents, I have chosen a qualitative, rather than a quantitative methodology (Postholm & Jacobsen, 2018).

Quantitative and qualitative research possess ontological, epistemological, and methodological differences which are the fundamental philosophical building blocks that direct the choice of method (Creswell, 2014). These fundamental philosophical

building blocks are known as paradigms, and in educational and special educational research, the term is used to describe a researcher's 'worldview' (Postholm & Jacobson, 2018; Hatch 2002). The paradigm choice permeates; the research question/s, participant selection, data collection instruments and collection procedures, as well as data analysis (Creswell, 2014; Krumsvik, 2013; Nilssen, 2012; Kivunja & Kuyini, 2017). It is therefore crucial that one begins their research by considering their own views of what reality is like (ontology), what kind of knowledge can be captured through method (epistomology) and how one should proceed to gain knowledge about reality (methodology) (Creswell, 2014).

While quantitative research is ingrained in the positivist paradigm, where one seeks causal determination, prediction, and generalisation of findings, qualitative research is guided by the interpretivist paradigm, where one systematically gathers and interprets textual data (Postholm & Jacobson, 2018). The creation of interpretivism came as a response to researchers grappling with the idea that several ideals of positivism are not appropriate in contexts where humans are involved. Thus, Interpretivism is a paradigm which rejects the ideal that the social world can be studied in the same way as the natural world (Postholm & Jacobson, 2018). Instead, the results will be the researcher's subjective interpretation of the sample's perspectives on, and/or experiences with the survey topic (Creswell, 2014; Guest et al., 2013).

Of the two ontologies; realism and relativism, the ontology of the interpretivist paradigm is rooted deeply in relativism. One core assumption in relativism is that humans create meaning by interpreting personal experiences and experiences in interaction with the world around them. Knowledge is therefore considered subjective and created in encounters with others (Creswell, 2014; King & Horrocks, 2010). While positivism has a relatively uniform epistemology, interpretivism consists of a number of different variants, for example; Phenomenology and Hermeneutics (Postholm & Jacobson, 2018). However, all the interpretive\constructive epistemologies have a common starting point, namely that the world is not objective, but rather something that we humans more or less actively construct (Postholm & Jacobson, 2018). Qualitative research interviews are preferable when the researcher strives to understand the interviewee's subjective perspective of a phenomenon rather than generating generalizable understandings of large groups of people (McGrath et al., 2018).

In this thesis, a qualitative, interpretivist, relativism paradigm was adopted with the assumption that a scientist interprets a research object in light of own meaning structures and lived experiences, and thus, no objective reality can be captured (Guest et al., 2013)

4.2 Choice of method – Semi-structured interviews

In the field of psychology and special education there is a range of different qualitative methods used to provide the researcher with a deeper understanding of the participants meaning of a phenomenon (Willig, 2013). Of the various methods, I considered two that could be the most appropriate for obtaining answers to the current study's research question; qualitative surveys, and interviews.

I initially considered using qualitative surveys sent to parents of children who have ADHD and professionals involved in the various stages of the screening and diagnosis process. These included; kindergarten and school teachers, as well as PPT advisors and health professionals at BUP. For obtaining thoughts and experiences from a relatively large sample, I felt that interviews would not be applicable. Indeed, the survey methodology is particularly relevant when investigating opinions and attitudes in large samples and populations (Befring, 2007). I was initially attracted to qualitative surveys being anonymous, which can lead to the informants answering more honestly (ibid). On the other hand, I had two main concerns with the research method. The first concerned the risk of the questions not being clear and concise enough, leading to misunderstandings by the informants. As I would not be in contact with the informants, I would therefore be unable to clarify the misunderstandings, thus decreasing the reliability of the answers (Polit & Beck, 2017, p. 243). Secondly, in order to gain valuable insights into the research question, I also felt that it was necessary to gain in-depth knowledge about the participants experiences on the topics. In order to have the opportunity to gain in-depth knowledge, I believed that I needed the flexibility to follow up on potentially valuable themes deemed important to the participants experience.

Based on these two concerns, I ultimately felt that interviews as a research method was the most appropriate method for attempting to gain insights into the research question in the current thesis. Indeed, when one wants to identify different aspects of human experience, qualitative interviews are a common way to obtain data (Kvale & Brinkmann, 2015). Qualitative research interviews represent several approaches:

structured interview forms with pre-formulated questions, semi-structured interviews and completely open interviews. Each method has its advantages and limitations, and the choice of approach depends on which perspective and phenomenon one wishes to understand (Kvale & Brinkmann, 2015).

Semi-structured interviewing is a widely used qualitative method for gathering data. This method was chosen for the current thesis. During a semi-structured interview, it is the researcher that chooses the theme of the conversation and asks prepared questions related to the particular topic of research. However, unlike a structured interview, the researcher does not follow a rigid list of questions asked in a specific order. Instead, open-ended questions are used to create a discussion to facilitate responses that reflects what the informant considers as important and meaningful (Malterud, 2011; Brinkmann & Kvale, 2015). Thus, reliability is not weakened by interviews only using subjective judgment in relation to what the informant tells.

The combination of an overview of the theme's questions, flexibility to adapt the order of the questions, as well as the option to ask additional follow up questions based on the participant responses was something I felt necessary when seeking to gather data from a group of people's experiences, told in their own words. This is because although I had researched the interview topics thoroughly, I knew that in the interview, I could expect that the informants would share experiences and stories that I had not been able to foresee (Malterud, 2012). I therefore wanted to provide the conditions for them to present their experiences without interruptions from themes that would be explored later in the interview, or themes I hadn't included in the interview guide. This was necessary in order for myself as a researcher to focus on what the informants were concerned with, and to obtain richer data material (Malterud, 2017). Moreover, as the interviews would be an interpersonal situation, where knowledge is created in the meeting between my views and those of the informants, I was aware that misunderstanding could occur from both parties. A strength of semi-structured interviews is the possibility of clearing up misunderstandings or ambiguities along the way (Kvale & Brinkmann, 2015).

4.3 Study design

4.3.1 Selection of informant groups

Originally, it was intended in the study to only interview the health professionals involved in the diagnostic process. This was due to the perception that it would be

challenging to recruit parents to be interviewed on a topic personal to them, particularly if they had a poor experience during the process. There was therefore a concern that only those parents that had a positive experience throughout the diagnostic process would be recruited, leading to screwed and unreliable data. However, after discussions with my supervisors, we felt that interviewing both the health professionals and the parents would be necessary in order to obtain answers to the thesis' research questions and aims. Indeed, without interviewing the parents, the study's data would have consisted of the parents' experiences from the perspective of the health professionals and not the actual voices from the parents. Obtaining experiences from both sides of the ADHD diagnostic process would likely provide far richer insights and a higher level of reliability[2]. Therefore, the study consists of semi-structured interviews with two informant groups, using two separate interview guides (see table 3):

Table 3: Informant groups and the informant names

Informant group I – Parents of children with an ADHD diagnosis	**Informant group II – Health professionals involved in the ADHD diagnostic process**
Parent 1; Noora,	Health Professional 1; Jakob
Parent 2; Olivia	Health professional 2; Isak
Parent 3; Frida	Health professional 3 Aksel
Parent 4; Iben	

4.3.2 Criteria and recruitment of informant group I

For informant group I, the main criterium for participation was that the informant was a parent or caregiver of a child who is under 16 years old and who has received an ADHD diagnosis through BUP in Norway. It was desirable, although not necessary, that the child received the diagnosis recently. This is due to the assumption that recent experiences of the diagnostic process could provide a more accurate picture of the current situation in the health system. After speaking with my supervisors, however, I

[2] [2] Here it should be noted that the terms "reliability" and "validity" are not always used in qualitative methods. Nevertheless, I use these terms in the current thesis in parallel with dependability, credibility, transferability. These terms will be described later in this chapter.

understood that I needed to be open to diagnostic processes that were carried out a number of years ago in order to successfully recruit the intended number of participants.

Today, and particularly in Norway with its egalitarian culture, it is no longer given that it is the mother who takes the lion share of the raising of children, and thus are the ones that are most natural to interview regarding their child's ADHD diagnosis. Moreover, it is also not a given that children grow up with both biological parents. They can for example live in a foster home, be adopted, or live with relatives or friends. I was open to recruiting any guardian of the child with an ADHD diagnosis, be that it's biological or adopted mother and\or father. I initially felt that recruiting a number of fathers in the study could provide more nuanced and rich data, but from reading previous studies where parents were interviewed regarding their child's diagnosis process, I was prepared that it would likely be the mothers. My experience was consistent with the literature as all four parent informants were the biological mothers of the child. There may be various reasons for why the fathers were not able to participate in the study. Perhaps the mother was divorced from the child's father, or perhaps the mother worked at home and was therefore more easily available during the day when the children were at school and the father was at work. Possibly it was the case that the fathers did not wish to open up and discuss such a personal topic with someone they had never met. Otherwise, an assumption could be that even in 2022, it is still the mother who bears the brunt of this type of caregiving. These are, however, speculations, and I didn't feel that it was my business, nor was it vital for the study to pry when carrying out the interviews with the mothers.

The recruitment of participants in informant group I was achieved gradually through snowball sampling (Parker et al., 2019). I recruited my first participant in informant group I through a work colleague. At the end of the first interview, the participant mentioned that she knew a few other mothers that also have children with an ADHD diagnosis. She informed me that she would inquire to see if they were interested in participating in an interview with me, and said that she would provide them with my phone number if they were. The following week, three parents sent me a text message and confirmed that they would be willing to attend an interview with me. All informants had children diagnosed with ADHD, where two had ADHD combined type (Olivia and Frida), and two had ADHD inattentive type (Noora and Iben).

All parent informants sent me their email address, where I sent them the study description before the interviews took place (see appendix 2). It included information regarding the project, confidentiality, expectations for the interview, their rights as a participant, and contact information if they had any queries. Moreover, as informed and free consent is a key principle of research ethics (Ringdal, 2018), the document included the consent form which was to be derived from the participants before conducting the interviews.

4.3.3 Criteria and recruitment of informant group II

The criteria for participation in informant group II was that the informants were health professionals who are involved in the ADHD diagnosis and treatment process for children. As already mentioned, there are numerous professions involved in the child receiving the ADHD diagnosis. These can include kindergarten and school teachers, teacher assistants, and special educators, as well as PPT advisors. However, only those health professionals working at BUP and HABU, namely psychologists, special educators and doctors, are able to provide an ADHD diagnosis and treatment, and were thus the only relevant candidates for the current study.

The recruitment of participants in informant group II was achieved by contacting both BUP and HABU and explaining my study, it's aims, and intended methodology. I inquired if any members of the staff involved in the screening and diagnostic process of ADHD in children would be available for an interview. As the project's theme was of relevance and interest to BUP, BUP were open to accommodating me, providing I was flexible with the date and time of the interviews. I aimed to recruit one of each health professional involved in the process, namely one doctor, one psychologist and one special educator. However, as only one doctor worked at the BUP office, her schedule was too full for an interview. Therefore, I was able to recruit and interview a total of three health professionals; one Psychologist and two Special Educators.

The leader at BUP sent me the health professional's email address, and I sent them the study description before the interviews took place (see appendix 3). It is worth noting that the study description document for the two informant groups were adjusted to each group in order for the information to be applicable and relevant. Both study descriptions were written in a clear and concise way, but more care was taken with the text formulation for the parent's document. Indeed, I was conscious that particularly the

parent informant group's knowledge of the condition may vary largely, and so I avoided overly theoretical terms.

4.3.4 The design of the interview guides

The two interview guides were designed to shed light on the following research questions:

> *How do parents experience the process of getting an ADHD diagnosis for their child and how do health professionals experience working with the parents of the patient?*

After a discussion with my supervisors, it was agreed that I would carry out the informant group I interviews before creating the interview guide for informant group II. The reasoning for this was to attempt to identify the prominent themes mentioned by the parents that provide an insight into the research questions, and then use these to guide the themes for the interview guide with the health professionals. This allowed me to carry out a theory informed process by using the findings from the first set of interviews to guide the themes for the second set (Malterud, 2012). Thus, once the interviews of the informant group I were conducted, I transcribed the interviews and, through the use of Malteruds (2012) "Systematic text condensation", carried out a preliminary analysis of the data. Meaningful units from the first set of interviews were highligted and then incorporated in the themes for the interview guide for informant group II.

The interview guide for informant group I was concentrated around two main themes (see appendix 4). The first theme; "The ADHD diagnostic process" (ADHD-diagnoseprosessen), focuses on the parent's experience throughout the diagnostic process. The second theme; "Important information on ADHD for choice of treatment" (Viktig kunnskap om ADHD for valg av behandlingstiltak), focuses on what the parent's found as important in the choice of treatment measures. Based on the meaningful units highlighted in the pre-analysis from the informant group I interviews, the interview guide for informant group II was also concentrated on 2 main themes (see appendix 5). The first section; "Perspective of the ADHD diagnostic process and experience advising parents" (Syn på ADHD diagnoseprosessen og opplevelse av å rådgi foreldre), focuses on the health professionals' own views of the process, as well as their experience of counselling not just the patient, but also their parents. The second

section; “Important knowledge of ADHD for parents” (Viktig kunnskap om ADHD for foreldrene), focuses on what the health professionals deem as important for the parents to know when making treatment decisions on behalf of their children. Moreover, an emphasis in the second section is placed on protocols that the health professionals follow in the cases of disagreements between the parents themselves, and between the parents and BUP.

4.3.5 Test interview

Conducting a qualitative research interview means that you may be asking your interviewees to reflect on matters that are potentially important to them, in some cases even life-changing. Therefore, it is appropriate to develop your interview guide in advance and conduct at least one test interview (McGrath et al., 2018) This is particularly important in the case of novice researchers, such as myself. The test interview provide the researcher with an opportunity to explore language, the clarity of the questions, and aspects of active listening.

Before commencing the interview process with each group, I carried out a test interview with a fellow student. I found this process to be immensely helpful in regards to learning to adjust the order of the interview guide questions based on what the participant stated. Initially, this felt very unnatural as I had practiced these questions in a specific order. I could feel the temptation to interrupt them and say that we will discuss that topic at a later stage of the interview. I was concerned that I would miss a question, but this concern was alleviated by crossing off each question as we went along and then double checking at the end. At the beginning of the test interview, I also felt the need to note the key points mentioned by the participant. This undoubtedly was also due to a concern of forgetting something of importance. I had to remind myself that the interview was being recorded via Dictaphone and that I could relisten to it numerous times. Once reminding myself of this, I was able to be more present in the interview and perhaps gain more in-depth answers.

After the interview, I asked the informant how she had experienced the interview situation, and whether there was anything I should have done differently. She mentioned that we had gone 12 minutes over the agreed time limit. Indeed, I quickly realised that I would need to manage the balance between allowing the participant to talk freely about their experience, whilst at the same time ensuring that we get through

all the interview guide within the agreed time frame. Furthermore, she advised me to allow the participant to sit in the silence whilst answering the questions, as they may come with more reflections if given the space to do so. This piece of advice ended up being incredibly useful in obtaining richer responses from the participants, but it was an instinct I had to fight in every interview.

