Pathways into Child and Adolescent Psychiatry

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BY
ANNA SOFIE KJÆRGAARD HANSEN

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by

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CV

I graduated as a medical doctor from the University of Copenhagen, Denmark in 2012. After completing my basic clinical training, I started my specialist training in child and adolescent psychiatry in 2013 at the Department of Child and Adolescent Psychiatry, Aarhus University Hospital, Denmark. In 2017 I took a leave of absence from my specialist training and started working at the Research Unit for Child and Adolescent Psychiatry, Aalborg University Hospital, Denmark and in 2018 I was enrolled as a PhD student at the Faculty of Medicine, Aalborg University, Denmark.

I have a keen interest in both advocacy and policy work within child and adolescent mental health as well as post graduate training and I've served on the Executive Board of the Danish Association for Psychiatric Trainees from 2015-2019 and from 2017-2019 I served as the 2nd Child and Adolescent Psychiatry representative for the European Federation of Psychiatric Trainees. From 2018-2020 and again from 2021 I have been on the Executive Board of the Danish Association of Child and Adolescent Psychiatry and since 2019 I have been the External Communications Officer for the European Union of Medical Specialists (UEMS) section of Child and Adolescent Psychiatry.

During my time as a PhD student I have taught medical students and students of medicine with industrial specialization at the bachelor level and master level medical students and psychology students. I have also presented my research at the 2019 ESCAP conference and the 2020 EPA conference and nationally to stakeholders from across service sectors in child and adolescent mental health. Internationally I've been involved in collaborations, publishing papers on the challenges faced by child and adolescent psychiatry as a result of the COVID-19 pandemic.

ENGLISH SUMMARY

Background: Mental disorders in children are common and childhood mental disorders are often persistent, with more than half of lifetime mental disorders having their onset before the age of 18. Mental disorders have a global impact on children's lives and are among the leading causes of disability adjusted life years (DALYS) among young people. Despite the large influence mental disorders have on children's health, education and well-being, research indicates substantial underutilization of child mental health services and significant delays in accessing specialized child and adolescent mental health services (CAMHS). At the same time CAMHS is faced with the challenge of balancing increasing demand with existing resources. Allocation of resources within CAMHS should to a certain extent reflect the current referral patterns, but research within this field is scarce so it is unclear if the limited resources are distributed according to the need of the target population. A high rejection rate for referrals from CAMHS also pose a challenge as it affects satisfaction with CAMHS from both families, referring professionals and policy makers. Child mental health services are often organized in accordance with a stepped care model and involve multi-agency collaboration across healthcare, education and social services. This organization of services reflects the global impact of childhood mental health problems, but probably also contributes to the complexity of help-seeking. To optimize service provision for children with mental disorders, there is a need for current knowledge on help-seeking patterns and barriers to timely access to relevant services.

Aim: The primary aim of this PhD project is to contribute to knowledge on help-seeking patterns and barriers to accessing services for children and adolescents with moderate to severe mental disorders. The PhD project consists of five studies with three overall objectives.

1) To contribute to knowledge on referral patterns to CAMHS
2) To investigate help-seeking pathways and barriers to accessing services
3) To test the effect of the Development and Well-Being Assessment (DAWBA) on referral decisions by CAMHS.

Methods: The PhD project consisted of four cross-sectional observational studies investigating changes in referral patterns to CAMHS from 2005-2018 (Study I), parental help-seeking patterns prior to referral to CAMHS (Study II), barriers to accessing services (Study III) and current referral pattern to CAMHS and factors associated with rejection of referrals (Study IV). In addition, the effect of the DAWBA as an adjunct to referral letters, on the accuracy of referral decisions by CAMHS was tested in a randomized feasibility trial (Study V). All five studies were conducted at the Child and Adolescent Psychiatric Department of the North Denmark Region and the primary eligibility criteria for all studies was referral to outpatient services.

Results: Referral patterns to CAMHS showed changes in distribution of referral reasons and referral source over time and for referrals for neurodevelopmental disorders there was an increase in the proportion of girls. A high proportion of children had a recurrent need for referral to CAMHS with a third of all referrals in 2018 being re-referrals.

More than half of children referred to CAMHS had parentally recognized mental health problems for more than 5 years prior to referral and there was an association between higher symptom severity at the time of referral and longer duration of mental health problems. Parents reported numerous barriers to help-seeking for child mental health problems with insufficient mental health literacy and challenges related to the multi-agency collaboration of services as the most frequent barriers to timely access to services. Help-seeking pathways differed by symptom duration and type of symptoms with educational services playing a more prominent role in the help-seeking pathway for children referred for assessment of a neurodevelopmental disorder and for children with longer symptom duration prior to referral. A quarter of referrals in 2018 were rejected and referrals for children placed in care and referrals from general practitioners had a higher risk of being rejected. Findings from Study V point to inappropriate destination of referrals or poor quality being the most likely explanation for this association. Results from Study V also showed that the accuracy of referral decisions by CAMHS in identifying children with a clinical need for assessment improved when the DAWBA was used as an adjunct to standard referral letters.

Conclusions: The findings from this PhD project confirm the complexity of help-seeking for childhood mental disorders and point to several potential targets for improvement of service provision for children with mental disorders. The use of the DAWBA as an adjunct to standard referral letters has the potential to reduce rejection rates by improving the quality of referrals, but the impact of using the DAWBA might be greater if the DAWBA is applied earlier in the referral process.

DANSK RESUME

Baggrund: Børne- og ungdomspsykiatriske lidelser er almindeligt forekommende. De har ofte et langvarigt forløb, og over halvdelen af al psykisk sygdom debuterer før 18-årsalderen. Psykiske lidelser påvirker store dele af børn og unges liv og er én af de primære årsager til øget sygdomsbyrde (DALYs) hos børn og unge. Til trods for den store indvirkning, psykiske lidelser har på børn- og unges helbred, uddannelse og trivsel, peger forskning på, at mange ikke modtager professionel hjælp, og at der er store forsinkelser, i forhold til hvornår børn med behov henvises til børne- og ungdomspsykiatrien (BUP). Samtidig er BUP udfordret af at balancere stigende henvisningstal med tilgængelige ressourcer. Fordeling af ressourcer i BUP bør til dels afspejle det aktuelle henvisningsmønster, men der mangler forskning indenfor dette område, og det er derfor uklart, om fordelingen af de begrænsede ressourcer afspejler det reelle behov. En anden udfordring for BUP er den høje andel af henvisninger, der afvises, hvilket påvirker tilfredsheden med BUP hos familier, henvisende instanser og politiske beslutningstagere. Indsatser for børn og unge med psykiske problemer er ofte baseret på tværfagligt og tværsektorielt samarbejde ud fra en model om gradueret indsats. Dette afspejler de mange aspekter af barnets eller den unges liv, der påvirkes af en psykisk lidelse, men de mange aktører bidrager formentlig også til at gøre det mere kompliceret for familier at finde den rette hjælp. For at sikre at systemet yder den optimale hjælp og støtte til børn og unge med psykiske lidelser, er der behov for opdateret viden om, hvilken hjælp der ydes til denne gruppe og hvilke potentielle barrierer der hindrer at børn og unge med psykiske lidelser modtager rette hjælp til rette tid.

Formål: Det primære formål med dette ph.d.-projekt er at bidrage til viden om, hvordan familier til børn og unge med moderat til svær psykisk lidelse søger hjælp, og hvilke barrierer de møder i forhold til at få adgang til relevante indsatser. Ph.d.-projektet bygger på fem studier med tre overordnede mål:

1) At bidrage til viden om henvisningsmønstre til BUP
2) At undersøge hvordan familier søger hjælp, og hvilke barrierer der eksisterer i forhold til at opnå adgang til relevant støtte og hjælp
3) At undersøge effekten af at anvende the Development and Well-Being Assessment (DAWBA) som supplement til almindelige henvisninger på visitering af henvisninger til BUP.

Metode: Ph.d.-projektet bestod af fire tværsnitsstudier, som undersøgte ændringer i henvisningsmønstre til BUP fra 2005-2018 (Studie I), hvordan forældre søgte hjælp til deres barn forud for henvisning til BUP (Studie II), barrierer i forhold til at få adgang til relevant støtte og hjælp (Studie III) og aktuelt henvisningsmønster og faktorer associeret med afvisning af henvisning af BUP (Studie IV). Herudover blev det i et randomiseret feasibility studie undersøgt, om anvendelse af DAWBA som

supplement til almindelig henvisning medfører mere korrekt visitation af henvisninger af BUP (Studie V). Alle fem studier blev udført ved Børne- og Ungdomspsykiatrisk Afdeling, Psykiatrien - Region Nordjylland, og det primære inklusionskriterie var henvisning til ambulant børne- og ungdomspsykiatrisk vurdering.

Resultater: Der er sket ændringer i henvisningsmønsteret til BUP med hensyn til fordeling af primær henvisningsårsag og hvem der henviser, og for neuro-udviklingsforstyrrelser er der sket en stigning i andelen af piger blandt henvisningerne. En stor andel af børn med psykiske vanskeligheder har behov for revurdering ved BUP, og genhenvisninger udgjorde en tredjedel af alle henvisninger i 2018.

Over halvdelen af børn henvist til BUP havde haft psykiske vanskeligheder i mere end 5 år, og længere symptomvarighed var koblet til større sværhedsgrad af symptomer på henvisningstidspunktet. Forældre rapporterede om mange barrierer i forhold til at få adgang til relevant støtte til deres barn. De hyppigste barrierer var manglende viden om børne- og ungdomspsykiatriske lidelser, og hvordan man søger hjælp, samt udfordringer relateret til den tværfaglige og tværsektorielle organisering af indsatser på området. Symptomvarighed og type af vanskeligheder havde en indflydelse på, hvordan familier søgte hjælp. Skolesystemet spillede en mere fremtrædende rolle i forhold til børn, der blev henvist til vurdering af en neuro-udviklingsforstyrrelse, og for børn med længerevarende symptomer forud for henvisning. En fjerdedel af alle henvisninger i 2018 blev afvist i visitationen af BUP, og der var en øget risiko for afvisning, hvis henvisningen kom fra egen læge, eller hvis det var en henvisning på et anbragt barn. Resultaterne fra Studie V indikerer, at den øgede risiko for afvisning for disse henvisninger primært skyldes manglende oplysninger i henvisningen, eller at det blev vurderet, at BUP ikke var den rette instans at henvise til. Resultaterne fra Studie V viste ligeledes, at anvendelse af DAWBA som supplement til standardhenvisninger medførte, at visitationen blev bedre til at identificere, hvilke henviste børn og unge der havde behov for vurdering.

Konklusioner: Fundene fra dette ph.d.-projekt bekræfter, at det er komplekst at søge hjælp til børn og unge, der har en psykisk lidelse, og resultaterne peger på flere potentielle mål for at forbedre den indsats, der ydes til denne gruppe. Anvendelsen af DAWBA som supplement til standardhenvisninger har potentiale til at reducere andelen af henvisninger, der afvises af BUP, men effekten af DAWBA er måske større, hvis den anvendes endnu tidligere i henvisningsprocessen, på stadiet før henviser beslutter sig for, om vedkommende skal henvise til BUP.

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LIST OF SCIENTIFIC PAPERS

The thesis is based on the following five papers:

I: Hansen, A.S., Kjaersdam Telléus, G. & Lauritsen, M.B. (2021) Changes in referral patterns to outpatient child and adolescent psychiatric services from 2005-2018. Nordic Journal of Psychiatry. DOI:10.1080/08039488.2021.1880636

II: Hansen, A.S., Kjaersdam Telléus, G., Færk, E., Mohr-Jensen, C. & Lauritsen, M.B. Help-seeking pathways prior to referral to outpatient child and adolescent mental health services. Clinical Child Psychology and Psychiatry. 2021;26(2):569-585. doi:10.1177/1359104521994192

III: Hansen AS, Telléus GK, Mohr-Jensen C, Lauritsen MB. Parent-perceived barriers to accessing services for their child's mental health problems. Child Adolesc Psychiatry Ment Health. 2021;15(1):4. Published 2021 Jan 29. doi:10.1186/s13034-021-00357-7

IV: Hansen, A.S., Christoffersen, C.H., Kjaersdam Telléus, G. & Lauritsen, M.B. Referral patterns to outpatient specialized child and adolescent mental health services and factors associated with referrals being rejected- A cross-sectional observational study. *(In review)*

V: Hansen, A.S., Kjaersdam Telléus, G., Mohr-Jensen, C., Færk, E. & Lauritsen, M.B. The effect of the Development and Well-Being Assessment as an adjunct to standard referral letters on referral decisions by Child and Adolescent Mental Health Services. A Randomized Feasibility Trial. *(In preparation*)

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ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ADD	Attention Deficit Disorder
ADJ	Adjusted
ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CAPA	Child and Adolescent Psychiatric Assessment
DALY	Disability Adjusted Life Years
DAWBA	Development and Well-Being Assessment
DF80-89 disorders	Disorders of psychological development
DF90-98 disorders	Behavioral and emotional disorders with onset usually occurring in childhood and adolescence
DISC	Diagnostic Interview Schedule for Children
DSM-5	Diagnostic and Statistical manual of Mental disorders version 5
GP	General Practitioner
ICD-10	International Classification of Diseases version 10
IQR	Interquartile Range
K-SADS-COMP	Kiddie Schedule for Affective Disorders and Schizophrenia- Computerized
MHS	Mental Health Services
NEM	Network-Episode Model
NPV	Negative Predictive Value
OR	Odds Ratio
PPV	Positive Predictive Value
RKKP	The Danish Clinical Quality Program– National Clinical Registries
SD	Standard Deviation
SDQ	Strengths and Difficulties Questionnaire

CHAPTER 1. INTRODUCTION

1.1. EPIDEMIOLOGY OF CHILD AND ADOLESCENT MENTAL DISORDERS

Children and adolescents (0-17 years of age, henceforth referred to as children) constitute a third of the world's population[1] and the estimated prevalence of mental disorder in this age group is 13.4%[2], with no differences between high-income and low-income countries in prevalence[3]. Mental disorders are among the leading causes of disability adjusted life years (DALYs) among young people in the Americas and Europe[4] and severely impact children's health, education and well-being[5]. It is also well-documented that mental disorders have a high economic impact on society[6,7]. Childhood mental disorders are often persistent[8] and 50% of life time mental disorders have their onset before the age of 14[9]. Despite this knowledge, investments in child and adolescent mental health services do not match the resources needed to provide services to all children with a need[10,11] and only around one third of children with a mental disorder in are in contact with specialized child and adolescent mental health services (CAMHS)[12].

However, in recent decades there has been a steep increase in service-use for mental disorders for children and adolescents[5,13] leading to substantial increases in diagnoses and treatment[5,14,15]. In Denmark the proportion of children diagnosed with a mental disorder before the age of 15 years doubled between 2010 and 2017[16] and there was a nine-fold increase in dispensed psychotropic medication from 1996-2010[15]. A recent register-based study from Denmark by Dalsgaard et al. found that 15.0% had been diagnosed with a mental disorder by the age of 18[17].

The dramatic increase in diagnosed mental disorders has led to concerns that children today are more susceptible to developing mental disorders than previous generations[18] and others have expressed concerns that normal childhood behavior is being medicalized resulting in overdiagnosing[19]. However, it is important not to equate the prevalence of diagnosed childhood mental disorders with the actual prevalence. To receive a registered diagnosis, you have to make contact with CAMHS, so the increase could also reflect that more children in need are now in contact with services. Gyllenberg et al. (2018) investigated temporal changes in incidence of treated mental disorders among Finnish adolescents comparing the calendar years 1999-2005 to 2009-2015 and found the largest absolute increase to be for emotional disorders and ADHD. Time trend studies from the Nordic countries specifically investigating changes in diagnosing of neurodevelopmental disorders (ADHD and autism spectrum disorders (ASD)) have also found increasing rates of diagnosing, and this has been most pronounced for girls[20–22]. However, a recent review of epidemiological surveys

of ASD from 37 countries worldwide by Fombonne et al. (2021) found a robust male to female ratio in both epidemiological and clinical samples over time[23].

When looking at epidemiological studies there is no evidence of increasing externalizing mental health problems[5,14,24] and the prevalence of neurodevelopmental disorders have been found to be stable over time[23,24]. There is however evidence of an increase in the prevalence for internalizing mental health problems, especially for adolescent girls[5,14,24,25]. However, this increase alone cannot account for the rise in diagnosed childhood mental disorders seen in the past decades.

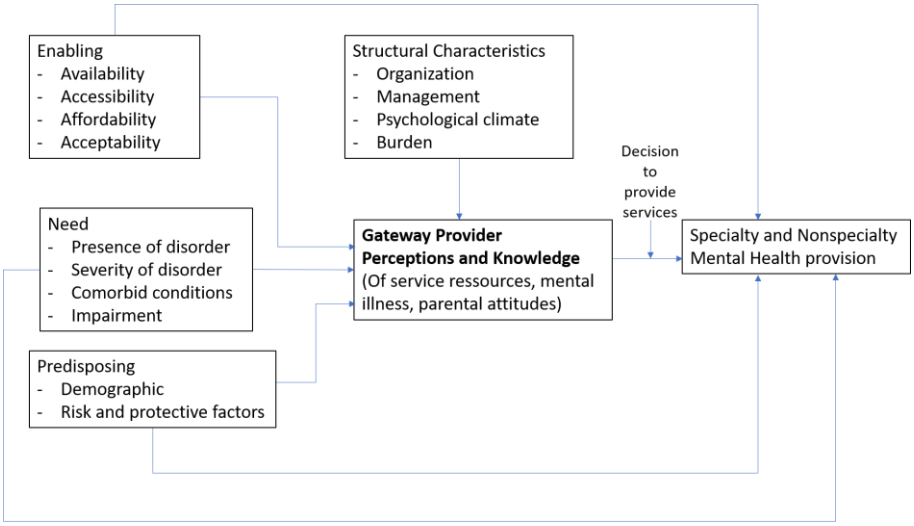
There are other potential explanations for the observed increase. Greater public awareness of mental disorders and increased knowledge among professionals in primary settings (e.g. educational services, primary health care and social services) [26] might result in improved identification of mental health problems in children[27]. Likewise, an increase in CAMHS resources[28,29] and reduced stigma associated with mental disorders[5,13] may result in increased help-seeking by families. Some have also argued that there is an increasing demand among parents for having their child assessed by CAMHS, due to provision of services for mental health problems in other sectors being dependent upon the child having a CAMHS verified diagnosis[27,30].

1.2. THEORIES ON HELP-SEEKING

In order to access child mental health services, families or other key adults must know when and where to seek help. Help-seeking can be divided into four overall steps: 1) recognizing the problem, 2) deciding to seek help, 3) selecting a source for help and 4) accessing care [31]. Rogler and Cortes defined help-seeking pathways as "the sequence of contacts with individuals and organizations prompted by distressed person's efforts and those of his or her significant others, to seek help as well as the help that is supplied in response to such efforts" (p555)[32]. However, the view that there is a linear progression to help-seeking has later been challenged by other help-seeking models[33] like the family network-based model of access to children's mental health services and the gateway provider model[34], which both propose that multiple influences dynamically affect how children with mental health problems access services. Studies have also shown that families are often concurrently in contact with several different services[33,35].

Both the family network-based model and the gateway provider model emphasize that the central agent, in gaining access to services, is not the afflicted child, but an adult agent (gateway provider) acting on behalf of the child[34,36]. The family network-based model is a reconceptualization of Pescolido's Network-Episode-Model (NEM)[37] to fit the special circumstances regarding help-seeking for mental health problems in children and adolescents, mainly that family play a much more central role, than in the help-seeking process of adults and the important role of schools in recognizing and managing children's mental health problems[36].

Figure 1: The Gateway Provider Model.
Replicated from Stiffman et al.: Building a model to understand youth service access: The Gateway Provider Model[34]



The gateway provider model is a synthesizes of the family network-based model and decision theory[38] with an addition of organizational dimensions[34]. As outlined in the model of the gateway provider model in Figure 1 the need of the child, as well as enabling and predisposing factors all contribute directly to service use, but the gateway providers perception of these factors mediate their impact on service use[34]. The gateway provider's perception and knowledge are in turn influenced by structural characteristics in their environment. Overall, the gateway providers decision-making with regards to providing services or a referral to services is influenced by their perceptions, knowledge and environment[34].

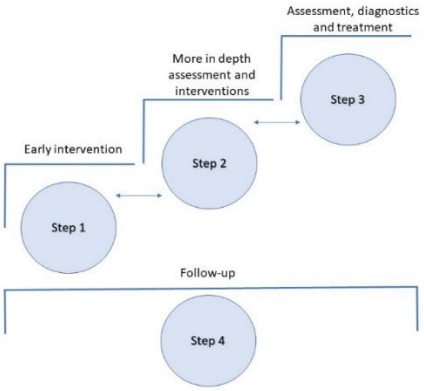
1.3. THE ORGANIZATION OF CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

The organization of child mental health services differs across Europe, but multi-agency collaboration across healthcare, education and social services has been at the center of many child mental health policies for the past decades[39]. This is reflective of the universal impact mental health problems have on children's lives resulting in a substantial number of contacts with all public sector services[40]. Services are often organized according to a stepped care/graduated care model[41] where milder cases of mental disorders are treated in primary care settings (educational services, social services and general practitioners) in close proximity to the child's everyday life, and

only children with moderate to severe mental disorders should be referred to CAMHS[42,43]. As previously mentioned the family network-based model for help-seeking emphasizes the important role of schools and as it has become evident that there are large unmet needs and barriers to accessing services for child mental health the role of schools in providing mental health services has gained increasing political focus[44] and interventions aimed at common mental health problems are being tested and implemented in school settings[45,46].