4.4 Conducting interviews with both informant groups

The participants from both informant groups were given the freedom to determine the place, date and time of the interview, and I accommodated this with liaising with my job. This was to ensure that the interviews were conducted in a familiar environment which is in accordance with Dempsey et al's. (2016) notion of providing a suitable time and location for the participants. Indeed, I was conscious that the interviews, particularly for the parents, would consist of potentially sensitive themes, and therefore wanted to eliminate any factors in my control that could negatively impact the data collected. Allowing the participants to choose the date, time and location for the interview can be seen to increase the validity of the interviews, as it is being carried out in a place where they feel safe (Malterud, 2011, p. 131). Three of the four parents chose to have the interviews at their homes, and one parent wanted to conduct it at my house whilst my wife and child were away. In regards to informant group II, all three health professional participants chose to have the interviews in their BUP offices. I found the parent informants to be open and candid with their experiences, particularly as the interview went on and they perhaps became more comfortable with the process. I experienced that the health professionals were personable and willing participants, but unsurprisingly, the tone was more professional than in the interviews with the parents.

The interviews in both informant group I and group II had a time frame of approximately 30-40 minutes. Although I felt that in all of the interviews, we could have discussed the matters for numerous hours, I feel that 30-40 minutes was an appropriate timeframe. It allowed for the participants to explain their thoughts openly without feeling rushed, whilst at the same time, I have the sense that the time limit assisted the participants to be more deliberate in their answers. The time limit, as well as the interview guide, also helped me as the interviewer to be deliberate in my follow up questions. As already mentioned, the flexibility of semi-structured interviews enabled me to ask follow up questions to themes I hadn't anticipated, but the time limit forced me to consider which themes I would and would not further explore. As I find the

overall theme of the study particularly interesting due to my personal and professional experience on the matter, I felt that this time limit and structure from the interview guide was necessary for me to carry out a professional interview and obtain quality data that would assist in answering the research questions of the study.

Overall, I feel that carrying out the interviews with both informant groups went as planned and was unproblematic. All participants kept to the date, time and location of the interview. In studies where audio recordings are used, informed consent must be obtained (Health Research Act, 2008 § 13; Malterud, 2011, p. 146). All participants had read the information document of the study and had completed the written consent form signed before the start of the interviews. Moreover, the participants were reminded that they could withdraw consent at any time (Health Research Act, 2008 § 16). They understood that the interview audio would be recorded via Dictaphone, that the content of the interview would then be transcribed and analysed, and that the data would be used in results and discussion section of the thesis.

4.5 Transcribing the interviews

I chose to record the audio of the interviews instead of taking notes, as according to Kvale & Brinkmann (2009), taking notes can be distracting because the free flow of the conversation is disturbed. The audio recordings of the interviews were transcribed verbatim. To ensure confidentiality, whilst also bringing the reader closer to the informants' experiences, fictional names were given to all informants in both informant groups.

4.6 Analysis

Data analysis is central to credible qualitative research, and is the process where the researcher attempts to "understand, describe and interpret experiences and perceptions key to uncovering meaning in particular circumstances and contexts" (Maguire & Delahunt, 2017, p.11). As this was the first time that I had undertaken an analysis of data, I felt the need to follow a practical, well regarded "instruction manual" to ensure that the process was carried out effectively so that the findings would be dependable, credible, and transferable. The analysis was therefore carried out using Malterud's (2012) Systematic text condensation. This form of analysis does not require the researcher to have theoretical training in advance (Malterud, 2011), and the reasoning for its selection was because; "The method offers the novice researcher a process of

intersubjectivity, reflexivity, and feasibility, while maintaining a responsible level of methodological rigour" Malteruds (2012, p. 1). Put another way, systematic text condensation is suitable for a novice researcher, whilst also being suitable for the development of new concepts and phenomena, something which was determinative for answering the current thesis' research question (Malterud, 2011).

Malterud's (2012) Systematic text condensation uses Giorgi's psychological phenomenological analysis as a basis for the analysis method. It is made of up the following steps: 1) total impression – from chaos to themes; 2) identifying and sorting meaning units – from themes to codes; 3) condensation – from code to meaning; 4) synthesizing – from condensation to descriptions and concepts. The pre-analysis of the informant group I interviews consisted of the first two steps (Malterud, 2012). It is usually the case in qualitative research that the process is not linear, but instead is often referred to as "The hermeneutic circle". The hermeneutic circle is an expression associated with the interpretation process, where the researcher starts from a prior understanding of what he wants to investigate, and then immerses himself in the material, and interprets and discovers new assumptions or phenomena along the way. Gradually, knowledge of the other's experience expands, and the researcher constantly discovers new phenomena and makes new assumptions, which leads to ever greater insight (Gilje & Grimen, 1993). This was certainly the case for me as a number of meaningful units found in the pre-analysis of informant group I were themes that I had not considered. An example was the descriptions from a number of the parents regarding the ways in which resistance from their spouse to the diagnosis and treatment impacted their experience. In addition, the parents spoke of a lack of knowledge of ADHD from their child's teachers, in particular with the ADHD inattentive subtype. Indeed, these themes turned out to provide rich data as a result of gaining the health professionals perspective. Thus, I feel that the strategy utilised was particularly effective in attempting to answer the research questions.

Once the second set of interviews was conducted, and the transcriptions completed, I begun the Systematic text condensation process for both sets of data. Although I had carried out a pre-analysis for the first set of interviews, I went back and re-read the transcripts in order to refresh my memory of the content before reading the health professional interview transcripts. I then completed step 2, identifying and sorting

meaning units, for informant group II so that both sets of data were are the same point of analysis before continuing the process.

The analysis yielded four overarching themes from the parent informants (see table 4):

Table 4

Knowledge of ADHD	**Mixed experience with kindergarten, school and PPT**	**Diagnosis as a relief**	**The aftermath of receiving the diagnosis.**
Level of knowledge of ADHD the parents possessed prior to the screening process The parent's opinions of the level of knowledge of ADHD possessed by their child's teachers.	Parent's experience before their child was referred to BUP for an ADHD screening. Parents contact with kindergartens\ schools and PPT.	The relief the parent informants felt when receiving the diagnosis. Why obtaining the diagnosis helped them, their child, and the family as a whole.	Parent's experience collaborating with BUP Considerations of an optimal treatment plan Attitudes towards medication as part of the treatment
"Why didn't she think about possible reasons for why she is not able to pay attention? That is something that I've questioned later on" (Noora).	"It has been a long battle" (Oliva). "We cooperated very well with the preschool, with the school, and we talked well together. We were well informed, and	"There were many years of uncertainty, but things really fell into place when we got that diagnosis" (Noora).	"[The child] received information on his level while the three of us sat together. Then [the child] was allowed to go out and play and then I got information on an

	they were good with our child" (Frida).		adult level. I think that was very good" (Frida).

Furthermore, the analysis yielded three overarching themes from the health professional informants (see table 5):

Table 5

The importance of working with the parents	**Medicine as part of the treatment**	**Concerns raised by the health professionals**
The health professional participants experience of working not only with the patient in the ADHD screening and treatment process, but also the patient's parents.	The experiences of the health professionals recommending medication as part of the child's ADHD treatment plan. The typical treatment plan offered by the health professionals and their rational for these choices.	Large variations in the screening quality for ADHD High number of patients at BUP Lack of knowledge of ADHD inattentive subtype and the difficulty of diagnosing the subtype
"It is the adult who is important for the further development of measures, in order for the children to bring out their potential" (Jacob).	"There needs to be a combination of medicinal measures and non-medicinal measures" (Isak).	"I have the experience that ADHD assessment is carried out in very different ways between BUPs in Norway, and also differently between different therapists within the individual BUP" (Isak).

4.8 Ethical considerations as a pre-requisite to the interviews

Ethics in research can be described as a system of moral values, where the approach follows professional, legal, and social obligations (Polit & Beck, 2020). An all-encompassing ethical principle in research is that the researcher's responsibility must first be shown to the research participants, then to the study and finally to the researcher him\herself (Fontana & Frey, 2000, cited in Postholm & Jacobson, 2018).

All research, whether qualitative or quantitative, must be carried out in accordance with recognised research ethics norms (Forskningsetikkloven, 2017, §1). In Norway, these research ethics norms that researchers must consider when preparing, implementing and analysing a research project are; informed consent, confidentiality, and accurate representation (Thagaard, 2013). Thus, ethical decisions do not belong to any one single part of the method, but must permeate throughout the entire research process (Kvale & Brinkmann, 2015). Furthermore, the guidelines applicable within the pedagogical field are laid out by General guidelines for research ethics (NESH, 2016). NESH acts as an advisory body within research ethics, where the overriding purpose is described as the following:

> They must contribute to develop research ethical judgment and reflection, clarify ethical dilemmas, and promote good scientific practice. They must also contribute to preventing scientific misconduct. (NESH, 2016, p. 5) [3]

With guidance from my master thesis supervisors, anonymity and confidentiality were ensured through approval of the project by Kunnskapssektorens tjenesteleverandør (SIKT) (see appendix 6). After submitting the project proposal to SIKT, they requested minor adjustments to the project to be made before they could approve it. The required adjustments were made and the project was approved the following week. Once approved, my project was registered in the University of Bergen processing of personal data in research and student projects system; Risiko og ETTErlevelse (RETTE) (see appendix 6).

The project description was sent to all informants before the interviews took place, where the information was adjusted for each of the informant groups (see appendices 2

[3] This quote was translated from Norwegian to English.

and 3). It included information regarding the project, confidentiality, expectations for the interview, their rights as a participant, and contact information if they had any queries. Moreover, as informed and free consent is a key principle of research ethics (Ringdal, 2018), the document included the consent form which was to be derived from the participants before conducting the interviews. Here it was emphasised to the participants that participation in the study is completely voluntary and that it is possible to withdraw at any time. This message was also reiterated during the interview. For the parent informants, this was the first time they had been involved in a master thesis interview. If they needed more information, they could contact me by phone or email. The intention was that they should feel confident that I, as a researcher, had great focus on following the regulations that apply to this type of project, and that they were confident that the principle of anonymity was implemented. Furthermore, as already mentioned, I also took time before the interviews for us to get to know each other a little to encourage their feeling of safety in the process. Lastly, according to Dempsey et al. (2016), the researcher must consider how to deal with potential distress and negative emotions portrayed by the participant in order to be prepared to protect their well-being. As the interviews, perhaps particularly the parent interviews, contained themes that could evoke strong emotions in the informants, I stayed attentive to the participants, looking for verbal or bodily signs of distress.

4.7 Considerations of reliability and validity

Research is both a process and a result, and consequently, research quality is not solely rooted in the study's results, but also how these results were obtained. The researcher must consider and articulate the limitations concerning their own research, as well how they themselves could have influenced the results. The first consideration relates to validity, whereas the second relates to reliability (Postholm & Jacobson, 2018). This study sought to investigate how parents experienced the ADHD diagnostic process for their child, as well as investigating how the health professionals experience advising these parents. Investigating such a nuanced process with two informant groups through interviews raises issues regarding reliability and validity.

The terms 'reliability' and 'validity' are often related to the methodological criteria of quantitative research, and are therefore sometimes exchanged with other terms when discussing qualitative research (Kvale & Brinkman, 2015). For example, Guba (1981) replaces reliability with dependability, internal validity with credibility, and external

validity with transferability. Accordingly, the current assignment will utilise these terms as they are arguably more appropriate when discussing quality in qualitative research.

4.7.1 Reflexivity

Reflexivity is concerned with how the researchers themselves could have influenced the results. In other words, it is about acknowledging your personal role in the research. In qualitative research, I am part of the research process, and my assumptions, beliefs and previous experiences, will influence my research process. A potential way in which I could impact the study's data that I was conscious of not only when writing the interview guides, but throughout the entire study, was my personal and professional experience with ADHD. I was aware that I had good knowledge of children with ADHD as a result of having the condition myself, from working with children who have it both in a school and kindergarten arena, and from reading much of the relevant literature. Although having this level of knowledge and experience of the condition has been extremely useful in the study, it could perhaps also bring prejudices that could impact the study's findings. My choice of the themes for the interview guides, the formulation and delivery of the interview questions, as well as my understanding of what the informants conveyed, is undoubtably coloured by my preconceptions. Nevertheless, I have tried to be as neutral as possible to the diagnostic process, the actions taken by the health professionals, and the decisions made by the parents.

Another way in which the study's data could be impacted by myself regards the fact that I am educated as, and have worked as a kindergarten and school teacher. In cases where critic is given to these profession groups by the informants, it was necessary for me to avoid becoming defensive. Indeed, although as a previous teacher I have an understanding of the typical demands of the profession, neither the informants, nor I, are able to possess a complete understanding of the teacher's decisions or experiences.

Both in regards to the fact that I have ADHD myself and have worked as a school teacher, I utilised Dewey's reflective thinking to assist me in analysing the problem through a more disciplined mind, rather than an instinctive and emotional one (Nerland, 2006 as cited in Klemp, 2014). Dewey believed that our experiences shape us, and when reflective practice is part of learning, meaning and relevancy is created, which initiates growth and change (Dewey, 1933). Here, I attempted to approach the interviews, analysis, results and discussion section in a similar manner to when I read articles

regarding teachers and their role in ADHD diagnosis process of children. Indeed, I know better than most the limitations teachers often have in this area as I have been involved in a number of ADHD referral cases for children in my class when working as a teacher. I am aware of, for example; the lack of emphasis placed on ADHD (particularly ADHD inattentive type), the referral process, and how to effectively lease with the parents and various institutions in both the teacher education and teacher training days. Furthermore, I can identify with the literature findings that typical behaviours of those with ADHD concerning hyperactivity and impulsivity can be incompatible with the academic and behavioural goals of a school. This incompatibility and lack of knowledge of ADHD has been attributed to the disproportionately high ADHD referals for children born late in the academic year. As already mentioned, this correlation is largely unknown by teachers and parents, and I can confirm that I myself was unaware of this during my time as a teacher.

Lastly, in terms of the dependability of interview studies, it is also necessary to evaluate whether or not the participants would respond in a similar manner with another interviewer, and whether or not another researcher would transcribe and analyse the collected data in a similar manner and, to a certain degree, produce similar results (Kvale, 2007). With all participants, I ensured that we took some time before conducting the interview to build a rapport, which lasted between 10-20 minutes. In regards to the parents, they were about to open up about a period of their life that was very personal to them. Although it is not possible to measure or determine for certain, I feel that building some rapport with both informant groups before conducting the interviews was something that assisted them to feel safe to talk more openly.

Building rapport and establishing comfortable interactions in the qualitative interview situation is very important and is preferably done in advance of the interview, but also during the interview itself. A challenge when conducting interviews is that there may be little time in the interview situation to build trust (DiCicco-Bloom & Crabtree 2006). Rapport is also crucial during the interview, enabling the respondent to provide a rich and detailed account of the experiences at the heart of the study. When setting up the interview, I ensured that I allocated enough time to build a basic level of rapport with them prior to the interview. Moreover, by sending the information description to the participants prior to the interview, we were able to use this time solely on getting to know each other a little.

4.7.2 Credibility and Transferability

Credibility and transferability are concerned with the researcher reflecting on and describing the possible limitations concerning their own research, and whether the understanding developed within the study can also be valid in other contexts (Thagaard, 2018). A limitation of the current study regards the study's scope. As the interviews with health professionals were conducted with participants from only one BUP clinic, caution will be necessary in regards to making generalisations, both to other BUP clinics and other support systems nationally (Willig, 2008). Indeed, it is important to point out that these three health professional informants were not to be interviewed as representatives of their healthcare facilities. This means that the informants' statements cannot be taken as the opinion of all those who work with screening and setting of an ADHD diagnosis.

Moreover, only some of the professions involved in the ADHD diagnostic process were interviewed, namely Psychologists and Special Educators working at this BUP office. I attempted, but was unsuccessful in recruiting a doctor as an informant at BUP. Obtaining an interview with a doctor at BUP undoubtably would have provided value to the study as it is the doctors that are often the most important and credible source of information regarding medication treatment for the family of the patient. Indeed, after the ADHD diagnosis is provided to the child, and in the cases where medication is recommended as the sole or part treatment, parents of the child are invited to a meeting with the doctor at BUP. Here, the parents are able to obtain vital information about the types of medication, how they work to help manage the child's ADHD symptoms, possible side effect, and how the trial period will be carried out. Moreover, these meetings provide the opportunity for the parents of the child to ask related questions and raise any concerns they may have with an expert. Fortunately, as a protocol, the health professionals interviewed in this study are always in attendance in such meetings. Thus, through my interviews with the Psychologist and Special Educators, I was able to gain some insight into the effectiveness of these meetings for the families.

In addition, the interviews did not include professions from the other arenas and institutions in the child's life. Interviews for example did not include: PPT advisors, Special Educators working at Fagavdeling Barnehage, kindergarten or school teachers\teacher assistants. The rational for the choice of professions interviewed has already been explained. It is, however, vital to note that data from these professions

would unquestionably have brought in a richer data set to the study. In particular, not having interviews with kindergarten and school teachers provides a limitation to the studies data regarding the experiences of the parents in cooperation with these institutions. Indeed, the data acquired concerning this area consists only of the perspective of the parents. Not having the side of the teachers presented, particularly in the cases where parents have been unsatisfied with the experience, is therefore a limitation.

5.0 Findings

The analysis yielded four overarching themes from the parent informants: “Knowledge of ADHD”, “Mixed experience with kindergarten, school and PPT”, “Diagnosis as a relief”, and “The aftermath of receiving the diagnosis”. Furthermore, the analysis yielded three overarching themes from the health professional informants: “The importance of working with the parents”, “Medicine as part of the treatment”, and “Concerns raised by the health professionals”. Since the study contains two informant groups, findings from analysing the interviews with parents are first given, followed by the findings from the interviews with health professionals. Next, a section will then be provided, where focus is placed on the pattern of consistencies between both groups. A final section is then presented, summarising all findings across both informant groups, which will be discussed in the next chapter of the thesis.

In the current section of the thesis, I refer to both the parent and health professional informants by fictional names. This is in an attempt to bring the reader closer to the informant’s descriptions, whilst at the same time ensuring confidentiality. Parent 1 will be called; Noora, Parent 2; Olivia, Parent 3; Frida, and Parent 4; Iben. As mentioned in the method section, Olivia and Frida have children with ADHD combined subtype, whereas Noora and Iben have children with ADHD inattentive type. Health Professional 1 will be called Jakob, Health professional 2; Isak, and Health professional 3; Aksel. The interviews are numbered according to the order in which they were conducted, and as previously mentioned, the parent interviews were conducted before the health professional interviews. Otherwise, I refer to "informant group I" and "informant group II" where I refer to experiences and stories related to informants as a group.

5.1 Parent's perspectives

5.1.1 Knowledge of ADHD

This theme is focused on informant group Is initial concerns for their child's behaviours, as well as their first suspicions that the cause could be due to ADHD. It then explores the level of knowledge of ADHD that the parents possessed prior to the screening process. In addition, it explores the parent's opinions of the level of knowledge of ADHD possessed by their child's teachers.

Initial diagnostic concerns and parents' prior knowledge of ADHD

A majority of parent informants described a feeling that there was something "extra" with their child from a very early age. The initial suspicion from Frida was caused by comments made by the staff at the child's kindergarten:

> I thought it's just the way he is, and I wasn't worried. But then he started preschool when he was a year and a half, and they started to make comments in the preschool when he was two or three years old. They said he was never able to calm down. All the other children were able to sit down, and they managed to relax, or they managed to fall asleep properly. He needed a lot of help to calm down. He was always very busy. So, it was the preschool that commented on the truth really. And that makes you think. (Frida)

Olivia spoke of suspecting that her child had ADHD since he was the age of three years old. She noticed already then, that her child struggled in a number of areas significantly more than other children:

> The defiance age was really something, but he also struggled a little extra with transition, and if things didn't go his way, then there were very strong reactions and emotions. We have diagnoses of both autism and ADHD in the family. It is in close family; siblings. That made me think that there was something extra with the child, and that this is not quite normal. That's when I started to get suspicious. (Olivia)

Similar to Olivia and Frida, Iben also had suspicions that there was something “extra” with her child from a very early age. This feeling however, did not lead her to consider that the cause could be ADHD as there was a lack of hyperactivity in the behaviour due to her child having the ADHD inattentive subtype. Iben explained: “I guess I've had a suspicion that something has been going on for many, many years, but I haven't quite managed to put my finger on what it was because he doesn't have hyperactivity”.

Indeed, her knowledge of ADHD prior to the screening process was centred around perhaps the stereotypical impulsive child who is unable to sit still or focus in the classroom. Indeed, on the topic of prior knowledge, Iben expressed: “Not really that much (knowledge). You know the classic ADHD kid with hyperactivity. I hadn't read books specifically about ADHD because it's a bit like, if you don't need it in everyday life, or in the work situation, then you don't do it”.

Of the parent informants, it was only Noora who did not have serious concerns until her child was at a school age. Although she noted that her child had always “been in her own world”, it wasn’t until beginning school where difficulties concerning concentration became apparent. Subsequently, Noora started a new job which included helping to run an ADHD course for parents. She explained that these two factors triggered her to start considering that her child may have ADHD inattentive type.

> When she started school, we noticed that homework was very difficult, and having to concentrate and stay focused. There was no real suspicion until I started my new job. I work in the coping centre at the hospital, and we work with patient psychoeducation courses. And that includes ADHD courses for parents. (Noora)

Most of the parent informants described a feeling that there was something “extra” with their child from a very early age. As can be seen in the descriptions above, however, there exists a noticeable contrast concerning the nature of the suspicions between those parents who have children with ADHD combined subtype, and those who have children with ADHD inattentive type. The nature of the suspicions from the parents was impacted by their level of prior knowledge on the ADHD subtype that their child possessed. Olivia and Frida have children with ADHD combined type, where their

child's hyperactivity and difficulties regulating their emotions quickly led the parents to consider ADHD as a potential cause. Noora and Iben had children with ADHD inattentive type, previously named ADD. The lack of knowledge of the inattentive subtype by Noora and Iben led to significant delays in recognising the symptoms and starting the screening process compared to in the cases of the other two parents.

Lack of teacher knowledge of ADHD, particularly ADHD inattentive subtype

Noora and Iben explained that they were surprised and disappointed that the school teachers did not possess knowledge of the inattentive subtype through their education and interacting with various children on a daily basis. Indeed, all parents in informant group I highlighted that the child's kindergarten and\or school teachers seemed to lack knowledge of ADHD, and particularly of ADHD inattentive type. Noora explained that this lack of knowledge was present even in the teacher deemed as one of the best in the school. Indeed, this teacher had initially enquired whether the child had hearing difficulties as the child seemed to have difficulties with concentration.

> The first-grade teacher wondered if she had bad hearing, and at that point I thought it was strange. But there was nothing more. This is something we thought about afterwards. That she was a rather experienced teacher, why didn't she think about possible reasons for why she is not able to pay attention? That is something that I've questioned later on. (Noora)

The contrast of knowledge on ADHD inattentive type compared to the ADHD combined type and ADHD impulsive/hyperactive type both from the general public and teachers was powerfully illustrated by the child of Noora in the following quote: "When we were going to receive the diagnosis, our daughter said; Mum, I hope I have ADHD and not ADD, because everyone knows what ADHD is" (Noora).

The answers from informant group I illustrated a lack of knowledge of ADHD in teachers, something which negatively impacted the screening and diagnostic process for the parents and their families. These opinions by the parents concerned all ADHD subtypes, but was emphasised in the cases of ADHD inattentive subtype.

5.1.2 Mixed experience with kindergarten, school and PPT

This theme is focused on informant group I's experience before their child was referred to BUP for an ADHD screening, and is thus focused on the parents contact with kindergartens\ schools and PPT.

A battle to get the required help

Olivia's child received special educator assistance mandated in the PPT expert assessment for the final year of kindergarten. However, due to improvement in the child's emotional regulation development during that period, the kindergarten recommended to the school that he stopped receiving it. It wasn't until the 5th grade that the school agreed to refer the child to PPT for an observation. From grade 1-5, the school attributed the child's concentration and emotional regulation difficulties to his parent's divorce. The parent acknowledged in the interview that the divorce between herself and the father undoubtably impacted her child. She disagreed, however, with the school that it was the root cause for his struggles, but mentioned that her opinions were not taken seriously. "The school made many excuses. They didn't see the same problem we did" (Olivia).

According to Olivia, the reason as to why her child was eventually referred to BUP in the 7th grade was solely due to the diagnosis being convenient for the school. Here, she expressed frustration that it was only when the child's ADHD symptoms led to physical outbursts with other children that the school started to collaborate effectively with the her.

> Interviewer: Did the school see what you saw?
>
> Olivia: Not until he started acting out more and becoming more violent. He was never met with understanding, so there was a lot of frustration in his body. He was told that he had to sit down, but it is difficult to sit down when your body is bubbling.

The informant further explained that there was almost no communication regarding updates once the school had decided to request that PPT come and observe the child. It wasn't until almost a year later that the school contacted her, but that was to inform her that his paperwork had been lost and had not been sent to PPT. Thus, her child didn't

receive the ADHD diagnosis until the end of 7th grade. She explained that due to the lack of communication from the school, as well as a feeling that her opinions had not being taken seriously, a negative relationship between the parent and school was developed. Indeed, Olivia characterised the collaboration process with the school as; «Det har vært en lang kamp».

The answers from Olivia regarding her experience collaborating with her child's kindergarten and school, tells us that her experience was characterised as a negative one largely due to poor communication and not having her opinions being taken seriously.

A feeling of being involved in the process

No other parent participants criticised the kindergarten or school for poor communication or for not taking the parent's opinions seriously, once again highlighting the variations in the parent's experience collaborating with these institutions. For example, Frida stated: "We cooperated very well with the preschool, with the school, and we talked well together. We were well informed, and they were good with our child". Consistent with Olivia's description, however, was that obtaining the ADHD diagnosis for Frida and Iben's child also consisted of significant delays. "They started (the assessment) when he was four/five and he was diagnosed when he was six and a half" (Frida).

Although significant delays in the process occurred for these three parents, there was a striking contrast between the parents' perspective towards the experience. Indeed, although it took almost more than two years to screen for and receive the ADHD diagnosis for Frida's child, the mother was very satisfied with the kindergarten, the school, and PPT in regards to their thorough assessment. She explained: "It was ADHD. They spent a very long time and were very thorough in their assessment of him, and I think that was very good" (Frida).

The large timescale was due to the father having severe physical and psychological difficulties during the time period, as well as the parents getting divorced during this time. Moreover, PPT pointed out to the mother that the child was born in December and the youngest in the school class, thus more time was necessary in order to rule out that the child's symptoms were being caused by these factors.

> There were a lot of things, and they didn't want to go straight to ADHD, because they thought about what we had to rule out; A dad who is mentally ill and physically ill. He had undergone heart surgery and had passed out in front of the boy. The father had ME (chronic fatigue syndrome), heart surgery, small traumas (for the child). (Frida)

It seems that the positive attitude from Frida to the significant delay was largely due to the institutions actions in explaining the reasons for the delay, as well as the feeling of being a part of the process, and a solid trust in the collaboration. Indeed, although the parent had suspected her child had ADHD for years, and understandably wanted the diagnosis set in order to acquire effective support for her child, she ultimately trusted that the institutions were acting in the best interests for her son. “I saw which way it went and that it was going to be ADHD. I got time off work, of course. I went with him to all assessments, conversations, observations, so it was very good” (Frida).

In sum, the analysis showed that the parent’s experience with kindergarten\school and PPT in regards to their child’s difficulties, varied enormously. Some parents described the process as positive, where “effective communication”, and that “the best interests of the child” were raised as key factors for the parent's positive experience in cooperation with these institutions. In these cases, good collaboration acted as a dampener to stress, where an experience of working as a team for the child was realised. For others, the collaboration has been characterised by little understanding of the parent’s concerns by the teachers, as well as the teachers possessing a lack of knowledge of ADHD. In these cases, poor collaboration led to a lack of trust in the institutions, a reduced confidence in the parent competency role, as well as heightened stress.

5.1.3 The diagnosis as a relief

This theme is focused on the relief the parent informants felt when receiving the diagnosis. It explores the various reasons given by the informants as to why obtaining the diagnosis helped them, their child, and the family as a whole.

<u>An answer to unanswered questions</u>

An important finding from the informant group I interviews was that they all found the ADHD diagnosis for their child a relief. «Alt med å få diagnosen har egentlig bare vært

positivt» (Noora). Unanimously, they reported that before the diagnosis, they were aware that their child struggled significantly more than other children in certain areas. Not knowing the cause for these struggles, nor the ways to optimally support them caused a great deal of stress to the parents.

> There were some challenges with remembering things, and we didn't understand what it was, so it caused quite a bit of irritation. Either he caught the school bus, or he remembered his schoolbooks, it was never both. Why are you never able to bring books home with you or why can't you catch the bus? So, it was a bit of a problem, and we couldn't put our finger on what it was. (Iben)

> When she took tests at school, she only did half of the assignment, and then she didn’t have time to do the rest. Then she hasn't shown what she is able do. She worked so much on her homework at home but didn't get to show what she could do. It was so frustrating as a mom. (Noora)

Obtaining the ADHD diagnosis was therefore often described by the parents as an answer to their unanswered questions. For example, Noora explained: “There were many years of uncertainty, but things really fell into place when we got that diagnosis”.

This sentiment was echoed by several of the other parents:

> Then I started reading up on ADD, I thought "here it is". It was kind of good to know it's ADD… Like I said earlier, getting the diagnosis might have helped me to better understand his challenges. (Iben)

Furthermore, a number of parents explained that the diagnosis also gave them more understanding and patience with their child in regards to their difficulties concerning concentration and forgetfulness. For example, Iben explained: “As I said earlier, getting the diagnosis may have helped me to gain a better understanding of his challenges. It has helped with the irritation and some anger that I felt. And it's easier to collaborate”.

Additionally, several noted the utility in having the diagnosis in writing as it provided them with the rights to acquire the support they needed. Frida emphasised the

dampening of stress for her in the situation once she was assured through obtaining the diagnosis that these rights would provide her and her child with more resources: “I relaxed more because I had gotten something on paper. That's what she said in kindergarten; You have now been diagnosed, so now you have rights and will get help”.

Perhaps one reason for the feeling of relief in acquiring additional resources from having the diagnosis in writing was due to her financial situation. Before starting the interview, Frida commented on the financial burden she faced. She clarified that this came not only from her divorce with the child’s father, but also through having to decrease her working hours in her job. She explained to me that due to being a single parent with two children; one with special needs, it became impractical to work full time in her job as a nurse. This was because working evenings, nights, weekends and school holidays is a necessary part of the job as a nurse in the hospital, something which is not compatible with the needs to two children currently in Primary school.

All parents reported a sense of relief when their child received their ADHD diagnosis. The reasons given concerned obtaining answers to concerns they had previously experienced, as these answers provided the parents with both the knowledge and resources to optimally support their child.

The stress of spousal disagreements

The analysis from Informant group I highlighted that Olivia and Frida met significant resistance from their spouse in obtaining an ADHD diagnosis for their child, and that this impacted their experience of the process in several ways. First, the resistance from their spouse for Olivia and Frida contributed to the process of obtaining an ADHD diagnosis for their child taking several years, with the process taking almost a decade with Olivia.