The Danish model for graduated care for children with mental disorders is outlined in Figure 2 below and has many similarities with the Tier model from the UK[47]. In both models school mental health services play a prominent role on the lower steps/tiers.

Figure 2: The Danish model for graduated care for children with mental disorders.
Adapted from Sundhedsstyrelsen: Forløbsprogram for børn og unge med ADHD[48]



	Professionals involved
Step 1	Professionals workin in universal services (such as GPs, health visitors, teachers and youth workers), who are not necessarily mental health specialists. They offer general advice and treatment for less severe problems, promote mental health, aid early identification of problems and refer to more specialist services.
Step 2	Specialists working in the community and primary care settings such as primary mental health workers, allied health professionals, educational psychologists and pediatricians. They offer consultation to families and other practitioners, outreach to identify severe/complex needs, more in depth assessment and training to professionals working on Step 1.
Step 3	Services provided by multidisciplinary CAMHS or private practicing child and adolescent psychiatrists. They offer a specialized service for those with more severe, complex and persistent disorders.
Step 4	Continuous follow-up of interventions from Step 1-3

In Denmark, legislation stipulates that all referrals that are accepted to hospital based healthcare (incl. CAMHS) are entitled to be assessed within 30 days[49] and in 2018 the average waiting time in CAMHS for the first appointment was 24 days[50]. However, there are not the same regulations with regards to waiting times for other specialized services in the graduated care model and lack of resources is an issue across services. In a systematic review of studies on multiagency collaboration, Cooper et al. identified a number of facilitating and inhibiting factors to ensuring positive outcomes of multiagency child mental health services[39]. The three most commonly cited facilitating factors were good communication across professionals/services, joint training and good understanding across professionals/services[39]. The most commonly cited barrier to multiagency collaboration was inadequate resourcing, followed by poor communication across professionals/services, lack of valuing, respect and trust and differing perspectives/cultures across professionals/services[39]. Parents generally agree that multiagency collaborations are helpful and important in ensuring the right help for children with mental health problems[51], but it also places a number of demands on the families, who have to obtain relevant information about the different roles of different services[52] and parents can be left with the frustrating feeling of chasing service providers[51] resulting in delays in relevant treatment[53].

1.4. SERVICE-USE FOR CHILDHOOD MENTAL DISORDERS

Ideally all children and adolescents with an impairing mental disorder should receive timely evidence-based interventions from relevant services, provided by professionals with the right level of expertise[54]. However, numerous studies have reported substantial underutilization of child mental health services[12,13,55–58]. Other studies have shown that children referred to CAMHS for assessment have often had symptoms for years prior to referral[33,59,60].

A study by Reardon et al. from 2020 found that 64.5% of parents of children with anxiety had sought help, but only 38.4% had received services for their child and less than three percent had received evidence-based treatment[58].

In order to begin to close the treatment gap it is important to be aware of predictors and barriers to service use.

1.4.1. PREDICTORS OF SERVICE USE

There is no clear association between socio-economic status and service use for child mental disorders[54]. Several parental factors (parental psychopathology, problem perception, perception of need, and parental burden) predict service use[54,61–63]. Problem perception by other important adults, like teachers, is also associated with service use[62,64]. The findings that problem perception among key adults predicts service use are in line with the gatekeeper model proposed by Stiffman et al.(2004)[34]. Parentally perceived stigma associated with mental health problems[65] and negative perceptions of CAMHS[66] are associated with reduced help-seeking by parents.

Hintzpeter et al. (2015) found the impairment of the child to be the strongest predictor for service use[67]. Other child factors predictive of service use are severity of symptoms[68], persistency of the disorder[57] and comorbidity[69]. However, Merikangas et al. (2011) found that only half of adolescents with severely impairing mental health problems had any service contact[68] and Lempinen et al. (2009) found the same to be true for children with comorbid disorders[69]. In a study by Ford et al. (2005) 61.6% of children who had symptoms of a mental disorder for more than three years were not in contact with services[57].
Therefore, in addition to knowing what predicts service use, we also need knowledge on the barriers to service access.

1.4.2. BARRIERS TO ACCESSING SERVICES

There are a number of studies investigating barriers to accessing mental health services among both adolescents[70,71] and parents[72,73]. Studies have been conducted both in community samples and among service users[70,72].

In a review from 2010 by Gulliver et al. investigating barriers to help-seeking in young people perceived stigma and embarrassment related to having a mental health problem, poor mental health literacy and a preference for self-reliance were identified as the most prominent barriers to help-seeking[70]. Schnyder et al. (2019) also identified stigma and poor mental health literacy as the main barriers among adolescents[71]. Other identified barriers were concerns regarding confidentiality, lack of accessibility, concerns about characteristics of service provider and fear about the help-seeking process itself[70].

Children and adolescents rarely seek professional help for mental health concerns independently[72]. As parents are most frequently the key gateway provider in the help-seeking process of minors[34], it is just as important to investigate parental perceptions of barriers to help-seeking[72]. Several studies have highlighted the parental perception that help-seeking for child mental health problems feels like a continuous fight to access services[58,62,74]. Barriers to accessing services are reported by the majority of parents of children in contact with services[62] and Sayal et al. (2015) found that similar barriers were reported by parents of children with mental health problems who were not in contact with services[62]. Based on these findings, barriers reported by parents of children referred to CAMHS will most likely be similar to barriers encountered when actively seeking help.

A review by Reardon et al. from 2017 identified 44 studies (20 quantitative, 22 qualitative) investigating parental perceptions of barriers[72]. However only 3 quantitative studies were conducted in a European setting, focusing either on a specific mental disorder (ADHD or conduct disorder)[62,75] or a specific ethnic group[76]. A later published study by Iskra et al. (2018) investigated parentally perceived barriers to accessing CAMHS or a Headspace center in Australia[73] and later studies have also

investigated parentally reported barriers specific to help-seeking for anxiety disorders in children[58,74,77]. Demand on services was reported as a barrier across studies from several countries, with waiting times and difficulties obtaining a referral as common barriers among service users[72,73]. Views and attitudes towards services were also a common theme for parent perceived barriers, and were often shaped by previous contacts with the mental health system[72]. Parents reported feeling ignored, dismissed or blamed by professionals and, in line with adolescents, also reported perceived stigma related to mental health problems as a prominent barrier[72]. Also, in line with findings from studies of barriers for adolescent help-seeking, lack of knowledge about both mental health problems and the mental health system were frequently reported barriers in studies of parent perceived barriers[72].

The final barrier to accessing CAMHS is obtaining a referral for assessment and having it accepted by CAMHS.

1.5. REFERRALS TO CAMHS

Allocation of resources within CAMHS should, to a certain extent, reflect the type and amount of referral problems[26]. In order to do so it is important to have updated knowledge on referral patterns to CAMHS, but studies in this area are scarce[26]. The organization of CAMHS differs across countries[47,78] with regards to how children are referred and what percentage of referrals are rejected without the child being seen[47,78]. In Denmark, as in many other European countries[79], referral to CAMHS requires a formal referral from a medical doctor or other professionals working with children. It has been suggested that the quality of information passed on in the referral process to specialized mental health care affect the quality of care provided by specialized services and interventions to improve the referral process might therefore also lead to enhanced quality of care[80]. In most European countries general practitioners (GPs) are the main gatekeepers to CAMHS[26,47,78,81,82], but educational services also play an important role in the referral process[35,47,64,78]. However, the majority of literature on barriers to the referral process has focused on referrals from GPs[83] and very little is known about barriers to referrals from other settings. A review by O'Brien et al. of GPs' perceptions of barriers to managing child mental health problems identified several barriers to the referral process[84]. There was a lack of knowledge among GPs about how child mental health services were organized[84]. In addition, unavailability of services was highlighted as a barrier, as was lack of communication with CAMHS and a desire for clearer referral criteria and better feedback on referrals[84]. The review also identified a lack of assessment tools developed specifically for children and adolescents as a barrier to identifying or diagnosing mental health problems, which is a prerequisite for referring the child onwards to more specialized services[84]. Both parents and professionals who refer children to CAMHS have expressed frustration with high rejection rates by CAMHS[74,85].

1.5.1. REJECTION OF REFERRALS TO CAMHS

Referral decisions are made by specialists in CAMHS based on the information in the referral letter. The decision to refer a child to CAMHS should be appropriate and the referral letter should include all relevant information[83]. In Denmark the rejection rate for CAMHS has been stable at 20-25% for the last decade [27,86]. This is in line with rejection rates for CAMHS in other Scandinavian countries and the UK [27,82,87]. Very few studies have investigated factors associated with referrals being rejected by CAMHS. Studies from the UK have found that referrals from GPs [82] and teachers [47] were associated with significantly higher odds of rejection, as were referrals for emotional and behavioral difficulties [47]. The most commonly stated reason for rejection is that the referral does not meet referral criteria (i.e. moderate-severe mental disorder), but missing information in the referral is also often stated as the reason for rejection[27,47]. However, to the PhD candidate's knowledge no previous studies have been conducted investigating what proportion of rejected referrals in fact do fulfill referral criteria for CAMHS. General practitioners do not agree that they make referrals for children not in need of specialized assessment[88], but they are constrained by limited time for consultations and a lack of systematic tools, both when assessing children and adolescents with mental health problems and when writing referrals[84]. Studies on interventions aimed at improving the referral process to CAMHS are therefore highly relevant. However, research on interventions to improve appropriateness of outpatient referrals is scarce[79,83]. To the best of the PhD candidates knowledge only two studies with small sample size have previously reported interventions aimed at lowering referral rates and improving appropriateness of referrals to CAMHS[89,90]. Both investigated the effect of joint consultations with CAMHS specialists and found a positive effect on quality of referrals and a reduction in numbers of referrals[89,90].

Research on clinical judgement has demonstrated that among specialists in mental health lack of comprehensiveness in the assessments is often a problem in routine clinical practice[91]. Hence, this is most likely an even bigger problem in primary care setting, where the professionals do not have the same amount of training in child mental health. Therefore, it is quite possible that a proportion of referrals are rejected because of deficient assessment by the referring professional or missing information in the referral letter leading to delays in accessing appropriate services for the affected child. A way to remedy this, without taking up more resources from the referring professionals, could be to systematically employ a web-based diagnostic interview, specifically developed for assessment of childhood mental disorders, as a supplement to standard referral letters. This could potentially be a help to the specialists making referral decisions in better determining whether presenting problems are consistent with the referral criteria for CAMHS[92]. In addition to improving referral decision making, more objective measures as a supplement to referral letters could facilitate more effective allocation of cases accepted by CAMHS[92,93] and might lead to an improvement in the quality of care provided[80].