> I tried to include the father at first, but there were so many arguments and disagreements that even he realized that there was no point in him joining. So I did everything alone because it was the easiest. (Frida)

Olivia and Frida experienced a divorce with their spouse during this time, where disagreements concerning their child’s difficulties were attributed as a contributing factor to the divorce. For example, Frida stated the following: “I started to think more

(about the diagnosis) than the father. We are not together anymore. We had huge disagreements. It started there".

Indeed, those parents who experienced significant resistance from their spouse, emphasised their relief of the diagnosis notably more than the other parent informants. This relief was not only illustrated verbally, but also through their body language during the interviews. The degree to what the ADHD diagnosis meant for Olivia is illustrated in the following quote:

> It has been a relief. It's like a burden being lifted. I almost cry when I think about it. That I was right all along. There were many who were sceptical about it and believed that he was a typical boy. Very good to have it confirmed. Those who did not believe me have come and apologized. (Olivia)

When asked about their thoughts on the potential reasons for the resistance from their spouses, Olivia and Frida attributed the resistance to their spouses having family members with ADHD, as well as a suspicion that their husbands themselves also have the condition. The spouse of Olivia has a sister with ADHD, something which she claimed caused him to have significant scepticism to the recommendations made by BUP.

> Our boy's father has a sister with ADHD. The child's father was a little negative about medication and such, because he has seen that his sister became quite lethargic and was not quite herself. So he was a bit negative about it then. (Olivia)

As mentioned above, both parents felt that the father of their child has ADHD. Having it undiagnosed was attributed as a factor in hindering them from being open to the diagnosis in general. Frida explained: "He didn't want to see it. His father certainly has ADHD too, but he didn't want to find out, and then there is nothing wrong with him and there is nothing wrong with his child either".

Since Frida's son received the ADHD diagnosis and begun treatment, her ex-husband has subsequently received a psychological disorder diagnosis, and takes medication accordingly as part of the treatment. She explained that now that he is more

psychological stable, he has begun to not only acknowledge that their son does have ADHD, but that he even sees similarities between him and his son's behaviours. Similar to Olivia, this acknowledgement that her suspicions were indeed correct was described as immensely positive by Frida.

> I just have to say something that is a bit funny now in retrospect. The father has now become more stable and has received his own diagnosis and is taking medicine. Now he says that he and his son are very similar. In many respects they are very similar. That is why the whole process has been so painful for the father, because he had many years where he was not ready to deal with his own challenges. Now he lives in Oslo and we live here. He comes and meets the child from time to time and he says; "He's just the way I was when I was little." He sees it now, so that's good. (Frida)

Those parents who experienced significant resistance from their spouse, emphasised their relief of the diagnosis notably more than the other parent informants. This additional relief was attributed to the momentous stress they experienced in battling with their spouse for their child to receive the diagnosis and the help they needed. In their child obtaining an ADHD diagnosis, these parents explained that they had confirmation that their suspicions were indeed correct. This confirmation seemed to provide the parents with immense relief that the battle they had fought, as well as the result, was worth it.

5.1.4 The aftermath of receiving the diagnosis

Once the child has been referred to BUP, the assessment is carried out and the diagnosis is given, the parents must then decide whether they accept or reject the diagnosis. If they accept the diagnosis, the next steps are to consider an optimal treatment plan. This theme explores the participants experience collaborating with BUP in this screening and treatment part of the process.

<u>Information tailored to both the parents and their child, and having a say in the treatment decisions</u>

Participants in informant group I were very satisfied with this part of the process at BUP. For example, Olivia explained: “They get nothing but praise from us. They welcomed us. They explained to him what it is like to have the diagnosis and what he might feel. No, it was absolutely fantastic”. Similarly, Frida stated “We had a very good dialogue (with BUP)”.

Furthermore, all parents were recommended medication as a part of the treatment for their child’s ADHD by BUP, and without exception, all were satisfied that medication was utilised as a part of the treatment, combined with measures at home and school. The analysis highlighted that the main reasons for this positive perspective towards collaboration with BUP, as well as ADHD medication, stemmed from several factors. First, the informant group felt that the health professionals provided adequate information on the condition and the treatment options to both them and their child, and that the information provided to their child was adjusted to their child’s level of understanding.

> In the first session, [the child] received information about ADHD, like; concentration difficulties, hyperactivity, impulsivity, and what do you recognize in yourself? Really good information for her. So, the information that was given was not only to us, but to the child. That's very good. (Noora)

> When we were at BUP, both [the child] and I had a conversation with a psychiatrist about it. [The child] received information on his level while the three of us sat together. Then [the child] was allowed to go out and play and then I got information on an adult level. I think that was very good. Then we had another long chat. (Frida)

Information highlighted by parents as particularly important concerned the types of medication, their potential symptom management effects and side effects, as well as details of the trial process with medications and dosages:

> The most important thing for us was that it was carefully explained what the medicine was for, because the boy wondered if he would be given drugs. There

were people around us who said that there were narcotics in the medication and that it could make you lethargic. Potential side effects and things like that were very carefully explained. (Olivia)

Me, my husband and [the child] sat down with the practitioners at BUP. They said that there are several types of medication, and explained which are the most commonly used. They said that we can change the medicine or stop taking it if the side effects are too great. (Noora)

As well as adequate information on the condition and recommended treatment, informant group I also described a feeling of the family being involved in the process, as well as both the child and parents having a level of influence over the treatment decisions as important.

We had some conversations along the way in relation to the dose. The child wanted to increase the dose. We had a good dialogue with BUP and we concluded that it was other things than the dose that made him uneasy. In the seventh grade, he was in a large class, change of staff, unorganized, chaos. So, we never increased the dose. (Iben)

It was really up to us and [the child]. We could consider whether we think everyday life is OK without medicine, or whether the measures at school are sufficient. They said we can change the medicine or stop taking it if the side effects are too large. In any case, this (using medicine) was a choice we made. (Noora)

He was asked questions about what he felt, and when the dose was to be increased, he was often asked what he felt inside his body because he is the only one who knows. So, he was included in the decisions. (Olivia)

The current section of the thesis highlighted the main reasons for the reported positive perspective towards collaboration with BUP from the parents, which stemmed from two main factors. The first factor was the informant group feeling as though they received adequate information from the health professionals which was tailored to both the parents and child. The second factor involved a feeling of the family being involved in the process, as well as both the child and parents having a level of influence over the treatment decisions.

Feeling more competent as a parent

The parents interviewed did not seem to mind that there was not a great deal of emphasis placed on measures, and none of them reported any sense of being pressured by the health professionals at BUP to use medication as part of the treatment. The analysis suggests that the overwhelmingly positive perspective towards medication was largely due to effectiveness in managing their child's symptoms. In being able to effectively manage their child's symptoms, informant group I described a feeling of having better control of the situation. Moreover, the parents described a feeling of comfort knowing that their child now has the opportunity to achieve things that previously seemed unattainable. For example, Noora stated: "Then she will be able to show her true potential, and that is very good for us parents too, not just her".

Iben reported that she was initially against medication for ADHD treatment before her son received the diagnosis, as she believed that it made children too passive. She was sceptical of taking the route of medication as part of the treatment, until she saw the effects it had on her son. «When you're in the midst of it, you think about it a bit differently», stated Iben. Her child started medication in secondary school, and she attributes the use of medication to assist him in his concentration at school and his academic success. Here, she spoke with immense pride when describing that her son achieved the following:

> But at the same time, he was concentrated and focused on what was happening at school, and I think it helped him. He is now in his second year of high school, and when he left the tenth grade, he had really good grades. He wanted to study on a course with only 15 places and 36 applicants. He was accepted. (Iben)

Three of the four parents noted that the strategies at home recommended by the health professionals at BUP and at the ADHD Parent course became far more effective after the use of medication. As already mentioned, Noora's child had difficulties concerning homework, where the grandmother, who is a former teacher, comes to help once a week. The help consists of a number of strategies with the intention of reducing distractions. Noora emphasised that combining medicine with these strategies has dramatically improved the situation: "It's not a challenge to get homework done. She is doing homework now. She sits down, occasionally on her own initiative. That has never happened before".

Olivia even mentioned that the strategies at home regarding her child's difficulties in regulating his emotions and physical outbursts were unnecessary once her child began taking the medication:

> Interviewer: And those (strategies) were used before the medicine, right? Have you tried these strategies since he started the medication?
> Olivia: No, we don't need it now. It is night and day.

In sum, the overwhelmingly positive perspective towards medication by the parents was caused by various reasons. Foremost, was the medicines effectiveness in managing their child's symptoms. Medicine as part of the ADHD treatment was also seen as a catalyst in increasing the effectiveness of other measures, and in some cases, causing the other measures to be unnecessary. Through better management of their child's symptoms, the parents reported a feeling of having better control of the situation, as well as a belief that their child would have the opportunity to reach their potential.

5.2 Health professional's perspectives

5.2.1 The importance of working with the parents

The first theme in this second section of the findings looks at the health professional participants experience of working with the patient and parents throughout the ADHD screening and treatment process.

Positive collaboration

The informants described a positive experience when counselling the majority of the parents, and the analysis illustrated that informant group II clearly recognised the

importance of having the parents of the child closely involved in the process. For example, Jacob stated: “It is extremely important to work with parents. It is good that the parents are involved. It is the adult who is important for the further development of measures, in order for the children to bring out their potential”. Moreover, Isak expressed: “I would say that most people who come to us go to the doctor to have their child referred on their own initiative, which means that they are positive towards an ADHD assessment”.

Another key point highlighted by Informant group II to help explain why the collaboration with parents is typically a positive one, was that they experience a sense of relief in response to the diagnosis of the child from the majority of the families they work with. It was explained by Jakob that this reaction is natural and understandable as the parents finally gain a better understanding of their child’s problem: “It is often the case that difficulties can be better understood by receiving a diagnosis”.

They clarified that those parents that have children with ADHD inattentive type often are surprised by the diagnosis, but after reading up on the symptomology, these parents usually find the diagnosis as something that is positive.

> But there are many people who are referred to BUP for something else, and then the therapist says; you have some concentration problems that have been there all along and we will assess this. Then you may find that parents are sceptical. But most of the people who come to us are referred for ADHD and are very prepared for it. (Isak)

It was emphasised by informant group II that another reason that parents *can* experience relief from their child obtaining an ADHD diagnosis is access to use of medication, which can often be effective in managing the child’s symptoms. “In order to receive medicine, one must have a diagnosis” (Jakob). “We see that measures often have a good effect, but then we also see that on a general basis, people with ADHD experience a good effect from medication” (Aksel).

Overall, informant group II described a positive experience in collaborating and counselling most of the parents they work with. They reported that the positive

collaboration is likely due to them meeting the needs of the families they work with, as well as the parents often seeing the diagnosis as something positive.

5.2.2 Medicine as part of the treatment

This theme involves the experiences of the health professionals regarding recommending medication as part of the child's ADHD treatment plan. It explores the typical treatment plan offered by the health professionals and their rational for these choices. It also looks at the different ways in which the health professionals experience the parent's reaction to the treatment recommendation.

Medicine is almost always recommended

Informant group II explained that they almost always recommend a combination of medication and measures at school and home as the treatment options for children's\adolescent's ADHD.

> There needs to be a combination of medicinal measures and non-medicinal measures. Medicine is not like a magic potion, there has to be a combination of understanding the condition and meeting the children in the right way, etc. There is so much more than just medicine, but my recommendation is a combination. (Isak)

However, both Isak and Aksel explained that of the two ADHD treatment strategies, medicine is often emphasised more over measures at kindergarten\school.

> It is stated in the guidelines that you should try measures first and then medicine, but in reality, it very often happens at the same time. That's what parents often want, and so does the school. Actually, we should be better at trying measures first. (Aksel)

The rational for a larger emphasis placed on medication as treatment over measures at kindergarten\school was provided by the health professionals. All believed that implementing measures in kindergarten\school tend to be more effective if the child is already medicated.

> From my point of view, I would always recommend medication because I do not believe that a child with ADHD can reach their goal simply with measures and without medication, at least not if they are heavily affected by the ADHD. (Isak)

Moreover, Aksel clarified that there are benefits of starting with medication as a treatment strategy as opposed to a combination.

> Yes, but it can be hard to know what works, right? You can, for example, get an assistant or get a daily schedule. But if you start with everything at the same time, it is difficult to know what it is that works. (Aksel)

He clarified further that starting medication as treatment for ADHD symptoms first can often assist in cases where the child has additional difficulties\needs. This is because these additional difficulties are often a result of untreated ADHD, thus it may be unnecessary to set in measures for these if the child has their ADHD treated effectively.

> With ADHD, it is very common to have comorbid conditions. In my experience, dyslexia is incredibly common, but also behavioural diagnoses. But we are quite cautious about giving such diagnoses before we have tried measures or medicine, because it could be caused by ADHD. (Aksel)

In this section of the findings, the health professionals explained that although they usually recommend a combination of medicine and interventions at kindergarten\school, they tend to place more emphasis on medicine. The health professionals believed that the interventions at kindergarten\school are often more effective if the child is already medicated. Furthermore, Aksel experiences that starting with medication as a treatment first can frequently alleviate some difficulties the child has due to them being a comorbidity of the condition.

Disagreements between the parents

All health professionals acknowledged that they experience concerns from parents once the ADHD diagnosis is provided, and that the parents have a right to have their concerns taken seriously. Informant group II explained that the majority of concerns are usually related to medication, and that they do what they can to address these concerns.

> When it comes to ADHD medication, I would argue that approx. 90% of all parents want to try medicine. But there are always some who are skeptical. I use to say that they are allowed to be because it is their own choice, and that they can take some time. (Isak)

Informant group II clarified that concerns from the parents, particularly regarding medication, can in some cases lead to resistance to the diagnosis given, and\or the recommended treatment. This resistance can come from both parents of the child, or there can be disagreements among the parents themselves. All health professional informants emphasised that ideally, they want both parents to be in agreement regarding the treatment for their child's ADHD as the process is more effective for the child and the family as a whole if all parties are on board. Aksel stated: "Accepting the diagnosis is the foundation, right? It is difficult for practitioners if parents do not accept it".

Informant group II described the initial protocol in these situations as first inviting the other parent to a meeting at BUP with the doctor so that his\her concerns can be listened to and addressed.

> They have many questions, so I recommend that they have a conversation with a doctor without having to start medicine for that reason, but that they have a conversation with a doctor to get answers to their questions. And finally, I also see that most people try out the medicine as well. They simply need some time. (Isak)

Whether this meeting is carried out with both parents at the same time or individually depends on the level of conflict between them and\or if they are living separately or not.

> If, for example, the father disagrees, and we have only spoken to the mother, then we also want to talk to the father so that we can hear his side. What experience does he have? But it can also be mothers. (Jakob)

Furthermore, Jakob clarified that an emphasis is always placed on the strengths of the child, and the positive elements of having the condition in order to diminish possible negative connotations parents may have with the condition:

> Often when talking about ADHD, the focus is on difficulties and problems, but it is good to have the parents involved to bring out more positive things. Research also shows that the children have a number of resources. I think it is important to strike a balance by focusing on both the child's challenges and resources so that parents understand their child's abilities and needs. The child must not stand alone. We tell parents that we give the child a diagnosis so that the child can realize his or her potential, because the symptoms can hinder the child's resources. (Jakob)

Additionally, the following strategy was also mentioned as a common protocol in such cases:

> If a parent disagrees, then I think it is important that we receive information from the school that may see more symptoms and more difficulties because the fact that there are more demands in school. If the father has the child every other weekend, he may not see the symptoms as clearly. (Jakob)

Informant group II confirmed that agreement is often achieved through these strategies, but in the cases where it is not, a number of options can be offered. If the disagreement concerns medication for example, treatment can involve only measures in school and at home first. If these measures are found to be effective in managing the child’s ADHD symptoms, then a level of agreement has been reached.