1.6. WEB-BASED DIAGNOSTIC INTERVIEWS

Web-based diagnostic interviews are a reliable, inexpensive, accessible and time-efficient way of assessing mental health problems[94]. They have been shown to be valid in assessing symptoms in primary care settings without taking up additional time from the responsible professional[95]. A number of studies have demonstrated that many find it easier to provide sensitive information in a web-based interview than face-to face with a medical doctor or other professional[91,94]. Web-based interviews also have several advantages for the informants. They are available around the clock, so they can complete them at a convenient time[94,96]. They also allow for informants to pause and think when answering questions without having to keep a professional waiting[94,96], potentially leading to more accurate answers[94]. Overall studies have found patients' reactions to web-based diagnostic interviews to be positive[93,94].
Web-based diagnostic interviews provide a valuable source of information to clinicians, but clinical judgment is still necessary in weighing information from all sources and computer generated reports should be coupled with clinical judgment[94].

There are a number of web-based diagnostic interviews available for assessment of mental health problems in children [97]. One of these is the Development and Well-being Assessment (DAWBA)[98] which has been translated into Danish[99].

1.6.1. THE DAWBA

The DAWBA is a web-based diagnostic interview, developed to identify mental disorders as defined by ICD-10[100] and DSM-5[101] applicable to 2-17 year olds[98,102]. It has a parent version, and for children aged 11-17 there is also a self-report interview[98]. In addition, there is a briefer teacher questionnaire covering conduct, emotional, and hyperactivity symptoms and any resultant impairment[98]. The DAWBA is constructed with a mix of structured closed questions and open-ended questions about different mental health symptoms and their impact[98]. If an informant completes a structured section, the section will be followed by open-ended questions where informants can give more detailed information about the specific symptoms and examples of how they impact the child's life[103]. Based on the structured sections in the DAWBA a computer algorithm assesses the likelihood that the reported symptoms and impairment meets the criteria for one or more specific mental disorders[103]. The completed DAWBA is then reviewed by an experienced clinician who brings all the available information together and decides to accept or overturn the diagnoses proposed by the algorithm[104]. The clinician may also add diagnoses not proposed by the algorithm.
Parents find the DAWBA easy to complete, and CAMHS clinicians find the information in the DAWBA useful[105]. Studies have found considerable agreement of diagnoses based on the DAWBA and diagnoses given after standard clinical assessment[98,106,107].

In a randomized controlled trial, Angold et al. compared the DAWBA with the Diagnostic Interview Schedule for Children (DISC) and the Child and Adolescent Psychiatric Assessment (CAPA) and concluded that the DAWBA was completed more rapidly and generated fewer diagnoses than both the DISC and the CAPA with the DAWBA identifying the more severe cases[108]. This makes the DAWBA a good candidate for use as an adjunct to the referral letter in deciding what referrals should be accepted by CAMHS. This use of the DAWBA has previously been proposed by Ford et al.(2013)[93] but has not been examined in a clinical trial before.

1.7. SUMMARY AND RATIONALE FOR THIS RESEARCH

More than half of lifetime mental disorders have their onset before the age of 18 and childhood mental disorders are often persistent and have a global impact on affected children's lives. The involvement of many professionals across service sectors in providing child mental health services is reflective of the global impact of mental disorders but it also contributes to the complexity of help-seeking for childhood mental health problems and studies have documented long delays in accessing services and low provision of evidence-based treatment to children with mental disorders. We therefore need research that sheds light on how families of children with mental disorders seek help and what challenges they encounter in their help-seeking in order to identify areas for improvement in service provision.

Currently CAMHS is faced with the dilemma of, on the one hand experiencing dramatic increases in referral rates, which are exerting a strain on available resources, while on the other hand research continues to document a substantial unmet need for CAMHS. In order to properly plan services for children with mental disorders, we need updated knowledge on referral patterns to CAMHS that goes beyond simply documenting increasing numbers of referrals, but also helps us to understand the potential reasons behind the increase. Simultaneously high rejection rates for referrals to CAMHS pose a challenge, as this affects satisfaction with services and might result in delays in access to relevant interventions which could prevent deterioration in the child's mental health. Despite a political focus on high rejection rates by CAMHS in Denmark, these have remained high at 20-25% in the last decade[27,29].

Research on referral decisions by CAMHS as well as investigations of interventions aimed at improving the quality of referrals are scarce. Efforts should also be made at increasing our understanding of why almost a quarter of referrals to CAMHS are rejected and to test interventions that aim to improve the referral process and thus reduce the rejection rate.

CHAPTER 2. AIM AND OBJECTIVES

The overarching aim of this PhD project was to investigate help-seeking patterns and barriers to accessing timely and appropriate services for children and adolescents with moderate to severe mental disorders. The thesis focuses on a clinical population of children referred to outpatient CAMHS.

The objectives of the PhD project were threefold.

1) To investigate changes in referral patterns to CAMHS over time.
   The intent of this investigation was to provide updated knowledge on the referral pattern to CAMHS, including changes in distribution of age, sex and primary referral reason as well as referral source for children referred to CAMHS (Study I).
2) To investigate help-seeking pathways prior to referral to CAMHS and barriers to accessing services, including factors associated with referrals being rejected by CAMHS (Study II-IV).
3) To test the effect of the DAWBA as an adjunct to standard referral letters on referral decisions by CAMHS (Study V).

Study I:

Aim: To investigate changes in referral patterns to outpatient CAMHS from 2005-2018.

The hypotheses were that there would be:

1) An increase in referrals for emotional disorders.
2) An increase in the proportion of girls referred for neurodevelopmental disorders.
3) An increase in referrals from educational services.

Study II:

Aim: To investigate parental help-seeking patterns prior to a child being referred to outpatient CAMHS and if these differed by 1) duration of mental health problems or 2) type of symptoms.

Hypotheses:

1) Educational services play a more prominent part in help-seeking pathways for children referred for neurodevelopmental disorders than children referred for emotional disorders.

2) Children referred for neurodevelopmental disorders have longer symptom duration prior to referral to CAMHS.

Study III:

Aim: To investigate parent perceived barriers to accessing services for their child's mental health problems.

The study was an exploratory study, with no hypotheses formulated in advance. It was guided by the following research questions:

1) Are parent reported barriers to accessing services associated with the age of the child?
2) Are parent reported barriers associated with type of symptoms or severity of the child's mental health problem?
3) Is there an association between duration of the child's mental health problems and parent reported barriers to accessing services?

Study IV:

Aim: To provide a descriptive overview of the current referral pattern to outpatient CAMHS and investigate what characteristics are associated with rejection of referrals.

The study was an exploratory study, with no hypotheses formulated in advance. The study was guided by the following research questions:

1) What are the characteristics of referrals to CAMHS?
2) What characteristics are associated with rejection of referrals by CAMHS?

Study V:

Aim: To test the effect of the DAWBA as an adjunct to standard referral letters on the accuracy of referral decisions by specialists in CAMHS. Secondarily to investigate what proportion of children referred fulfill referral criteria for CAMHS.

Hypothesis:

1) The use of the DAWBA will lead to more accurate referral decisions made by CAMHS.
2) The use of the DAWBA will lead to a reduction in rejection rates by CAMHS, mainly from GPs.

CHAPTER 3. METHODS

3.1. SETTING

All five studies in the thesis were conducted at the Child and Adolescent Psychiatric Department of the North Denmark Region, which provides multidisciplinary specialist mental health services to children aged 0-17 with moderate to severe mental health problems. The center is one of six hospital based CAMHS in Denmark. It is the only hospital based CAMHS in the North Denmark Region, with a catchment area covering both urban and rural areas with around 114,000 inhabitants aged 0-17[109]. Referrals are generally processed within days of being received, to ensure that the accepted referrals are seen within 30 days. In 2018 more than 95% of accepted referrals at the study center were seen for their first appointment within this timeframe[50]. Hospital based CAMHS in Denmark is tax-funded and free of charge to the patients. CAMHS is a specialist health service, and access is dependent on a referral from a professional from primary settings like GPs, educational psychologists and case workers in social service or from a medical doctor from another specialist health service.

3.2. PARTICIPANTS

The primary eligibility criteria for all studies in this Ph.D. project was referral to outpatient services at the study center, regardless of whether the referral was afterwards rejected by CAMHS.

The flowchart in Figure 3 shows how participants in Study I-IV are related. Study I included all outpatient referrals to the study center in 2018 (0-17 years) and compared them to referral data from 2005 and 2010. Participants for study II-III were recruited among families who had a child aged 2-17 referred to the study center from July to December 2018. The age limitation was set, to account for the parent version of the Strengths and Difficulties Questionnaire (SDQ)[110] used in these two studies, not being validated for children under the age of 2[111]. Study II included all participants who completed the Children's Services Interview[112] while Study III only included participants with a parental role (biological, step or foster parent). In Study IV, all children referred for assessment of a mental disorder in 2018 were included.

Figure 3: Flowchart for Study I-IV

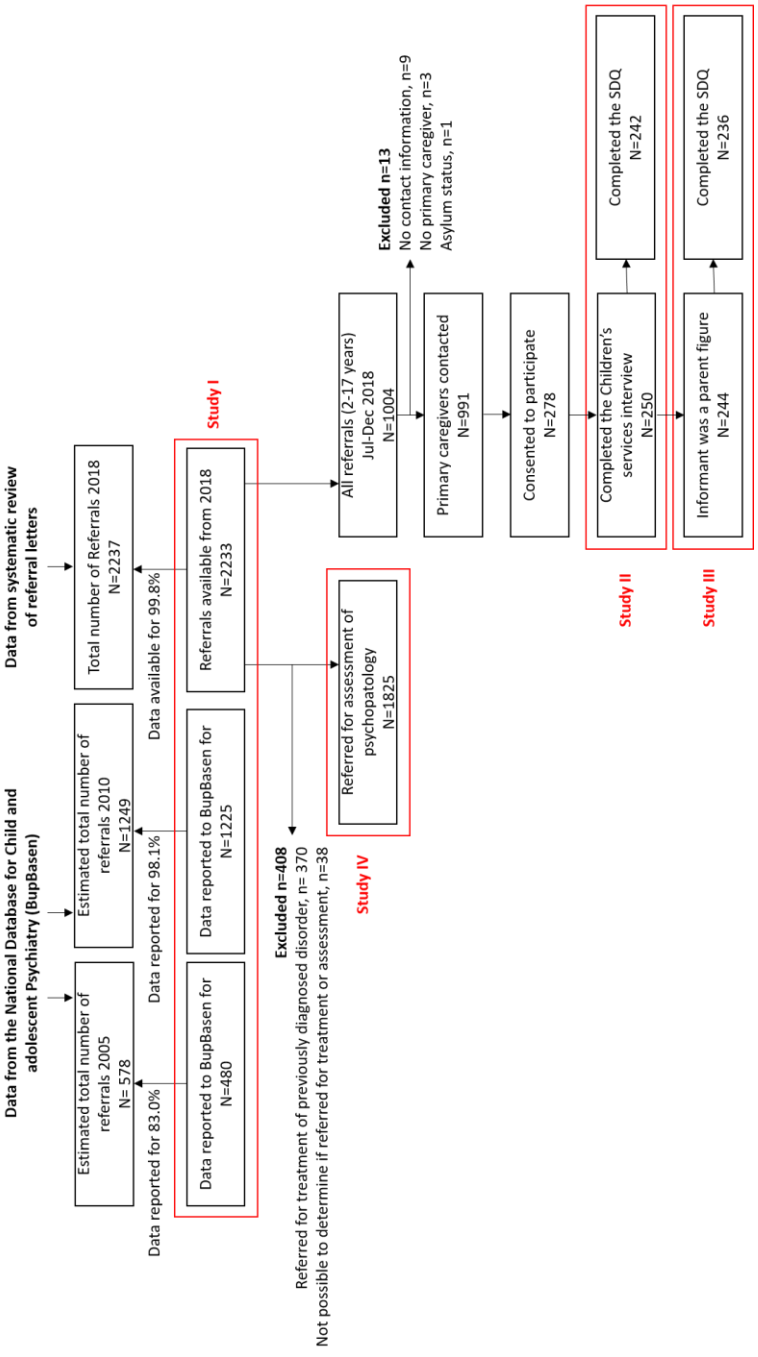


Figure 4: Flowchart for inclusion of participants in Study V (Study V)