> The agreement may be that we should not medicate, we’ll try other measures first, and then we wait with medication, for example. There are several paths to take. If parents think that the other measures are not enough (after trying), then it is easier to try medication because we have tried other things first (Jakob).

Jakob and Aksel did clarify that when interventions at school are implemented with the absence of medication due to disagreements between the parents, almost all parents re-refer their child to BUP to try medicine at a later date. “But they come back and are re-referred, or they have time to change their mind before we close the case. They come back and tell us that my child needs to try medication after all” (Jakob).

Moreover, when asked if the parents usually choose to continue their child on ADHD medication after reaching agreement, Jakob said; “Those who have changed their mind and come back wanting to try medicine, they continue, for the most part”. However, once attempts have been made to facilitate agreement between the parents, and no agreement has been reached, informant group II pointed out that consent to treatment is only required from one parent, providing the parent is the primary caregiver: “It is the case that it is sufficient for only one of the parents to consent to treatment” (Isak).

Responses from Jakob and Aksel concerning their role in facilitating agreement between the parents of the child gave the impression that they were active in the process. Isak differed slightly than the other two health professional informants in his stance to his role in supporting the parents to reach an agreement in the treatment options. “We cannot resolve the conflict between them. That is someone else’s job” (Isak). Ultimately however, informant group II clarified that significant conflict between the parents they work with in regards to accepting or declining the diagnosis, as well as choice of treatment options, is *not* something that they experience often. Indeed, Aksel explained: “It is very rare that people do not accept it. Most parents agree with the recommendations made by us and the school”. Similarly, Isak stated: “What you’ve just said doesn't happen often, but it does happen from time to time, and then we argue for what we think is right”.

In sum, the health professionals explained that disagreements they experience from the parents, or disagreements between the parents themselves, are most often related to medication. It was described by informant group II that they strive for agreement between all parties as this tends to make the treatment for the child and the family as a whole more effective. The typical protocols for addressing disagreement were laid out by the informants. It was however, highlighted that once all efforts have been made, and no agreement has been reached, BUP requires only one parent’s consent to treatment.

5.2.3 Concerns raised by the health professionals

Informant group II did raise a number of concerns with the screening and treatment process of children with ADHD. These concerns will be addressed in this section of the findings.

Large variations in the screening quality for ADHD

Isak mentioned that there are large variations in the screening quality for ADHD by him and his colleagues at BUP.

> I have the experience that ADHD assessment is carried out in very different ways between BUPs, and also differently between different therapists within the individual BUP. It is a standardized assessment that everyone should basically use and follow, but there are parts that are done, which do not need to be done and vice versa. Not everyone does it as precisely and accurately as others. (Isak)

This point was echoed by Aksel, who stated; “It is a bit random. It is different from therapist to therapist, because a structure has not been set up for the children to the same extent as, for example, with autism" (Aksel).

Drowning in patient numbers

Another concern with the screening and treatment process highlighted by the health professionals was in regards to long waiting times in the referral, screening and treatment process. It was clarified that long waiting times are unfortunately not uncommon due to the high number of patients currently referred to BUP. Aksel explained that due to the number of children\adolescent referred to BUP for screening of ADHD, he feels that he has too little time with each family. “Children with ADHD account for almost 40% of referrals to BUP. There are so many of them that you drown. We are not able to follow them up to the same extent as I would have liked to” (Aksel).

Of importance, he also explained that this is a contributing factor to the health professionals placing more emphasis on medication for treatment compared to other measures in kindergarten\schools. “There are actually quite a few facets that one should perhaps address to a greater extent, but then I guess it is easy because there is a pill (Aksel).

Lack of knowledge of ADHD inattentive subtype and the difficulty of diagnosing the subtype

The final concerns raised by Informant group II regards the ADHD inattentive subtype. Informant Group II emphasised that knowledge of ADHD inattentive type among both teachers and parents tends to be significantly less than the other two types. For example, Isak stated: “There are actually many people who do not know what ADD is”. Similarly, Aksel asserted: “There is far less knowledge about ADD. Information about ADD is at least to a lesser extent available”.

The health professionals did mention that when an ADHD diagnosis is given, no matter the subtype, they conduct a meeting with the child’s teacher. Here, the health professionals can provide information on the subtype and recommendations of how to optimally manage the symptoms at school. Isak explained: I don't know if I have ever experienced that they are not positive about us initiating talks with the school. It is wanted by everyone. So we always do”.

With this in mind, informant group II also explained that responsibility to increase the teacher’s awareness of the inattentive subtype does not fall under their mandate, and that there is no structured psychoeducation that they provide to teachers on the subtype. BUP health professionals do, however, provide psychoeducation to the parents, including information on the subtype. Informant group II explained that in cases where the child has ADHD inattentive subtype, the health professionals often experience a higher level of scepticism to the set diagnosis from the parents. However, all health professionals interviewed emphasised the determinative role that information can play in helping the parents understand the condition better, something which often can alter their stance on the matter.

> Yes, there is an ADHD stereotype regarding hyperactivity, so when you have a child who is apparently calm on the outside, parents are often a little more uncertain about the diagnosis. But when they get the information, we see a lot falling into place. Then the child describes things that the parents were not aware of. “Yeah, dad and mom, I'm actually restless, but you can't see it, it's on the inside”. Many children say this. (Jakob)

> With parents like that, they know that there is something up with the child, and they wonder what it is. But they are unable to make the connection that this is actually ADHD. Often when they stumble upon the right information, they recognise it very well. (Aksel)

Moreover, the health professionals reported ADHD inattentive type as being far more difficult to diagnose than the other two types of ADHD due to the absence of the hyperactivity element. As a result of this, ADHD inattentive type is referred to BUP and diagnosed far less than the other two types of ADHD. Isak explained: "It is definitely more difficult. With ADD, there are concentration difficulties alone, and there can be a million other reasons for concentration difficulties. We do not give ADD diagnoses at BUP.

Moreover, Isak remarked that individuals with other subtypes of ADHD tend to lose the hyperactivity element of the symptomology as they become older. Therefore, he experiences that if these individuals are referred to BUP for an ADHD screening as an adult, correctly identifying the ADHD diagnosis is a far more difficult task than if they had been referred as a child.

> It becomes more and more challenging as the child gets older. I often see a 16/17-year-old girl or boy come in, with little physical hyperactivity. But if we begin to look back and make a phone call to the early year schoolteacher, we are often told about a boy who could not sit still and who was outside running every single recess because the older they get, the hyperactivity disappears, it becomes less visible. He is left with concentration difficulties. (Isak)

Aksel further explained that the difficulty of diagnosing ADHD inattentive subtype becomes even more complex by the fact that typically, those who receive an ADHD combined type or ADHD impulsive/hyperactive type were referred to BUP for a screening of ADHD, but that this is often not the case with ADHD inattentive type. Indeed, he explained that children\adolescents who end up obtaining an ADHD inattentive diagnosis are often referred to BUP for a range of psychiatric disorders such as anxiety, depression or eating disorders, and that this referral tends to occur when the

individual is older. After a thorough screening at BUP, the health professionals are then able to identify that the reason for referral was actually a comorbidity disorder of ADHD inattentive type. Importantly, Aksel stressed that this coincidental nature suggests a risk of underdiagnosis of children, particularly girls with the ADHD inattentive subtype.

> Those who are noticed first are the once who disrupt interactions with others in the preschool or school. It's mostly the highly active boys. We see that the school has tried throughout the whole first grade, and then these children are referred to us in the autumn in the second grade because it isn't working. The teacher is fed up. And as you say, there are many of those 'head in the cloud' girls who sit quietly and become underachievers. They are often referred later, but I think that there are a great many girls with ADD who are never referred. (Aksel)

In sum, a number of concerns raised by the health professionals were laid out in this part of the findings. The concerns consisted of; large variations in the screening quality for ADHD at BUP, high number of patients, and a lack of knowledge of ADHD inattentive type among both teachers and parents.

5.4 Pattern of consistencies between the two informant groups

The analysis found no significant inconsistencies between informant group I and IIs answers. This is not to suggest that there are no inconsistencies between the two groups, but that none were highlighted from the questions asked in the interview guide. A number of consistencies between informant group I and II, however, were highlighted. These will now be described, and then further discussed in the following chapter.

The statements produced by informant group I regarding their mixed experiences with kindergarten, school and PPT were consistent with the feedback the Health professionals receive from parents on a daily basis. Moreover, the description of the «coincidental nature» in obtaining an ADHD inattentive diagnosis by Isak was consistent with both parents in the study who have a child with ADHD inattentive type. In both cases, obtaining an ADHD inattentive type for their child was coincidental.

Nooras suspicions that her child had ADHD inattentive type came only due to working on system maintenance at the ADHD parent course at BUP. Indeed, as she was working, she listened to the description of symptoms of ADHD inattentive type given by a speaker. The parent recognised these symptoms not only in her daughter, but also in herself. She showed the symptomology list to her husband and the child's school teachers, and only then did she seek referral for her child to BUP with her General Practitioner.

Ibens child was referred to acute BUP as the family was in crisis for other reasons. Here, the health professional at BUP identified that her son had the diagnosis, and they started treatment immediately. The parent recalled that she was on holiday when the health professional contacted her by phone and explained that her son had the diagnosis, and that she wasn't aware the type even existed. Furthermore, she stated that her family was lucky that her son even received the diagnosis of ADHD inattentive, as she explained that BUP informed her that they rarely set a diagnosis for this subtype.

Furthermore, the analysis found consistencies between informant group I and IIs answers to the quality of information, often referred to as psychoeducation, provided by BUP. All parent informants praised BUP for providing quality knowledge to both them and their child regarding the condition and medication. Aksel stressed the importance of placing the screening test findings into context for the families, and avoiding the use of overly complicated language in order to ensure the all parents can access the information. Jakob also pointed out that some parent's possess incorrect information on the condition, which could hinder decisions concerning the treatment. Thus, he explained that providing psychoeducation to tackle these misconceptions is prioritised before providing treatment recommendations.

At the other end of the spectrum, the health professionals also spoke of those parents who possess a strong knowledge of the condition and the treatment options. These parents tended to be those that have other members of the family with ADHD. Furthermore, it was raised by Jakob that in such cases, the process from recommending the medication to trying out the medication is sped up.

In regards to the genetic component of ADHD and its influence in the screening and diagnostic process for informant group I, we heard a variety of ways, both positive and negative, that it impacted their experience. Indeed, Noora found having family members

with the condition as helpful in normalising the condition for her child. Olivia and Frida however, experienced significant resistance and immense stress from family members, potentially even the spouses themselves, having the condition.

5.5 Summary of the findings

In this section, the findings from both informant group I and II will be summarised, which will serve as a reminder before moving on to the discussion chapter.

Most of the parent informants described a feeling that there was something "extra" with their child from a very early age. However, there is a noticeable contrast concerning the nature of the suspicions between those parents who have children with ADHD combined subtype, and those who have children with ADHD inattentive type. Here, those parents who had children with ADHD combined, displaying stereotypical ADHD behaviours, suspected that the cause could be ADHD. On the other hand, the parents who had children with ADHD inattentive type possessed a lack of knowledge of the subtype symptoms, and thus did not suspect the cause to be ADHD until the child was older. All parents reported that the child's teachers at kindergarten and school also seemed to have a lack of knowledge of ADHD, and particularly of the ADHD inattentive subtype.

Informant group Is answers illustrated large variations in their experience of collaborating with the child's kindergarten and\or school. Some experienced good dialogue, where the child's best interests seemed to be present in the decisions made. Others, however, felt that they were met with poor communication and not having their opinions taken seriously.

Consistent among all participants in informant group I was a feeling of a sense of relief when their child received their ADHD diagnosis. Obtaining answers to concerns they had previously experienced, and thus being able to better support their child, were provided as reasons for this relief. The sense of relief was also expressed notably stronger in parents who experienced significant resistance from their spouse compared to the other parent informants. This was attributed to these parent's gaining confirmation that their suspicions were indeed correct. Obtaining the diagnosis for their child seemed to provide these parents with an acceptance that the challenging period had been worthwhile.

Although there were mixed experiences with the collaboration between the child's kindergarten\school and the parents, informant group I reported a positive collaboration with BUP. This was attributed to the informants feeling as though they received adequate information from the health professionals which was tailored to both the parents and child. It was also described as being due to feeling that the family was involved in the process, as well as both the child and parents having a level of influence over the treatment decisions. An overwhelmingly positive perspective towards being recommended medication by BUP was also highlighted by the parent informants. The use of medicine in the ADHD treatment for the child proved to be not only effective in managing their child's symptoms, but also in increasing the effectiveness of the non-pharmacological interventions. Informant group I explained that this led to them believing that their child would be able to reach their potential, something which they hadn't felt previously.

The health professionals in informant group II described a positive experience of collaborating and counselling most of the parents they work with. They felt that the positive collaboration is likely due to them meeting the needs of the families they work with, as well as the parents often seeing the diagnosis as something positive. They clarified that they almost always recommend a treatment plan consisting of a combination of medicine and interventions at kindergarten\school. The health professionals did, however, mention that they tend to place more emphasis on pharmacological treatment over non-pharmacological treatment. The reasons given for this decision were a belief that that the non-pharmacological treatment often become more effective if the child is already medicated. In addition, it was even suggested that starting pharmacological treatment first can often alleviate some difficulties that the child has, due to them being a comorbidity of the condition.

Informant group II stated that although they collaborate effectively with the majority of the parents they work with, disagreements occur from time to time. These disagreements can occur between the parents and BUP, or between the parents themselves. The most common reason for disagreements in the collaboration process is in relation to medication. The health professionals explained that they always strive for agreement between all parties as this tends to make the treatment for the child and the family as a whole more effective. The typical protocols for addressing disagreement were laid out by the health professional informants. These included inviting the

disagreeing parent to a meeting at BUP with the doctor present so that his\her concerns can be listened to and addressed, placing an emphasis on the strengths of the child, and receiving additional information from the school. It was, however, highlighted that once all efforts have been made, and no agreement has been reached, BUP requires only one parent's consent to treatment.

Lastly, a number of concerns regarding the screening and treatment process of children\adolescents at BUP were raised. Interestingly, these were raised not by the parent informants, but exclusively by the health professionals. The concerns consisted of; large variations in the screening quality for ADHD at BUP, high numbers of patients, and a lack of knowledge of ADHD inattentive type among both teachers and parents. The large variations in screening quality were attributed to a lack of structure in the screening guidelines for ADHD. This lack of structure can lead to a room for interpretation by the health professionals, and thus a lack of consistent practise. The high number of patients was presented as a concern by the health professionals as it can result in placing more emphasis on medication as the recommended treatment. A lack of knowledge of ADHD inattentive subtype among both teachers and parents was raised as a concern in relation to the coincidental nature of receiving the diagnosis. With a lack of knowledge of the subtype from both parents and teachers, the health professionals explained that these children are often missed when they are young.

A number of consistencies between informant group I and IIs answers were highlighted in the analysis. First, there were consistent statements produced by both informant groups regarding significant variations in experiences collaborating with kindergartens, schools and PPT. Moreover, both informant groups spoke of the «coincidental nature» in obtaining an ADHD inattentive diagnosis due to the lack of knowledge on the subtype possessed by both parents and teachers. Furthermore, the analysis found that parent informants were satisfied with the psychoeducation provided to them by BUP, and the health professionals reported experiencing a similar impression from the parents they work with. Finally, the genetic component of ADHD was recognised by both informant groups. The parents illustrated the genetic component impacting their experience in a variety of ways, both positively and negatively. The health professionals also acknowledged that although having family members already diagnosed with ADHD can be positive for the family due to increased knowledge of the condition and medication as a treatment, it can also hinder the process.

6.0 Discussion

Through the use of semi-structured interviews, the current study examines the experiences and perspectives of four parents in obtaining an ADHD diagnosis for their child. It also examines the experiences and perspectives of three health professionals collaborating with the parents of the children they provide an ADHD diagnosis for. In the following section, I will discuss the main findings in the study in an attempt to gain an insight into the thesis' research question: *How do parents experience the process of getting an ADHD diagnosis on their child and what do health professionals experience advising parents in process.* I will begin by exploring possible explanations as to why mixed experiences with kindergarten, school and PPT were reported by the parents. Next, I will discuss the unanimously positive experience expressed by the parents in collaborating with BUP throughout the screening and treatment process of ADHD for their child. Attention will then be turned to the descriptions given by both the parents and health professionals regarding the diagnosis being seen as a relief. The discussion will be informed by theoretical perspectives and previous research on the topic. At the end of the current section, implications of the findings, as well as ideas for further studies will be explored.

6.1 Mixed experience with kindergarten, school and PPT

The distribution of power between the parties

Due to the relatively recent findings from NICE (2018) and Surén et al. (2018) showing that a significant number of parents do not feel their family's needs are being adequately met, it was anticipated that some parents would describe a negative experience collaborating with BUP. However, participants in informant group I were highly satisfied with the screening and treatment process. The informant group felt that the health professionals provided adequate information on the condition and the treatment options to both them and their child, and that the information provided to their child was adjusted to their child's level of understanding. Furthermore, informant group I also described a feeling of the family being involved in the process, as well as both the child and parents having a level of influence over the treatment decisions. These descriptions by the parents suggest them possessing a strong Sense of Coherence (Antonovsky, 1979). Indeed, the parents emphasised that the information received from BUP helped them to both understand the situation (comprehensibility), and gain faith that the

recommended treatment would effectively treat their child's ADHD symptoms (manageability). As a result of this, the parents expressed openness and eagerness in attempting the treatment options recommended by BUP (meaningfulness).

On the other hand, the current analysis found that the parent participants experience in collaborating with kindergarten\school and PPT varied enormously. Some parents described the feeling of being able to influence the decisions concerning their child. Some also reported regular communication from the school, as illustrated by Frida regarding the thorough screening process of her child. Others, however, stressed a feeling of not having their opinions taken into account, as described by Olivia regarding disagreements with the school on the root cause for her son's struggles. In addition, a lack of communication regarding updates in the process was also reported by Olivia in the instance where the referral papers to PPT had been lost. Furthermore, a number of parents spoke of a lack of knowledge of the condition in teachers as impacting the experience, highlighted particularly by the parents of children with ADHD inattentive subtype. From this result, it can be interpreted that the way in which parents' needs are met in the process of obtaining an ADHD diagnosis for their child is highly individual.

When assessing whether it is the parents or the school who has the primary responsibility to facilitate effective collaboration, The Ministry of Education (2006) point out that although there is a level of mutual responsibility, more emphasis should be placed on the school. This is due to the asymmetric relationship between parents and staff in the school, where the staff are the most powerful party. Indeed, kindergartens and schools are governed by legislation, and they have the most expertise, and thus have the greatest responsibility for ensuring quality in the collaboration (Juul & Jensen, 2003). In sum, it is the kindergarten\school, as the professional partner in the collaboration, which must take responsibility for facilitating an effective collaboration with the parents of the child. LaRouque et al., (2011) explains that some fundamental pillars required to achieve this include; clarifying what the school-home collaboration entails, establishing and maintaining contact with the parents, as well as finding strategies that are suitable for the individual family. This, of course, also relates to when disagreements and conflicts arise. It is the teacher and the school, as the professional partner in the collaboration, who have the main responsibility for trying to resolve the situation.

According to Nordahl (2007), collaboration problems between home and kindergarten\school are often rooted in problems of the power dynamic. In a counselling perspective, the dynamics of power refers to how the professionals, be that BUP or PPT advisors, or kindergarden\school teachers, inherently have more influence and control over the clients they work with (Nordahl, 2007). In the parent interviews, some parents described difficulties resulting from the power dynamic between them and the kindergarten\schools. This was illustrated powerfully by Oliva where she characterised the collaboration process with the school as; "A long battle". In such cases, the parents attempted to put forward their thoughts on the matter and gain some level of influence on decisions concerning their child. However, these parents experienced that the child's teacher reacted negatively and adopted a defensive position instead of setting up a dialogue. Based on these descriptions, the school and the teachers in these cases appear to have maintained their institutional power, where the parents are in a situation characterised by powerlessness. As explained in the Theoretical framework chapter, institutional power refers to the power that resides in the school and those who work there (Engelstad, 2004). Put differently, when the parents do not engage in dialogue with the teachers and do not participate in important matters in the school, one can say that the teachers and the school use institutional power to protect themselves and reproduce their position. Thornquist (2009) cautions that in the collaboration process, the stronger party must be conscious of symmetrical and asymmetrical power-relationships. This is because there exists a risk of the parents, as a weaker party, perceiving a power imbalance and a lack of control. In such situations, conflicts can easily arise about who has the correct perception of reality, and the teacher can use his\her power to decide that they understand the situation at school best (Nordahl, 2007). According to Lassen (2014), such an attitude may lead to the parent's self-esteem being undermined, as well as feeling detached from the process, thus reducing the chance of success.

Not having their opinions taken into account

An example of the collaboration process between home and school being impacted by the power relationship was provided by Olivia. She described how she was met by the school in their disagreement regarding the root of her child's difficulties. For two years, the school attributed the child's concentration and emotional regulation difficulties to the parent's divorce. When Olivia challenged this assumption, she felt that her opinions

were not taken seriously, and thus experienced a lack of influence and control in the process.

This approach from the school can be seen as consistent with the expert-model (Cunningham & Davis, 1985), where the perception is that the stronger party knows best. In this instance, there seemed to lack elements of empowerment, something that is emphasised in the opposing; partnership-model (Befring, 2019). Feeling recognised, valued and respected for one's role in interactions and relationships with others can be understood as a fundamental psychological and existential need of people (ibid). A prerequisite to fulfilling this need is feeling seen, heard and understood. This involves not just hearing the words that are said by the parent, but is also about being present in the process, and having an ability to take the other's perspective (Lassen, (2014). Indeed, if one looks at the descriptions provided by Olivia in light of Rogers (1975) three characteristics that form the core part of positive counselling or collaboration, one could say that that the collaboration relationship is lacking *congruence*, *unconditional positive regard*, and *accurate empathic understanding*. Here, the stronger party was unable to demonstrate the ability to recognise and sincerely care about the advice seekers thoughts and feelings on the matter. Furthermore, the school was unsuccessful in sensitively (but not sympathetically) tuning into Olivia's feelings on the situation. In doing so, the school was unable to create a relationship based on trust with Olivia.

As previously mentioned, Olivia experienced little control of the situation, not only due to not having her opinions taken into account, but also due to a feeling of a lack of influence of decisions affecting her child. Much of the relevant literature stress the need for the parents to feel as though they have a level of influence over decisions made (Grythe og Midtsundstad, 2002; Nordahl, 2007; Antonovsky, 1979; Bae, 2006; Habermas, 1991; Haug 1993). Moreover, the fact that the family has a level of influence over decisions regarding their child is mandated in a number of laws; The Norwegian Constitution (Grunnloven, 2014, § 104), the UN Convention on the Rights of the Child (Barnekonvensjonen, 1989, artikkel 12), and the Children's Act (Barneloven, 1981, § 31-33). These laws apply not only to decisions regarding treatment for the child after the diagnosis is given, but are also applicable in the national guidelines for cooperation between home and kindergarten\school. Although the laws must be adhered to by the kindergartens and schools, it is clear from the current findings that a mismatch between

what is deemed the best interests of the child between the parents and kindergarten\school can, and in some cases did, occur.

Effective communication and formulisation of roles and expectations

The expert approach from the school described above led to a deterioration in the relationship of trust between Olivia and the school. Another experience described to negatively affect the process was receiving poor communication from the school regarding updates in the process to begin screening for ADHD. As previously mentioned, when the school eventually agreed to refer the child to PPT, the parent did not receive an update for over a year. When the school did ring Olivia, it was to inform her that his paperwork had been lost and had not been sent to PPT. She had sensed an uneasiness in relation to her son's development, and described having to convince the school to contact PPT for additional support. The fact that no one at the school followed up with further information and updates regarding the referral, added to the feeling of a lack of control. It was decided to not further question the reason for why she did not request an update from the school during this time period. This decision was made in an attempt to avoid her feeling attacked or that she had any element of blame in the situation. The fact that she did not request an update from the school, however, could possibly suggest that she felt uncomfortable to do so due to her previous experiences with school on the matter.

Although significant delays in the process occurred for not only for Olivia, but also Frida, there was a striking contrast between the parents' perspective towards the experience. Frida experienced effective communication with regular updates during the long process. She described that this facilitated the feeling that the school and PPT had the child's best interests at the heart of the decisions. Indeed, it could be deduced that this positive attitude from Frida to the significant delay was largely due to the institutions actions in explaining the reasons for the delay. Although the parent had suspected that her child had ADHD for years, and understandably wanted the diagnosis set in order to acquire effective support for her child, she ultimately trusted that the institutions were acting in the best interests for her son. Grythe & Midtsundstad (2002) point out that sufficient contact and communication between the home and the kindergarten\school is especially important for children with special needs. Moreover, Reinke et al. (2013) found that in many cases, the collaboration between home and

school works worst for the pupils who need it most, often those with special needs. Collaboration with regular meetings and updates for the parents should therefore be particularly tight in cases of children with special needs, something which was present in the current case. These points are echoed by The Ministry of Education (2006-2007), where they emphasise that a pre-requisite to good collaboration between the school and parents is clear communication. In addition, it is highlighted in the Norwegian government's guidelines for parental involvement in school that the coloration must be characterised by active interaction towards common goals, that the school must show commitment and willingness to cooperate, and that the parents must be informed about the child's situation at school (Meld. St. No. 14 1997-1998).

Olivia's description of her negative experience does suggest a lack of structure and clarity in the roles of each partner, where no individual seemed to take control. A study carried out by Nordahl (2007) showed that this is not an uncommon situation, where he found that half of Norwegian parents stated that they were unsure of the school's expectations of them as parents in the school. He describes this criterion within cooperation between home and school as; "formalisation", that is "the extent to which there are formal rules for the collaboration" (Nordahl, 2017, p. 32). He explains further that in a good collaboration, there will be a certain degree of formalisation, and this can for example be in the form of clear rules for when, where and how meetings are to be held. In more formalised collaborations, there will also be rules for what kind of contact there should be between school and home, how to make contact, and when this contact should take place (Nordahl, 2017).

Level of knowledge of ADHD from teachers and PPT advisors

As previously mentioned, experiencing that teachers possess strong knowledge of the condition and ways in which to manage the symptoms in the classroom was deemed as vital by the parents. In order to optimally meet the needs of children and adolescents with ADHD, it is thus of crucial importance that those around the child gain knowledge about the condition, as well as about the individual child in particular (Lassen, 2014). The current findings showed both signs for optimism regarding professionals' knowledge of ADHD, as well as signs for concern that require a focus.

As already mentioned in the results section, one of the reasons for the delay in referral to BUP for Fridas child was due to the child being born late in the year. It is important

to note that in this case, it was PPT, not the school, that was aware of the association between the youngest children in class being twice as likely as their classmates to receive a diagnosis of ADHD (Meerman et al., 2017). A number of studies have shown that not only teachers, but also health professionals are unaware of this association (Folkehelseinstituttet, 2017; Elder, 2010; Evans et al., 2010; Halldner et al., 2014). As the PPT advisor was aware of this correlation, as well as informant group II informants displaying a knowledge of this finding, the findings from the current study could therefore suggest a that Health professionals are increasingly becoming aware of this important factor.

The finding that a number of the parents experienced that the teachers were sceptical that the child had ADHD, and that this scepticism delayed the referral for ADHD, is inconsistent with previous literature. According to Walter et al. (2006 as cited in Meerman et al., 2017), the lack of knowledge from teachers on ADHD can often cause teachers to seek the screening for an ADHD diagnosis with less caution than necessary, potentially leading to mis\overdiagnosis of the condition.

All parents in informant group I highlighted that the child's kindergarten and\or school teachers seemed to lack knowledge of ADHD, and particularly of ADHD inattentive type. This perception was also consistent with the impressions of the health professionals. Aksel stressed that there is therefore a risk of underdiagnosing children, particularly girls with the ADHD inattentive subtype. When it comes to Aksel's concern regarding the gender ratio, it has been found that boys are more often referred to, and receive treatment from, the specialist health service BUP (HelseNorge 2020). A number of studies have found that girls are at a higher risk of their ADHD going unrecognised by teachers (Bussing et al., 2003; Froehlich et al., 2007; Gaub & Carlson, 1997; Graetz et al., 2006). Possible explanations for this often centre around different symptom expression in boys and girls, where it is proposed a higher prevalence of the inattentive subtype in girls (Biederman et al., 2002; Levy, et al., 2005). Even when girls are referred for screening of ADHD, it is suggested that there is a risk of gender-biases and thus a risk of underdiagnosis from the health professionals due to the fact that the original diagnostic criteria for ADHD was based on hyperactive boys (Young et al., 2020).

Interestingly, however, the large European ADORE study of clinically referred children found no evidence to suggest that core ADHD symptomatology differed between genders (Nøvik et al., 2006). Furthermore, the study from Moldavsky et al. (2012) found no evidence that teachers were less likely to recognise ADHD in girls than in boys. Instead, recognition of ADHD in children from teachers and correct diagnosis provided by health professionals was less dependent on the gender of the child, and more dependent on the subtype of ADHD the child has. Indeed, Moldavsky et al's. (2012) study explored the influence of ADHD subtype on teachers' recognition of ADHD, and found that teachers were far less likely to identify the ADHD inattentive type in children than the other two subtypes. These findings are also in agreement with a previous study by Groenewald et al. (2009), which found higher rates of recognition for ADHD combined type and ADHD impulsive/hyperactive type. Thus, the 'coincidental nature' of obtaining an ADHD inattentive diagnosis found in the current thesis suggests a risk of underdiagnosing children with the ADHD inattentive subtype, regardless of whether the child is a boy or girl. This is one of the most important findings of the study as much of the literature on ADHD focuses on the concerns of overdiagnosis of ADHD, where calls are made for additional consideration by both teachers and health professionals in referral and diagnosing ADHD. The current study supports this concern; however, it also illustrates the importance of increasing teacher's awareness of the various ADHD subtypes so that children, irrespective of the type of ADHD, are able to obtain the support they require.

NICE guidelines (2018) do indeed recognise both this lack of knowledge of ADHD and the teacher's critical role in identifying and supporting students with ADHD. They have accordingly recommended additional training on ADHD for teachers. This is in light of several studies alarmingly finding that teachers have received little, if any, training related to ADHD (Bussing et al., 2002; Jerome et al., 1994; Sciutto et al., 2016; Kos et al., 2004). In addition, the government also recognise a lack in knowledge of special needs in teachers, and is currently utilising PPT advisors to help address this through the project; "Kompetanseløftet for spesialpedagogikk og inkluderende praksis" (Meld. St. 6 Kunnskapsdepartementet 2019).