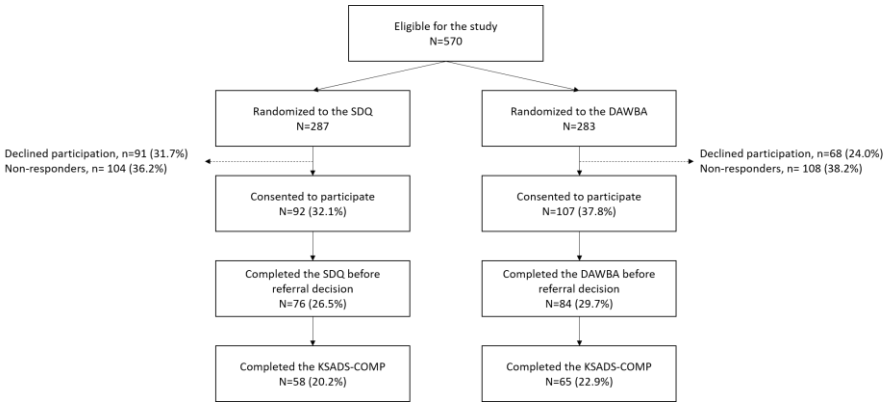


Figure 4 shows the flowchart for inclusions to Study V. Children aged 6-17 were eligible to participate in Study V if they were referred to the study center a random week of the month from March 2019 to March 2020. Due to the paucity of previous studies of referral process interventions in CAMHS, it was not possible to make justified assumptions on how big an impact the use of DAWBA could have on CAMHS referral decisions, and therefore a sample size calculation was not performed for Study V. Participants were recruited every month of the year to account for variation in referral patterns throughout the year and to ensure that study participants were as representative as possible for the clinical population. The age limitation was set to account for the web-based Kiddie Schedule for Affective Disorders and Schizophrenia (KSADS-COMP)[113], which was used for the reference standard in the study, not being validated for use in children younger than 6 years of age.

3.3. STUDY DESIGNS AND METHODS

Study I-IV were all cross-sectional observational studies, whereas Study V was a randomized feasibility trial.

Study I+IV were based on a systematic review of referral letters to outpatient CAMHS from 2018. In Study I all referrals from 2018 were compared to referral data from BupBasen[86] for 2005 and 2010.

In Study II+III information from referral letters were combined with background information on the participating families as well as parent reported SDQ scores and information from the Children's Services Interview.

In Study V participants were randomized to two groups (DAWBA or SDQ) in a 1:1 randomization stratified by sex.

DAWBA group: Informants (parents and children ≥ 11 years) were asked to fill out the DAWBA. The DAWBA was afterwards rated by a medical doctor or a research psychologist with a minimum of 4 years of clinical experience in CAMHS. The CAMHS specialist making the referral decision had access to both the referral letter and the clinician rating of the DAWBA including the SDQ.

SDQ group: Informants (parents and children ≥ 11 years) were asked to complete the SDQ. The CAMHS specialist making the referral decision (accept/reject) had access to the referral letter and the SDQ.

The SDQ was collected from all participants in order to ensure information on impact of the child mental health problems for both groups. Also, this ensured that both groups had to complete a questionnaire in order to be included in the study, making the conditions for inclusion more similar. For both groups, the CAMHS specialist also had access to information from previous assessments in the electronic patient record if the child had previously been assessed.

3.4. PROCEDURES

All referral letters to outpatient CAMHS from 2018 as well as all referral letters for children included in Study V were systematically reviewed using an ad hoc form developed for this research project. Data extraction was performed by 3 graduate level psychology students and the PhD candidate. The form can be found in Appendix A.

For Study II, III and V families were invited to participate at the time the CAMHS center received a referral for the child. A letter explaining the study along with a consent form was sent to a primary caregiver of the referred child using e-Boks which is a secure digital mailbox linked to a personal registration number. e-Boks is routinely used in communication between public sector services and citizens in Denmark. For Study II and III two reminders of the study invitation were sent to all eligible participants, whereas only one reminder was sent in Study V due to the short timeframe for eligibility (3 days).

Study II+III: After consenting to participate a primary caregiver completed an electronic questionnaire with background information and the extended version of the SDQ as well as the Children's Services Interview, which was conducted via telephone by a research psychologist or the PhD candidate, who both have clinical experience in CAMHS. Responses obtained by telephone from the primary caregiver were simultaneously recorded by the interviewer in a standard electronic form set up in REDCap[114]. For Section b (see Appendix b) parents who endorsed 'reluctance to ask for help' or any of the specifically listed obstacles to accessing help, where asked to expand on why they endorsed the specific question and these responses were recorded as free text answers in the form. Participants were only included in the studies if they completed the Children's Services Interview.

Study V: All eligible participants were randomized to either filling out the DAWBA or the SDQ prior to the study invitation being sent. All parents were asked to complete the assigned assessment instrument (SDQ/DAWBA), and if the child was ≥11 years there was also a self-report version for the child. The assigned assessment instrument was completed using a link for an electronic version of the instrument. To be included in the SDQ group in the study at least one informant had to complete the SDQ. To be included in the DAWBA group at least one informant had to complete the SDQ and a minimum of one diagnostic section of the DAWBA. The assigned assessment instrument had to be completed before a referral decision was made by CAMHS, giving the family approximately three days to complete the assessment instrument from the time of the invitation for the study. All participating families were asked to complete a psychiatric diagnostic interview (KSADS-COMP) after inclusion in the study. The clinicians conducting the KSADS-COMP interviews were not informed of the content of the DAWBA/SDQ or the content of the referral letter and referral decision prior to the interview. However, in some cases the families revealed this information during the interview. The KSADS-COMP interviews were conducted as face-to-face interviews, apart from the participants included in March 2020 (n=11), where interviews were conducted via secure video calls, due to COVID-19 restrictions.

3.5. MATERIALS

Table 1 gives an overview of data sources for the research project and what information was obtained from each source. Below is a more thorough description of the different sources.

BupBasen: Data on referrals from 2005 and 2010 for Study I came from BupBasen, which was a quality assurance database for CAMHS in Denmark, separate from the national patient registers. From 2004 to 2010 all public hospital based CAMHS in Denmark systematically reported referral data (sex, age, municipality, referral source and primary referral diagnosis) to BupBasen[86]. Data coverage for BupBasen has been calculated by comparing data from BupBasen to the National Patient Registry[86,115]. In 2005 referral data was reported to BupBasen for 83 % of all referrals to the study center[115]. In 2010 BupBasen the coverage was 98.1% [86].

The Children's Services Interview was used to collect data on help-seeking pathways and barriers to accessing services in Study II+III. The interview starts with a section of open-ended questions about any service use for mental health concerns, followed by a section enquiring about parental perception of barriers to help-seeking[112]. If a parent endorses a barrier, they are asked to specify how they experienced the specific barrier[112] and this information was written down by the interviewer. The last section of the interview is a structured screen to check for any service contacts that the informant might have forgotten in the unstructured section[40,112]. The primary caregiver

was interviewed about service contacts for the last two years prior to referral but were enquired about barriers for the full duration of their help-seeking. The Children's Services Interview has been shown to generate moderately valid and reliable data on service use[112]. The interview guide was translated into Danish for this PhD project following standard guidelines[116]. Two independent forward translations were conducted, one by a bilingual lay-person and one by a CAMHS clinician, followed by a consensus translation agreed upon by the two. Next the Danish version was reviewed by professionals within healthcare, CAMHS, social services and educational services to ensure that no relevant services in a Danish context were omitted. Following this an independent back-translation was conducted by an authorized translator and this was shared with the copy-right holder of the Children's Services Interview, and any inconsistencies were settled. To establish when and how the families initially sought help, two questions were added asking "How old was your child, the first time you sought help for these difficulties?" and "Who/what professional did you first contact to get help for your child?". Minor adaptions were made to the questions in the interview guide regarding perception of services (section b), to adapt it to the current study setting. The full version of the Children's Services Interview used in this study can be found in Appendix B.

The extended version of the Strengths and Difficulties Questionnaire (SDQ)[110] was used as a measure of symptom severity in Study II, III and V. It is a validated 25 item behavioral and emotional assessment tool with an impact supplement[110]. It generates a total difficulties score and subscale scores for emotional problems, conduct problems, hyperactivity/inattentiveness problems, peer problems and a prosocial score as well as an impact score[110]. The SDQ has satisfactory to strong psychometric properties[117–119] and is well-validated[117]. Danish norms for SDQ scores exist[120]. Problem scores and impact scores above the 80th percentile are considered above the norm and scores above the 90th percentile as "High". For the prosocial score values below the tenth percentile are considered "Low" and values below the 20th percentile are considered below the norm[120].