> Kompetanseløftet er et tiltak for ledere og ansatte i barnehager, skoler og PP-tjenesten, og skal bidra til at den spesialpedagogiske hjelpen er tett på de barna

> som har behov for det. Målet er at alle barn og unge opplever et godt tilpasset og inkluderende tilbud i barnehage og skole. (Udir, 2020)

Here, pupils in kindergarten and schools with reading and writing difficulties, maths difficulties, concentration difficulties and behavioural difficulties are now out of Statped's responsibility. Teachers who have pupils with these difficulties in their classrooms must now have the know-how to solve these challenges themselves, with the help of local PPT office (Udir, 2020). In order to achieve this, efforts will be made to increase the special needs competency of those who work closest to the child, namely teachers and PPT advisors. The goals of the project are aiming to address some of the shortfalls found in the current study, and the results in 2025 will be exciting to follow. However, it is concerning that it is up to the individual kindergarten and school leader to identify the specific educational support they feel is necessary. This concern is grounded both in previous literature, as well as the current findings that highlight the significant variations in the quality of these institutions.

The finding from the current study of the «*coincidental nature*» of children obtaining an ADHD inattentive diagnosis, as well as numerous others indicating that teachers' knowledge of ADHD, particularly that of ADHD inattentive subtype was insufficient, highlights that children with the subtype are at risk of remaining undiagnosed and therefore untreated (Moldavsky et al., 2012; Groenewald et al., 2009; Alkahtani, 2013). It is therefore suggested that emphasis should be placed on increasing teachers' awareness of inattentive subtype of ADHD as a possible cause of difficulties at school and home.

6.2 Positive experience with BUP

A focus on resources as well as stressors

All participants in informant group I were highly satisfied with the screening and treatment process of ADHD at BUP. The finding that all parent participants were satisfied with the collaboration with BUP, and that all health professional participants confirmed that most parents report positive experiences with BUP, is inconsistent with the rapport by NICE (2018). Indeed, the rapport highlighted that a number of parent's felt that their concerns were not being listened to by the health professionals. The current study's findings also contest the rapport's finding that a number of parents

claimed they were not provided with adequate information of the condition by the health professionals upon request (NICE, 2018).

In addition to receiving adequate information on the condition and treatment options, informant group I also described a feeling of the family being involved in the process. They emphasised that having a level of influence over the treatment decisions was fundamental in their positive perception of collaborating with the institution. Interestingly, despite the BUP advisors making treatment recommendations to the parents for the management of their child's ADHD symptoms, informant group II felt that the decisions were ultimately up to themselves to make. Thus, it seems as though the parents feel that they themselves made the treatment decisions, and thus gained ownership of these decisions. The importance of the advisor assisting the parents in identifying and executing the solution to the problem in order for the parents to gain ownership and responsibility for their situation has already been described above (Lassen, 2014).

As all parents were recommended medicine as the backbone of the treatment plan, and all parents agreed to medicate their children, it is interesting that the parents felt that they themselves made the decisions around treatment. One would expect some positive descriptions of the medication reducing or even alleviating the ADHD symptoms for their child. However, one could arguably also expect some level of scepticism or resistance from the parents towards being recommended medication as a form of treatment by the health professionals. Nevertheless, all parent informants were positive to the recommendation of medication by BUP. On reflection, it can perhaps be seen that the health professionals were incredibly effective in offering professional advice of a way forward, whilst at the same time not pressuring the parents to accept the recommendations.

Furthermore, both informant groups spoke of treatment decisions being grounded in a well-rounded perspective of the child and the situation. Indeed, informant group II clarified that an emphasis is always placed on the strengths of the child, and the positive elements of having the condition in order to diminish possible negative connotations parents may have with the condition. Jakob further explained that assisting the parents to strike a balance by focusing on both the child's challenges and resources, can assist in gaining a better understanding of the child and the situation. This corresponds to

Antonovsky's "Sense of Coherence" (SoC) model of stress management, where a greater focus on the potential resources and opportunities in the situation can assist in more effective coping outcomes to stressors. This approach of balancing the focus on both resources as well as stressors may also have contributed to the parents gaining a better understanding of the situation, and also feel as though the health professionals have the best interests of the child at heart.

6.3 Diagnosis a relief for the parents

As an ADHD diagnosis can provide an answer to previously unanswered questions, open the door to potentially highly effective treatment options and interventions, and potentially improve relationships with their child (Moen et al., 2011; Harborne et al., 2004; Davis et al., 2008), it is perhaps unsurprising that the parent participants in the current study express an element of relief from their child receiving the ADHD diagnosis. This finding is also consistent with previous research. For example, Moen et al. (2011) found that the genetic explanation of ADHD gave parent participants a feeling of relief which also helped to minimise their self-blame (Moen et al., 2011). Moreover, it was found that parents experienced that their child became less challenging once they learned how to cope with the parenting role (Moen et al., 2011). From reading the relevant literature, however, it was also expected that some parents would have a negative perspective on their child receiving an ADHD diagnosis. Moen et als. (2011) study, for example, also had a number of parents who describe a type of grieving process. Yet, an important finding from informant group I in the current study was that they all found the ADHD diagnosis for their child a relief.

All three findings described above can be seen to be connected, where a positive experience cooperating with BUP, as well as positive effects from the medicine, seems to contribute to the parent not only obtaining a deeper understanding of their child's difficulties, but also being able to support their child in a better way. This better understanding of the situation and the acquisition of tools to optimally support their child were highlighted by the parents as the main reasons as to why they saw the diagnosis in a positive way.

Furthermore, as explained in the results section, those parents who experienced significant resistance from their spouse during the diagnostic process, described an even greater feeling of relief when receiving the diagnosis, compared to the other parent

informants. Resistance from the spouse, and its impact on the experience of the diagnosis as a relief, was not a theme that was anticipated as being of significance when beginning this study. In hindsight, perhaps it should have been expected that this theme was to play an important role in the current study. Indeed, when considering the challenges associated with ADHD, as well as the myriad of common comorbid disorders often related to ADHD (e.g., anxiety disorders, sleep disorders, mood disorders, learning disabilities, substance-use disorders [Kooij et al., 2012]), one can easily imagine some of the additional challenges parents of children with ADHD could experience, and the toll this could have on a relationship.

Numerous studies have investigated the link between ADHD in children and the stability of parents' relationships. Some argue that the family might be brought closer together as appropriate support for the child demands a joint effort from both parents (Reichman et al., 2008), thus reducing the risk of divorce. However, the majority of the literature tends to agree that the association between ADHD in children and the stability of parents' relationships is negative (Kvist et al., 2013; Barkley et al., 1990; Wymbs et al., 2008). These findings were also supported by a large Danish study which found the following:

> We observed 172,299 pairs of parents from 1990 to 2007 of which 2457 have a firstborn child diagnosed with ADHD and 169,842 have a firstborn child without ADHD. Ten years after the birth of the child, parents of children diagnosed with ADHD have a 75% higher probability of having dissolved their relationship and a 7-13% lower labor supply. (Kvist et al., 2013, p30)

These mentioned studies found various reasons as to why children with ADHD could affect parents' outcomes, including; influencing siblings negatively (Currie & Stabile, 2006), as well as higher psychological and economic costs (Corman & Kaestner, 1992; Wehmeier et al., 2010). Further, Moen et al. (2011) highlights common challenges concerning the child's behaviour as potentially putting extra strain on the relationship. These can include; temper tantrums, a lack of concentration and an ability to control impulsive behaviour, as well as a poor delay of gratification:This strained situation led some parents to divorce or put their careers on hold (Moen 2011, p 452).

It has been widely maintained that enduring and healthy romantic relationships are critical to quality of life in adulthood, and can buffer the impact of adversity, including psychological disorder. It is important to improve our knowledge about the particular characteristics of families at risk of separating to prevent distress for the families and their child. Based on previous, as well as the current findings, it can be argued that more attention should be paid on supporting and strengthening couples during their child's ADHD assessment and diagnostic process.

6.4 Limitations of the current study

In the following paragraphs, potential limitations of the current study will be described and discussed.

Absence of the father's voice

Although the resistance from the spouse came from the fathers of the children in the current study's data set, it is important to note that resistance can, of course, come from the mother as well. In fact, a limitation of the current study is the absence of the father's voice on the matter. Indeed, we have heard the thoughts of the mothers, as well as referring to the literature, but perhaps these situations are more nuanced. The findings in the present study highlight the importance of including both mothers and fathers to provide a more equal understanding of the child.

Absence of the teacher's voice

It is vital to acknowledge that the voices of the teachers discussed by the parents are not heard in this thesis. Teachers are faced with a plethora of demands. In a hectic everyday life, it can be difficult to set aside enough time to listen to the parents, and in that way gain an understanding of their experiences. Similar to the absence of the father's voice, the situations described by the mothers are only their personal perspective on the matter. Arguably, one would therefore gain a fuller understanding of the situation if the perspectives of the teachers were also taken into account.

Unable to recruit a doctor participant

Not all professions involved in the ADHD diagnostic process at BUP were interviewed. I was able to obtain interviews with a Specialist Psychologist and two Special Educators, but was unsuccessful in recruiting a doctor. Obtaining an interview with a doctor at BUP would likely have provided value to the study. The health professional

informants explained that it is the doctors at BUP that are often the most credible source of information for the family regarding medication treatment for the patient. After the ADHD diagnosis is provided to the child, and in the cases where medication is recommended as the sole or part treatment, parents of the child are invited to a meeting with the doctor at BUP. Here, the parents are able to obtain vital information about the types of medication, how they work to help manage the child's ADHD symptoms, possible side effect, and how the trial period will be carried out. Moreover, these meetings provide the opportunity for the parents of the child to ask related questions and raise any concerns they may have with an expert. Fortunately for the credibility and transferability of the current study, as a protocol, the health professionals interviewed in this study (Psychologists and Special Educators) are obliged to be in attendance in such meetings. Thus, as the Psychologists and Special Educators collaborate closely with the doctors at BUP, a limited insight on the thesis' research question from the doctor's perspective was gained.

Having ADHD myself

In the Reflexivity section of the thesis, I raised my own ADHD diagnosis as a potential limitation, as well as source of opportunities, of the current study. In many ways, having lived with the condition all my life has proven to be immensely useful in the process of completing this thesis. This concerns not only a heightened motivation and interest in the subject, but also perhaps providing me with the opportunity to better understand and relate to the informant's descriptions. However, I was also aware that having the condition could bring prejudices that could impact the study's findings. I therefore actively attempted to be as open as possible to a variety of perspectives towards ADHD. This is something which I feel I was largely able to do. Nevertheless, before conducting the study, I had clearly underestimated the impact that having a child with ADHD can have on a couple's relationship, and how this can significantly impact the screening and diagnostic process for the child. I acknowledge that this was likely a blind spot due to having ADHD myself, where I perhaps didn't want to believe that I as a child caused momentous additional stress for my parents. Underestimating the significance of this finding suggests that there were still nuances I was unable to see due to my relationship with the condition.

7.0 Conclusions and future directions

Overall, the study showed that the parent participants experience with collaborating with kindergarten\school and PPT varied enormously, whereas with BUP, the experience was unanimously positive. some parents experienced good communication where they felt heard and able to influence the decisions concerning their child. Others, however, experienced powerlessness, a lack of control and not having their opinions taken into account. From this result, I find that how parents' needs are met by the kindergarten\school and PPT in the process of obtaining an ADHD diagnosis for their child, is highly individual. Consistent, however, among all participants was a belief that the teachers in kindergartens and schools possessed a lack of knowledge of ADHD, something which significantly impacted the collaboration experience. This finding is also established in the literature (Meerman et al., 2017; Moldavsky et al., 2012; Groenewald et al., 2009; Alkahtani, 2013). The lack of knowledge of ADHD from teachers was especially apparent in the ability to recognise ADHD inattentive subtype. As a result of this inadequate knowledge of the ADHD inattentive subtype, informant group II explained that there is a coincidental nature of obtaining the diagnosis. This is because those who obtain the subtype diagnosis tend to be referred to BUP for a comorbidity disorder, rather than for ADHD itself. Thus, this "coincidental nature" finding suggests a risk of underdiagnosing children with the ADHD inattentive subtype, regardless of whether the child is a boy or girl. This is one of the most important findings of the study as much of the literature on ADHD focuses on the concerns of overdiagnosis of ADHD, where calls are made for additional consideration by both teachers and health professionals in referral and diagnosing ADHD. The current study supports this concern; however, it also illustrates the importance of increasing teacher's awareness of the various ADHD subtypes so that children, irrespective of the type of ADHD, are able to obtain the support they require.

When talking about their experience of collaborating with BUP in the screening and diagnostic process, all of the parent participants emphasised a positive experience. Key reasons for this were attributed to adequate information of the condition and the recommended treatment provided from the health professionals, as well as effective results from medication in managing their child's ADHD symptoms. The unanimous positive reports of collaborating with BUP are not consistent with the findings from the Evidence rapport by NICE (2018) and Surén et al. (2018). These studies showed that

many parents did not feel their family's needs were being adequately met by health professionals at BUP, that their concerns were not listened to, and that they did not receive adequate information. It may be that the new chapter in the "Patient Pathway" (pakkeforløp), providing health professionals with general principles for feedback to the child and parents from the Norwegian Directorate of Health, is having a positive effect on the parent's experience.

However, consistent with the findings by NICE (2018) and Surén et al. (2018), the current study found that Informant group II reported an inconsistent ADHD assessment practise carried out by health professionals in BUP. Indeed, Informant group II explained that ADHD assessment lacks the same degree of clear, structured guidelines as in the case of screening for Autism. Interestingly, it was the health professionals, rather than the parents that pointed this limitation out. Thus, it seems that the objective of providing health professionals clear recommendations for both the assessment and management of ADHD in the mentioned new chapter is yet to be fully realised.

Another important finding from the current study was that all participants in informant group I found the ADHD diagnosis for their child to be a relief. The relief was attributed to a greater understanding of their child's difficulties, as well as increased resources to support the child in managing their ADHD symptoms. In reference to these resources, ADHD medication was viewed as an incredibly important factor from both informant groups. Although the parent participants were all recommended medicine as the backbone of the treatment plan, none reported any sense of feeling pressured by the health professionals, and all parents emphasised the positive effects of the form of treatment. Nevertheless, this emphasis placed on medication rather than measures at the kindergarten\school was highlighted as problematic by informant group II, and attributed to the overwhelming patient case load at BUP.

Furthermore, for those parents who experienced significant resistance from their spouse (Noora and Frida), the relief of receiving a diagnosis was notably greater than for the other parent informants. Due to differing opinions on the cause of their child's difficulties with their spouse, these parents reported extreme levels of stress and conflict in obtaining the diagnosis and support for their child. The diagnosis for these parents was described as a confirmation that their suspicions were indeed correct, something which perhaps provided them with a level in comfort.

7.1 Implications for further research

The results from this thesis highlight several topics for further research on how we can more optimally support parents during the ADHD screening and diagnostic process for their child. Firstly, to provide a more nuanced understanding of the ADHD screening and diagnostic process, future research could benefit from including the voices of both fathers and teachers. Due to the lack of knowledge found in teachers regarding the ADHD inattentive subtype, the literature showing that ADHD negative consequences become more severe overtime (Fredriksen et al., 2014; Kooij et al. 2012), as well as the fundamental role of early intervention highlighted in by the Norwegian Government (Meld. St. 6 Kunnskapsdepartementet 2019), it would be of interest to investigate optimal ways to increase teacher awareness of the subtype in children.

In addition, the health professionals explained in the current study that the intense workload and patient numbers experienced at BUP contributes to them placing more emphasis on medication, rather than measures in kindergarten\schools as the recommendation for treatment. However, to my knowledge, no previous studies have explored a potential correlation between high patient numbers and the higher emphasis om medication compared to alternative measures.

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Appendices

Appendix 1: Table 2. Relevant topic areas and authors

Topic area	**Author\s**
The condition and it's symptomology	American Psychiatric Association, (2013); adhdnorge, (2022)
The prevalence of ADHD	Fayyad et al., (2016); Surén et al., (2018)
Comorbid conditions	Katzman et al., (2017); Hannås, (2015); Reale et al. (2017); Kooij et al., (2012)
Diagnostic process	Helsedirektoratet, (2022); adhdnorge, (2022);
Inconsistent practises in Norway	Surén et al., (2018); Befring & Uthus, (2019)
ADHD treatment and measures	Fabiano et al., (2009); Kooij et al., (2019); NICE guidelines, (2018); Helsedirektoratet, (2022)
Influential factors in parent's decision	Taylor & Antshel, (2021); Storhaug & Ulfseth, (2018), NICE guidelines, (2018); Dillon, (2011)
Risk of over or misdiagnosis	Meerman et al., (2017); Hannås, (2015); Gualtieri & Johnson, (2005)
ADHD and gender	Nøvik et al., (2006); Fresson et al., (2018); Young et al., (2020); Hannås (2015)
The aetiology of ADHD	Larsson et al., (2014); Sprich et al., (2000); Galéra et al., (2011); Hjern et al., (2010); Froehlich et al., (2009)

Appendix 2: Study description for parents

UNIVERSITETET I BERGEN

Vil du delta i forskningsprosjektet

«Når barn får en ADHD-diagnose: Foreldres opplevelser og hjelpe-apparatets erfaringer»

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Mitt navn er Conor Healy og jeg er masterstudent i spesialpedagogikk ved Universitetet i Bergen. I dette skrivet gir jeg deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet er en masteroppgave i spesialpedagogikk ved Universitet i Bergen (UiB).

Utredningen av ADHD består av en blanding av observasjon, spørreskjemaer og objektive tester utført av en rekke aktører i hjelpeapparatet. Når en ADHD-diagnose er gitt, må beslutninger og valg av passende behandlinger tas. Dersom barnet er under 16 år er det imidlertid foresatte som gir samtykke til helsehjelp, og som velger behandlingstiltak på vegne av barnet. Disse beslutningene har vist seg å være påvirket av foresattes kunnskap om ADHD, og opplevelsene foresatte og barnet har av prosessen rundt diagnostisering.

Formålet er å få innsikt i hvordan foreldre opplever prosessen med å få en ADHD-diagnose på sitt barn. Vi er også interessert i å undersøke hvilken kunnskap om ADHD som var viktig for foreldre med tanke på behandlingsvalg. Vi er opptatt av at barn med ADHD får best mulig støtte. Vi ønsker derfor å intervjue deg om din og din families opplevelser med prosesser dere har tatt del i.

Hvorfor får du spørsmål om å delta?

Du blir spurt om deltakelse fordi ditt barn har fått en ADHD-diagnose gjennom BUP og er under 16 år.

Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du deltar i et intervju. Det vil ta deg ca. 30-40 minutter og vi blir sammen enige om tid og sted. Det vil bli tatt lydopptak og notater fra intervjuet.

Det er frivillig å delta

Det er helt frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen nedenfor. Du kan når som helst trekke ditt samtykke, og du trenger ikke oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg eller barnet ditt hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Det er kun jeg, Conor Healy, og prosjektansvarlige, Kari Hagatun og Ingunn Ness, som vil ha tilgang til lydfilene. Ved transkripsjon vil alle navn anonymiseres, og alt skriftlig datamateriale vil bevares i anonymisert form under passordbeskyttelse. Alle kontaktopplysninger vil kodes, og kodelisten lagres adskilt fra øvrige data.
På oppdrag fra Universitetet i Bergen har Personverntjenester vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?

Alle svarene du gir vil bli anonymisert i masteroppgaven. Det vil si at ingen skal kunne finne ut at det er du som har gitt de svarene du har gitt. Når masteroppgaven er ferdig, høst 2023, vil opptak slettes og alle navn anonymiseres. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektansvarlige (se kontaktinformasjon nedenfor).

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- å protestere
- innsyn i hvilke personopplysninger som er registrert om deg
- å få rettet personopplysninger om deg,

- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Vårt personvernombud

Janecke Helene Veim

Hvis du har spørsmål knyttet til Personverntjenester sin vurdering av prosjektet, kan du ta kontakt med:

- Personverntjenester på epost (personverntjenester@sikt.no) eller på telefon: 53 21 15 00.

Med vennlig hilsen

Prosjektansvarlig (Forsker/veileder)

Student

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *«Når barn får en ADHD-diagnose: Foreldres opplevelser og hjelpe-apparatets erfaringer»*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju

Jeg samtykker til å delta i prosjektet og til at mine personopplysninger brukes slik det er beskrevet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Kontaktinformasjon

Kari Hagatun
Epost: kari.hagatun@uib.no
Telefon: 92499776

Ingunn Ness
Epost: ingunn.ness@uib.no
Telefon: 95780544

Conor Healy
Epost: ham018@uib.no
Telefon: 48392098

Appendix 3: Study description for the health professionals

UNIVERSITETET I BERGEN

Vil du delta i forskningsprosjektet

«Når barn får en ADHD-diagnose: Foreldres opplevelser og hjelpe-apparatets erfaringer»

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Mitt navn er Conor Healy og jeg er masterstudent i spesialpedagogikk ved Universitetet i Bergen. I dette skrivet gir jeg deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet er en masteroppgave i spesialpedagogikk ved Universitet i Bergen (UiB).

Antall ADHD-diagnoser i Norge er økende. Når en ADHD-diagnose er gitt, må beslutninger og valg av passende behandlinger tas. Dersom barnet er under 16 år er det imidlertid foresatte som gir samtykke til helsehjelp, og som velger behandlingstiltak på vegne av barnet. Disse beslutningene har vist seg å være påvirket av flere faktorer, hvorav de fleste er knyttet til foresattes kunnskap om ADHD, og opplevelsen for både foresatte og barnet gjennom diagnoseprosessen.

Formålet med prosjektet er å undersøke hvordan foreldre opplever prosessen med å få ADHD diagnose på sitt barn og hva aktører i hjelpeapparatet uttrykker som viktig kunnskap i møte med foreldrene i slike prosesser.

Hvorfor får du spørsmål om å delta?

Du blir spurt om deltakelse fordi du er involvert i ADHD diagnose- og behandlings prosessen med barn og deres foreldre.

Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du deltar i et intervju. Det vil ta deg ca. 30-40 minutter og vi blir sammen enige om tid og sted. Det vil bli tatt lydopptak og notater fra intervjuet.

Det er frivillig å delta

Det er helt frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen nedenfor. Du kan når som helst trekke ditt samtykke, og du trenger ikke oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Det er kun jeg, Conor Healy, og prosjektansvarlige, Kari Hagatun og Ingunn Ness som vil ha tilgang til lydfilene. Ved transkripsjon vil alle navn anonymiseres, og alt skriftlig datamateriale vil bevares i anonymisert form under passordbeskyttelse. Alle kontaktopplysninger vil kodes, og kodelisten lagres adskilt fra øvrige data.
På oppdrag fra Universitetet i Bergen har Personverntjenester vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?

Alle svarene du gir vil bli anonymisert i oppgaven min, det vil si at ingen skal kunne finne ut at det er du som har gitt de svarene du har gitt. Når masteroppgaven er ferdig høst 2023, vil opptak slettes og alle navn anonymiseres. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte meg eller prosjektansvarlige (se kontaktinformasjon nedenfor).

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- å protestere
- innsyn i hvilke personopplysninger som er registrert om deg
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og

- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Håper du ønsker å delta i prosjektet mitt. Hvis du er interessert i å delta, ta kontakt med Conor Healy (se kontaktinformasjon nedenfor).

Vårt personvernombud
Janecke Helene Veim

Hvis du har spørsmål knyttet til Personverntjenester sin vurdering av prosjektet, kan du ta kontakt med:

- Personverntjenester på epost (personverntjenester@sikt.no) eller på telefon: 53 21 15 00.

Med vennlig hilsen

Prosjektansvarlig (Forsker/veileder)

Student

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *«Når barn får en ADHD-diagnose: Foreldres opplevelser og hjelpe-apparatets erfaringer»*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju

Jeg samtykker til å delta i prosjektet og til at mine personopplysninger brukes slik det er beskrevet.

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Kontaktinformasjon

Kari Hagatun
Epost: kari.hagatun@uib.no
Telefon: 92499776

Ingunn Ness
Epost: ingunn.ness@uib.no
Telefon: 95780544

Conor Healy
Epost: ham018@uib.no
Telefon: 48392098

Appendix 4: Interview guide for informant group I

Tema	Hovedspørsmål	Oppfølgingsspørsmål
A. ADHD-diagnoseprosessen Innledende spørsmål	Ca. hvor gammel var barnet ditt da han\hun fikk diagnosen? Hvor mange år siden var det?	Når følte du for første gang bekymring for barnet?
Oversikt over prosessen	Hvor lang tid fra første gang det ble meldt bekymring (på helsestasjonen, i barnehagen, på skolen, hos lege, PP-tjenesten eller andre), til barnet fikk diagnose?	Hvilke instanser og aktører ble barnet ditt henvist til i løpet av prosessen?
Opplevelse av prosessen	Hvordan opplevde du møtet med hjelpeapparatet?	Hvordan opplevde du å bli ivaretatt i møtet med hjelpeapparatet? På hvilken måte? Opplevde du noe som positivt i denne prosessen? Var det noe som kunne vært gjort annerledes i møte med deg?
Reaksjoner og holdninger fra barnets omgivelser	Hvordan opplevde du at familie og nære venner reagerte på ditt barns ADHD diagnose?	Var det noen av reaksjonene fra familie og nære venner som overrasket deg? I tilfelle, hvordan?

Enighet eller uenighet mellom foreldre og aktører i det tverrfaglige hjelpeapparatet	Ble det enighet om en ADHD diagnose mellom de ulike aktørene i hjelpeapparatet, og i hvilken grad var du enig i diagnosen og anbefalte behandlingstiltak?	Påvirket reaksjoner fra familie og venner dine avgjørelser angående ditt barns ADHD-behandling? Opplevde du å ha innflytelse over beslutningene? Synes du at det ble lagt til rette for at barnet ditt hadde innflytelse over beslutningene?
Tema	**Hovedspørsmål**	**Oppfølgingsspørsmål**
B. Viktig kunnskap om ADHD for valg av behandlingstiltak ADHD kunnskapsinnhenting	Før barnet ditt begynte prosessen, hvilken kunnskap hadde du om diagnosen og har oppfatningene dine endret seg siden da?	Fra hvilke kilder fikk du kunnskapen din om ADHD?
Nøkkelinformasjon om ADHD som påvirker behandlingsvalg	Hva mener du var den viktigste informasjonen om ADHD som påvirket dine valg av behandlingstiltak?	

Kommunikasjon fra aktører i det tverrfaglige hjelpeapparatet	Fikk du denne informasjonen før eller under prosessen? Føler du at aktører i hjelpeapparatet ga deg og din familie tilstrekkelig informasjon under og etter prosessen?	(Hvis det var under prosessen) Hvordan fikk du denne informasjonen? Hvordan ble denne informasjonen gitt (for eks; verbalt, henvisning til nettsteder, dokumenter om lidelsen osv)?

Appendix 5: Interview guide for informant group II

Tema	Hovedspørsmål	Oppfølgingsspørsmål
A. Syn på ADHD diagnoseprosessen og opplevelse å rådgi foreldre Innledende spørsmål Generelle meninger om prosessen Arbeid med ikke bare pasienten, men også foreldrene	Kan du først fortelle litt om din rolle i utrednings- og diagnostiseringsprosessen? Hva er ditt syn på ADHD-diagnoseprosessen som helhet for barn i Norge? På grunn av pasientens alder er det til syvende og sist foreldrene som tar beslutninger om behandling på vegne av barnet sitt. Hvordan opplever du å rådgi foreldre i denne prosessen?	Er det deler av prosessen som er spesielt effektive? Er det deler som kunne forbedres?

Tema	Hovedspørsmål	Oppfølgingsspørsmål
B. Viktig kunnskap om ADHD for foreldrene	Hva er ditt inntrykk av kvaliteten på ADHD-	

Foreldrenes forkunnskap om ADHD Faktorer som påvirker prosessen Nøkkelinformasjon om ADHD som påvirker behandlingsvalg Informasjonsoverføring Uenighet mellom foreldre, og uenighet mellom aktører i hjelpeapparatet og foreldre	kunnskapen foreldre allerede har ved første møte med deg? Opplever du noen forskjell på foreldres kunnskap for de som har barn med ADHD vs ADD? Hvilke utfordringer opplever du at foreldre møter når de må ta avgjørelser om barnets ADHD behandlingen? Hva mener du er den viktigste informasjonen foreldre trenger når de tar avgjørelser rundt barnets ADHD-diagnose? Hvordan sikrer du og dine kolleger at foreldrene får denne nøkkelinformasjonen før mulige behandlingstiltak blir diskutert? I tilfeller der foreldrenes forståelse av barnets problem ikke er i samsvar med hverandre,	Har foreldre opplyst om kildene de har brukt for å få informasjon om ADHD? Føler du at aktører i hjelpeapparats kunnskap om ADD er tilstrekkelig? Generelt sett, har foreldre allerede tilegnet seg denne informasjonen før de møtte deg? Hva er ditt syn på foreldrenes opplevelse av å motta informasjonen fra BUP? Kan du tenke deg andre, mer effektive måter å gjøre dette på?

	eller det er uenighet mellom foreldre og dere; hvordan går dere videre? Opplever du at foreldres familie og/eller venners meninger kan spille en viktig rolle i behandlingsvalgene for barnet?	Slik du oppfatter det, på hvilke måter kan manglende enighet mellom foreldre, eller mellom foreldre og dere, påvirke opplevelsen for barnet?

Appendix 6: Proof of registration in Risiko og ETTErlevelse (RETTE) and project approval NSD\SIKT

Bergen 05.05.2023

Bekreftelse på at personopplysninger i masterprosjekt er vurdert, behandlet og registrert i henhold til Universitetet i Bergen sine personvernrutiner.

All behandling av personopplysninger i forsknings- og studentprosjekter ved UiB skal være registrert i UiBs forskningsprosjektoversikt RETTE, i samsvar med kravet i personvernforordningen artikkel 30 (krav om protokoll). Veileder er prosjektansvarlig for masterprosjekter ved UiB og må dermed også godkjenne registreringen i RETTE.

Vitenskapelig forskning som omfatter sensitive personopplysninger, har rådføringsplikt med personvernombud. UiB har avtale med SIKT sin om personvernrådgivningstjeneste for å oppfylle rådføringsplikten.

Jeg bekrefter med dette at Conor Healy sitt masterprosjekt er registrert i RETTE og har vært vurdert av SIKT sin personvernrådgivningstjeneste.

Kai Hagatun

Signatur veileder