Table 1: Overview of data sources for Study I-V

Data source	Data on	Study	Comments
BupBasen	Characteristics of the child - Sex - Age Characteristics of the referral - Referral source - Primary referral reason	I	Compared to data from the systematic review of referral letters
Systematic review of referral letters	Characteristics of the child Characteristics of the referral Content of the referral letter - Previous interventions - Previous assessment outside the study center - Impact on schooling - Self-harm and suicidal ideations	I-V	Data extraction completed using an ad-hoc form by three graduate level psychology students and the PhD candidate
Electronic records	Placement outside the home Previous assessment at the study center Age at first ever referral to the study center Referral decision	I-V	Data collected by a research secretary
The Children's services interview	Age of parental recognition of onset First help-seeking contact Help-seeking contacts last two years Barriers to help-seeking	II+III	Data collected by telephone interview by a PhD level clinical psychologist and the PhD candidate
The extended version of the SDQ	Symptom severity - Subscale problem scores - Total difficulties score - Impact score	II, III, V	In Study II+III only parent reported In Study V collected from parents and from children ≥11 years old.
The DAWBA	- SDQ scores	V	A clinician rating of the DAWBA incl. tentative ICD-10 and DSM-5 diagnoses were used as the intervention tested in Study V
The KSADS-COMP	Mental disorder present (DSM-5 criteria)	V	Used in combination with impact score from the SDQ as the reference standard for correct referral decision

The Development and Well-being Assessment's (DAWBA) usefulness as an adjunct to standard referral letters in aiding referral decisions was tested in the randomized feasibility trial in Study V. The DAWBA is described in more detail in chapter one. The DAWBA has been validated[98] and clinician diagnoses based on the DAWBA have shown good reliability[106]. The extended version of the SDQ is administered initially in the electronic version of the DAWBA interview utilized in this study. The clinician's summary of the DAWBA including diagnostic codes (ICD-10 and DSM-5) decided by the rating clinician and all free text responses by the informant(s) was made available to the CAMHS specialist making the referral decision. Study V did not test the accuracy of the DAWBA in diagnosing mental disorders, but strictly tested whether the clinician's summary of the DAWBA and free text responses as an adjunct to standard referral letters was an aid for CAMHS specialists in correctly deciding if children fulfilled referral criteria for CAMHS or not.

The computerized Kiddie Schedule for Affective Disorders and Schizophrenia (KSADS-COMP)[113] was used in Study V as the reference standard for correct referral decision in conjunction with a high impact score from the SDQ. K-SADS-Present and Lifetime (K-SADS-PL)[121] is a semi-structured diagnostic interview and is considered a gold standard for assessment of psychopathology in children and adolescents[122]. The KSADS-COMP is a web-based version of the K-SADS-PL which has been updated to reflect DSM-5 diagnostic criteria and also provides associated ICD-10 diagnostic codes[113]. Good convergent validity has been demonstrated for KSADS-COMP[113]. This study utilized the clinician administered version of the KSADS-COMP that has recently been translated into Danish. The translation was undertaken by the Research Unit for Child and Adolescent Psychiatry, Aalborg University Hospital and the PhD candidate had a central role in the work. The KSADS-COMP interview was administered to one or both parents and to the child. When the child was placed in care a foster parent or a primary contact person from the residential home provided "parent" information. For children younger than 11 years, the parent(s) was interviewed first and for children ≥11 years, the child was interviewed first. The KSADS-COMP interview was included in the data analysis if at least one informant completed the full interview.

3.6. DEFINITIONS OF VARIABLES

In the following constructed variables for the research project are defined.

Primary referral diagnosis was defined as the ICD-10 diagnostic code assigned based on the referral letter. For all accepted referrals this was assigned by the CAMHS specialist making the referral decision. If the referral was rejected, the referral diagnosis stated on the referral letter was taken as the primary referral diagnosis. In case of multiple referral diagnoses on a rejected referral, the primary referral diagnosis was decided based on the referral letter by the PhD candidate who is a 5th year child

and adolescent psychiatric trainee. Primary referral diagnoses were grouped as emotional disorders (affective disorders, anxiety disorders and eating disorders), neurodevelopmental disorders (attention deficit disorders (ADHD/ADD), autism spectrum disorders (ASD) and tics disorders) and other disorders (psychosis, conduct disorders, attachment disorders, personality disorders, and unspecified mental health problems). The groupings in neurodevelopmental and emotional disorders were made based on age of onset of symptoms and type of symptoms. Neurodevelopmental disorders have their onset in childhood[123] and more often display externalizing symptoms whereas emotional disorders become increasingly more prevalent from early adolescence[124] and predominantly display internalizing symptoms. This was suspected to influence help-seeking pathways. The grouping of neurodevelopmental disorders together is also supported by the diagnostic categories in ICD-10[100] and DSM-5[101]. The grouping of "other" disorders was based on these diagnoses being relatively rare among referrals.

Previously assessed was defined as a child who had previously been assessed for a mental disorder, either by a child and adolescent psychiatrist or by a pediatrician with a special interest in child and adolescent psychiatry. A child was defined as previously assessed if the medical record indicated that the child had previously been assessed by the study center or if it was indicated in the referral letter that the child had been assessed for a mental disorder by another CAMHS or by a private practicing pediatrician or child and adolescent psychiatrist.

Delay in time-to-referral in Study II was defined as the time from parentally recognized child mental health problems until the first-time the child was registered with a referral to the study center.

Symptom duration in Study II+III was defined as the parentally reported duration of the child's mental health problems until the current referral (time of inclusion in the study) to CAMHS.

Primary vs. Specialized services: Service contacts were categorized as specialized if access was dependent on referral or decision by a professional to involve the specific service (i.e. educational psychologists, psychosocial interventions by social services, specialist healthcare services). In contrast services were categorized as primary if parents had free access to them (i.e. teachers, contact with a case worker from social services, GPs).

Correct referral decision: A correct referral decision in Study V was defined as a referral for a child with a clinical need for assessment being accepted or a referral for a child not fulfilling criteria of clinical need being rejected. Clinical need was defined as one or more mental disorders based on the KSADS-COMP interview and a high impact score on the SDQ (above the 90th percentile compared to the Danish norm). This approach was taken, because previous research has established that combining

diagnostic criteria and a measure of impairment is the most robust approach for defining clinical need[125].

3.7. STATISTICAL ANALYSES

Descriptive statistics are reported as N (%) for all categorical variables. For continuous variables that are not normally distributed the median (interquartile range (IQR)) is reported whereas the mean (SD) is reported for continuous variables which do display a normal distribution. For categorical variables, either the Chi-squared test or Fisher's Exact test was applied. Fisher's Exact test was applied for 2x2 contingency tables in the studies with smaller N (Study II, III and V) whereas Chi-squared was applied when testing for differences in categorical variables across more than two groups and across two groups in Study I and IV which had a high number of participants. ANOVA was used when testing for differences in continuous variables across more than two groups (Study II). Otherwise t-test was applied to continuous variables. In the studies with smaller sample sizes t-test with bootstrap[126] using 100 repetitions was used for continuous variables.

It was not possible to obtain data that would allow for the conduction of attrition analysis for study II, III and V, but as an approximation the study samples were compared to all referrals from 2018 (Study I) to investigate for representativeness of the samples.

Linear regression was used to investigate changes in referral source over time in Study I. Logistic regression was used to examine for changes in proportion of primary referral diagnosis over time in Study I and to test the specific association of parentally perceived barriers' association with age, primary referral diagnosis, symptom duration and SDQ impact score in Study III. In Study III all logistic regression analyses were tested with bootstrapping[127] using 200 repetitions due to the small numbers in some of the groups. In Study IV logistic regression was used to examine for factors associated with a referral being rejected by CAMHS.

Post-hoc pairwise comparison tests were conducted in Study I to investigate for changes from 2005-2010 and 2010-2018. Also, subgroup analyses were conducted for the four major referral reasons (affective disorders, anxiety disorders, DF80-89 disorders and DF90-98 disorders).

To examine for why a specific barrier was endorsed in Study III, the free text responses of specifications of barriers to help-seeking given by parents were systematically examined by two independent coders using semantic thematic analysis[128]. This qualitative method was selected, despite the data not fulfilling the criteria for qualitative data, as it is not verbatim transcriptions, to better understand the different reasons as to why parents perceived different barriers to exist. The analysis was conducted from a realist/essentialist perspective using an inductive

approach. The thematic analysis was conducted across all free text responses to each question item in the interview guide independently, identifying potential themes for endorsing each specific barrier. To be identified as a theme in the initial search a specific reason for endorsing a barrier had to be specified by at least five different primary caregivers. Following this the themes were reviewed and refined by each coder. Any differences in identified themes between the two coders were discussed and a consensus agreement was reach on prominent themes, which was defined as the most frequently identified themes. Following the initial thematic analysis of data from each individual question item the themes identified for the individual items were revisited and common over-arching themes across the different barriers were identified.

To check for reliability of the data extraction from the referral letters 20 randomly selected referral letters reviewed by each of the graduate level students were also reviewed by the PhD candidate. Reliability of the data extraction from the referral letters was calculated using an average of Cohen's Kappa for all extracted variables comparing each graduate student to the PhD candidate.

When calculating sensitivity, specificity, positive predictive values (PPV) and negative predictive values (NPV) for the referral decision in each of the two randomized arms in Study V, the referral decision was compared to the constructed reference standard for clinical need (KSADS-COMP diagnosis+ high SDQ impact score).

The level of statistical significance was set at 5% for all analyses. All statistical analyses were executed using Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC.

3.8. ETHICAL CONSIDERATIONS AND APPROVALS

The studies were conducted in compliance with the Helsinki Declaration[129]. The Danish Patient Safety Authority approved the review of referral letters from 2018 (ref-number 3-3013-2794/1). Authorization for access to data from BupBasen was granted by The Danish Clinical Quality Program– National Clinical Registries (RKKP). For the studies which included parents as informants (II, III and V) written consent for participating in the study was obtained from both parents in cases with shared custody of the child even if only one parent actively participated in the study as an informant. This was to ensure that both parents received information about a study involving information about their mutual child. In Study V, which also included the referred child as an informant, all children older than 15 years of age also gave written consent themselves in accordance with Danish legislation.

In Study V, clinical raters had access to diagnostic information from the DAWBA prior to the outpatient clinic. Therefore, there were fixed procedures for how to act, if

a rater became aware of symptoms or conditions posing an acute threat to the referred child. If a child included in Study V had their referral rejected by CAMHS the family received a written summary of the diagnostic conclusions from the KSADS-COMP interview along with recommendations on what services to contact to ensure appropriate help for the child's mental health problems. If the clinical rater of either the DAWBA or the KSADS-COMP became aware of conditions which required involvement of social services to support either the child or the family, then the family was informed that a letter of concern would be sent to social services.

The research project was reported to the Danish Data Protection Agency in accordance with Danish research legislation (ref-number 2019-58, ref-number 2018-109, ref-number 2018-186). The North Denmark Region Committee on Health Research Ethics deemed that no further ethical approval was required as the studies did not involve active treatment or collection of biological material.

CHAPTER 4. RESULTS

This chapter will present a summary of the main findings from Study I-V.

4.1. CHARACTERISTICS OF THE STUDY SAMPLES

Table 2 is a summary and comparison of the characteristics of the study populations in Study I-V. Across all the studies the majority of the referred children were boys (54.2-60.8%), and the median age of the referred children ranged from 12.8-13.8 years of age. Just over a third (37.6%) of all outpatient referrals in 2018 had previously been assessed for a mental disorder, but this proportion was statistically significantly smaller in Study II-V (24.8-30.4%).

In all study populations general practitioners were the primary referral source (49.2-61.3%) followed by educational psychologists (21.9-34.4%). Neurodevelopmental disorders were the most common primary referral reason constituting more than 50% in all the studies.

Results marked in bold in Table 2 indicate factors where the individual study samples showed statistically significant differences from all referrals to the study center in 2018.

Table 2: Characteristics of the study populations for Study I-V

	Study I						**Study II**		**Study III**		**Study IV**		**Study V**	
Inclusion period	Jan-Dec 2005		Jan-Dec 2010		Jan-Dec 2018		July-Dec 2018		July-Dec 2018		Jan-Dec 2018		Mar 2019-Mar 2020	
Total population size	N=480		N=1225		N=2233		N=250		N=244		N=1825		N= 160	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Child characteristics														
Boys	286	(59.6)	763	(62.3)	1251	(56.0)	152	(60.8)	148	(60.7)	989	(54.2)	91	(56.9)
Median age (IQR)	13.5	(9.6-15.6)	12.8	(9.1-15.4)	13.6	(9.7-16.0)	12.8	(9.8-14.7)	12.8	(9.8-14.6)	13.5	(9.5-16.0)	13.8	(10.5-15.7)
Placement in care	-	-	-	-	184	(8.2)	27	(10.8)	21	(8.6)	135	(7.4)	11	(6.9)
Placed in special education program	-	-	-	-	403	(18.1)	46	(18.4)	43	(17.6)	304	16.7	**17**	**(10.6)**
Previously assessed for a mental health disorder					840	(37.6)	**76**	**(30.4)**	**73**	**(29.9)**	**452**	**(24.8)**	**41**	**(25.6)**
Referral source														
General practitioner	223	(46.6)	706	(56.6)	1252	(56.1)	**123**	**(49.2)**	**120**	**(49.2)**	983	(53.9)	98	(61.3)
Other medical doctor	125	(26.1)	171	(14.0)	271	(12.1)	24	(9.6)	24	(9.8)	**173**	**(9.5)**	18	(11.3)
Educational psychologist	84	(17.5)	247	(20.2)	595	(26.7)	**85**	**(34.0)**	**84**	**(34.4)**	**568**	**(31.1)**	35	(21.9)
Case worker social services	47	(9.8)	101	(8.2)	115	(5.2)	18	(7.2)	16	(6.6)	101	(5.5)	9	(5.6)
Primary referral diagnosis														
Neurodevelopmental[1] disorders	225[a]	(46.9)	881[a]	(71.9)	1218	(54.6)	149*	(59.6)	146*	(59.8)	**937**	**(51.3)**	86	(53.8)
Emotional disorders[2]	156	(32.5)	199	(16.2)	604	(27.1)	76*	(30.4)	74*	(30.3)	**557**	**(30.5)**	**56**	**(35.0)**
Other	99	(20.6)	145	(11.8)	411	(18.4)	34*	(13.6)	**32***	**(13.1)**	331	(18.1)	**18**	**(11.3)**
Referral rejected	93	(19.4)	381	(33.9)	536	(24.0)	53	(21.2)	50	(20.6)	462	(25.3)	43	(26.9)

[1]Neurodevelopmental disorders: ADHD/ADD, autism spectrum disorders and tics disorders. [2]Emotional disorders: Affective disorders, anxiety disorders and eating disorders

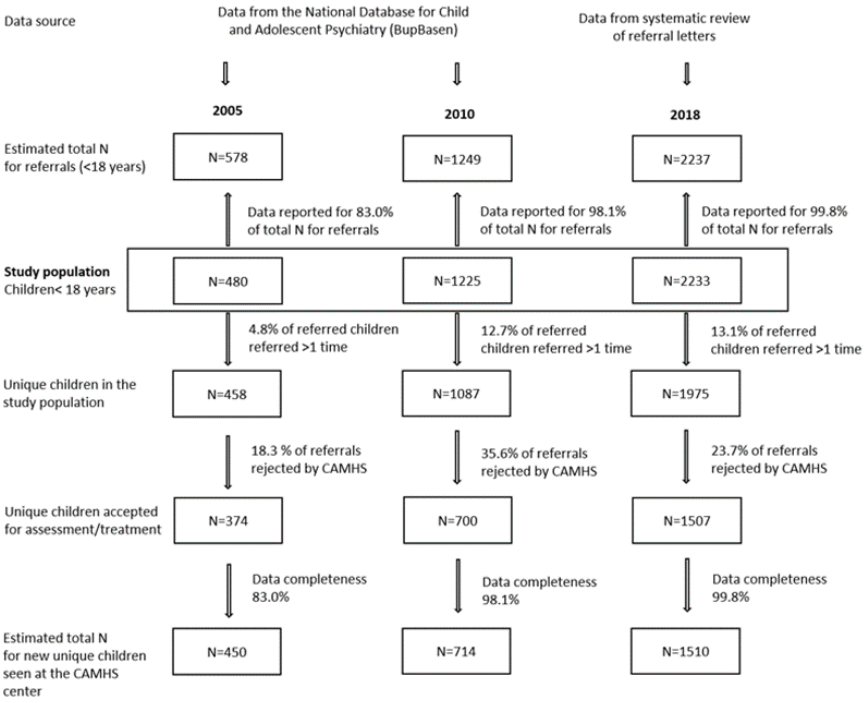
[a] In 2005 and 2010: Neurodevelopmental disorders covers all DF80-89 and DF90-98 diagnoses,

*N>100% due to co-morbid neurodevelopmental and emotional disorders

Bold: Statistically significant difference from all referrals from 2018

4.2. TEMPORAL CHANGES IN REFERRAL PATTERNS TO OUTPATIENT CAMHS

Figure 5: Changes in referrals to CAMHS from 2005-2018 (Study I)



Study I showed that the overall number of referrals to outpatient CAMHS in the North Denmark Region increased 3.9 times from 2005-2018, with 3.4 times increase in unique children referred for assessment or treatment by CAMHS (Figure 5).

From 2005-2018 there were statistically significant changes in the referral pattern to outpatient CAMHS. Overall, there was an increase in proportion of referrals from GPs (9.4%, $p<0.001$) and educational psychologists (9.1%, $p<0.001$). In 2018 GPs were responsible for 83.4% of referrals for affective and anxiety disorders and 38.7% of referrals for disorders of psychological development (DF80-89 disorders) and behavioral and emotional disorders with onset usually occurring in childhood and adolescence (DF90-98 disorders). Educational psychologists referred 5.5% of children referred for affective and anxiety disorders and 40.5% of referrals for DF80-89 disorders and DF90-98 disorders in 2018.

Distribution of primary referral diagnosis also changed between 2005, 2010 and 2018. Table 3 shows the changes in proportion of referrals for the four main primary referral diagnoses. For affective disorders and anxiety disorders, there was a statistically significant decrease from 2005 to 2010 (OR 0.44, 95%CI 0.32-0.60 and OR 0.55, 95%CI 0.33-0.91 respectively) followed by a statistically significant increase from 2010 to 2018 (OR 1.42, 95%CI 1.12-1.80 and OR 3.66, 95%CI 2.59-5.18 respectively). The opposite pattern was observed for DF80-89 disorders and DF90-98 disorders with a statistically significant increase in the proportion of referrals from 2005 to 2010 (DF80-89 OR 1.76, 95%CI 1.35-2.29 and DF90-98 OR 1.95, 95%CI 1.55-2.44) followed by a decrease from 2010 to 2018 (DF80-89 OR 0.65, 95%CI 0.55-0.76 and DF90-98 OR 0.80, 95%CI 0.69-0.92).

Table 3 also shows the changes in sex distribution and referral age. More girls were referred for DF80-89 disorders (24.0% vs. 14.1%, p=0.05) and DF90-98 disorders (33.0% vs. 22.1%, p=0.02) in 2018 compared to 2005. The median referral age increased from 2005-2018 with 1.9 years for girls referred for anxiety disorders (p=0.01) and for referrals for DF80-89 disorders there was an increase in age for both sexes (girls 6.6 years, boys 2.2 years, p<0.01).

The girls referred for DF90-98 disorders were statistically significantly older than the referred boys throughout the time period, but there was a decrease in the median age difference throughout the period from 2.9 years in 2005 to 1.6 years in 2018. For DF80-89 disorders, there was a statistically significant sex difference in median referral age only in 2018 (girls 13.5 years vs. boys 10.1 years, p<0.001).

Table 3: Temporal changes in age and sex distribution for the four most common referral diagnoses to outpatient CAMHS (Study I)

		2005		2010		2018		PW compare*
Specific referral reasons	**All referrals**	N=480		N=1225		N=2233		
	Boys, n (%)	286	(59.6)	763	(62.3)	1251	(56.0)	2010>2018
	Referral age (Girls), Median (IQR)	14.9	(12.8-16.0)	14.4	(11.2-16.2)	14.8	(12.1-16.4)	2005>2010<2018
	Referral age (Boys), Median (IQR)	11.7	(8.3-15.0)	11.7	(8.5-14.7)	11.9	(8.4-15.3)	NS
	Affective disorders	N= 86	(17.9)	N= 107	(8.7)	N= 267	(12.0)	2005>2010<2018
								2005>2018
	Boys, n (%)	32	(37.2)	50	(46.7)	84	(31.5)	2010>2018
	Referral age (Girls), Median (IQR)	15.2	(14.6-16.2)	15.1	(14.2-16.7)	16.0	(14.6-17.2)	2010<2018
	Referral age (Boys), Median (IQR)	15.3	(14.0-16.8)	14.4	(11.9-15.6)	16.3	(14.1-17.1)	2005>2010<2018
	Anxiety Disorders	N= 27	(5.6)	N= 39	(3.2)	N= 244	(10.9)	2005>2010<2018
								2005<2018
	Boys, n (%)	16	(59.3)	14	(35.9)	96	(39.3)	NS
	Referral age (Girls), Median (IQR)	13.2	(9.4-14.0)	15.3	(13.5-16.6)	15.1	(12.3-16.7)	2005<2010, 2018
	Referral age (Boys), Median (IQR)	13.7	(11.5-15.9)	13.6	(11.6-15.6)	14.2	(12.0-15.9)	NS
	Disorders of psychological development (DF80-89)	N= 85	(17.7)	N= 336	(27.4)	N= 438	(19.6)	2005<2010>2018
	Boys, n (%)	73	(85.9)	257	(76.5)	330	(76.0)	2005>2018
	Referral age (Girls), Median (IQR)	6.9	(5.1-16.1)	11.1	(7.1-14.0)	13.5	(10.3-15.4)	2005, 2010<2018
	Referral age (Boys), Median (IQR)	8.0	(5.5-11.5)	9.9	(6.7-13.0)	10.2	(6.8-13.6)	2005<2010, 2018
	Behavioral and emotional disorders in childhood (DF90-98)	N= 140	(29.2)	N= 545	(44.5)	N= 872	(39.1)	2005<2010>2018
								2005<2018
	Boys, n (%)	109	(77.9)	356	(65.3)	584	(67.0)	2005>2010, 2018
	Referral age (Girls), Median (IQR)	13.3	(10.7-15.3)	13.9	(10.3-15.8)	12.5	(9.1-15.6)	2010>2018
	Referral age (Boys), Median (IQR)	10.4	(8.3-13.6)	11.6	(8.5-14.5)	10.9	(8.2-14.7)	NS

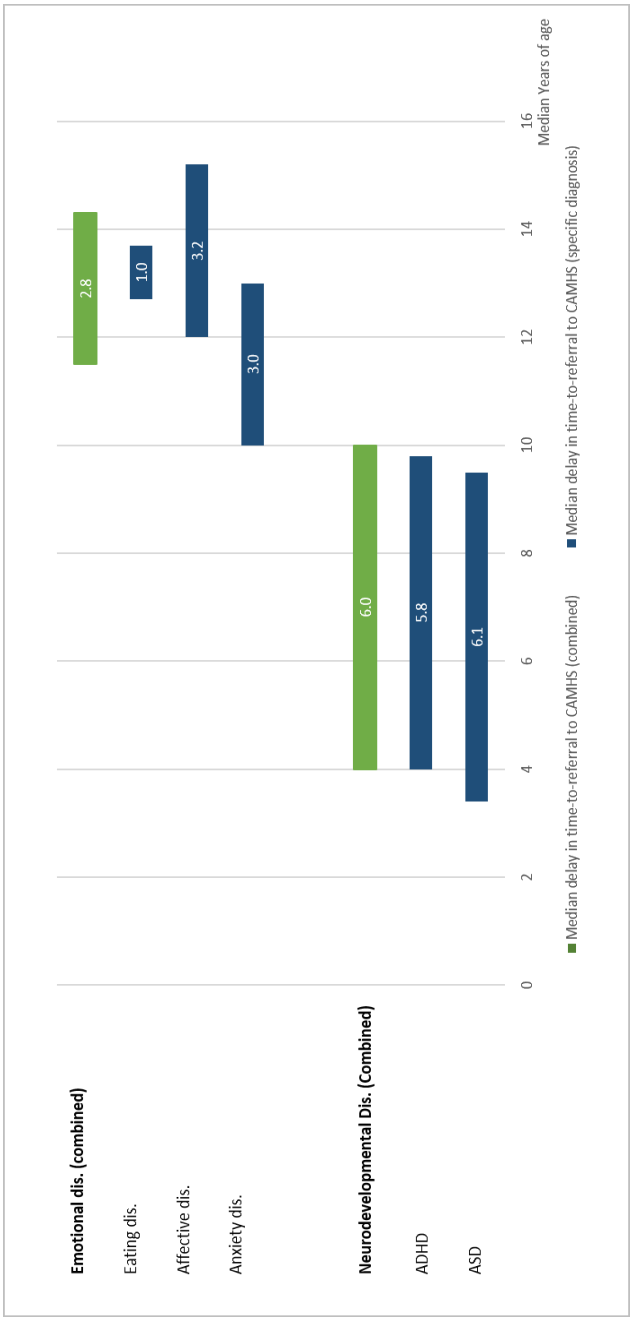
NS = nonsignificant
*Pairwise comparison post-hoc analysis carried out if there were significant differences

4.3. SYMPTOM DURATION PRIOR TO REFERRAL TO CAMHS

More than half (54.1%) of the children referred to CAMHS in Study II+III had parentally recognized mental health problems for more than five years prior to their current referral to CAMHS (Table 4), and only 10.1% were referred within the first year of the parent recognizing the child's symptoms.

Of the 30.4% (n=76) referrals in Study II who had previously been assessed for a mental disorder (Table 2), 81.6 % (n= 62) had previously been assessed by the study center. Delay in time-to-referral depicted in Figure 6 was calculated as the time from first parental recognition of the child's mental health problem until first ever registered referral to the study center. Neurodevelopmental disorders had the earliest median age of parentally recognized mental health problems (ASD 3.4 years (IQR 1.0-7.0), ADHD/ADD 4.0 years (IQR 2.0-6.0)) with symptoms of emotional disorders emerging later in childhood. Compared to children referred for emotional disorders, children referred for neurodevelopmental disorders had a statistical significantly longer delay in time-to-referral to CAMHS (2.8 years (IQR 1.0-6.5) vs. 6.0 years (IQR 3.4-8.5), $p<0.00.1$). There was no statistically significant sex difference in reported age of onset of symptoms ($p=0.99$) or delay in time-to-referral ($p=0.27$) for neurodevelopmental disorders. However, parents reported significantly earlier onset of symptoms (5.0 years (IQR 03.0-10.1) vs. 12.3 years (IQR 8.0-13.8 years), $p<0.001$) and longer delays in time-to-referral (6.8 years (IQR 2.4-8.1) vs. 2.2 years (IQR 0.6-4.6 years) $p=0.002$) for boys referred for emotional disorders compared to girls.

Figure 6: Age-of-onset of mental health problems and delay in time-to-referral to CAMHS (Study II)



*Tics not included in this figure due to small N in the sample.

4.4. HELP-SEEKING PATHWAYS FOR CHILDREN WITH MENTAL DISORDERS

The most common first help-seeking contact was educational services (57.5%), but this differed according to symptom duration. Healthcare services were the most common (40.0%) first help-seeking contact for children referred within the first year of onset of symptoms, whereas only 15.9% of children with mental health symptoms for more than five years initially sought help from healthcare services (Table 4). There was also an association between primary referral reason and first help-seeking contact, with more children referred for neurodevelopmental disorders having educational services as their first help-seeking contact, compared to children referred for emotional disorders (67.2% vs. 44.8%, p=0.03) (Table 4).

Symptom duration was associated with referral source with more children with shorter symptom duration referred by healthcare services (84.0% (<1 year) vs. 60.2% (1-5 years) vs. 48.9% (>5 years), p<0.001) and fewer referred by educational services (≤16 % (<1 year) vs. 28.4% (1-5 years) vs. 42.9% (>5 years), p=0.001) (Table 4).

The majority of families in Study II had been in contact with educational services (94.0% primary, 73.6% specialized), primary healthcare services (81.2%), and social services (56.4% primary, 59.6% specialized) in the two years prior to referral. As seen in Table 4, there were some associations between symptom duration and help-seeking pathways. Longer symptom duration was associated with a higher proportion of families being in contact with specialized educational services (p<0.001) and with social services (p=0.04 for primary and p=0.05 for specialized). Shorter symptom duration was associated with a higher proportion of families being in contact with non-specialized healthcare (p=0.004) and non-specialized MHS (p=0.002) before referral.

Table 4: Help-seeking pathways' association with duration of mental health symptoms (Study II)

	Total sample N=246[a]		Symptom duration <1 year N= 25 (10.1%)		Symptom duration 1-5 years N=88 (35.8%)		Symptom duration >5 years N=133 (54.1%)		P-value
Parent reported SDQ score	N=238		N=24		N=84		N= 130		
Emotional problem, n (% above the norm)	162	(68.1)	16	(66.7)	56	(66.7)	90	(69.2)	**0.92**
Conduct problem, n (% above the norm)	140	(58.8)	8	(33.3)	49	(58.3)	83	(63.8)	**0.02**
Hyperactivity, n (% above the norm)	140	(58.8)	7	(29.2)	46	(54.8)	87	(66.9)	**<0.01**
Peer problem, n (% above the norm)	191	(80.3)	20	(83.3)	70	(83.3)	101	(77.7)	**0.55**
Prosocial, n (% below the norm)	93	(39.2)	≤4	(≤16.7)	37	(44.6)	52	(40.0)	**0.05**
Total difficulties score, n (% above the norm)	206	(86.6)	15	(62.5)	73	(86.9)	118	(90.8)	**<0.01**
SDQ impact score, n (% above the norm)	205	(86.1)	17	(70.8)	71	(84.5)	117	(90.0)	**0.04**
Help-seeking pathways	N=244[b]		N=25		N=87		N=132		
First contact, n (%) *									
- Educational services	141	(57.5)	8	(32.0)	52	(59.8)	81	(61.4)	**0.03**
- Healthcare services	49	(20.0)	10	(40.0)	18	(20.7)	21	(15.9)	**0.03**
- Social services and MHS	21	(8.6)	≤4	(≤16.0)	6	(6.9)	11	(8.3)	0.37
- Other	33	(13.9)	≤4	(≤16.0)	11	(12.6)	19	(14.4)	0.96
Contacts in the previous 2 years	N=246		N=25		N=88		N=133		
Number of sectors contacted for help (mean, SD)	2.9	(0.9)	2.9	(1.0)	3.1	(0.9)	2.9	(0.9)	0.28
Number of sectors the family received specialized services from, mean (SD)	1.9	(1.0)	1.5	(1.1)	2.0	(1.0)	2.0	(0.9)	**0.03**
Educational services, n (%)									
- Primary	235	(94.0)	24	(96.0)	80	(90.9)	127	(95.5)	0.36
- Specialized	184	(73.6)	13	(52.0)	59	(67.1)	112	(84.2)	**<0.001**
Healthcare services, n (%)									
- Primary	203	(81.2)	24	(96.0)	77	(87.5)	98	(73.7)	**<0.01**
- Specialized	49	(19.6)	≤4	(≤16.0)	19	(21.6)	28	(21.1)	0.33
Mental Healthcare Services (MHS), n (%)									
- Primary	27	(10.8)	7	(28.0)	13	(14.8)	7	(5.3)	**<0.01**
- Specialized	89	(35.6)	9	(36.0)	32	(36.7)	47	(35.3)	0.98
Social services, n (%)									
- Primary	141	(56.4)	8	(32.0)	54	(61.4)	75	(56.4)	**0.04**
- Specialized	149	(59.6)	9	(36.0)	56	(63.6)	80	(60.2)	**0.05**
Referral	N=246		N=25		N=88		N=133		
Referral source, n (%)									
- Healthcare Services	141	(56.4)	21	(84.0)	53	(60.2)	65	(48.9)	**<0.001**
- Educational Services	84	(33.6)	≤4	(≤16.0)	25	(28.4)	57	(42.9)	**<0.01**
- MHS or Social services	25	(10.0)	≤4	(≤16.0)	10	(11.4)	11	(8.2)	0.72
Referral diagnosis[c], n (%)									
- Neurodevelopmental	146	(59.4)	5	(20.0)	40	(45.5)	101	(75.9)	**<0.001**
- Emotional	74	(30.4)	17	(68.0)	31	(35.2)	26	(19.6)	**<0.001**

[a]4 missing values when stratified by symptom duration, due to the informant not knowing the age of onset of mental health.
[b]2 missing values for first contact due to the informant not knowing the child at the initiation of help-seeking
[c]9 with both emotional and neurodevelopmental disorders

Help-seeking contacts also differed according to primary referral diagnosis (Table 5). Fewer children referred for a neurodevelopmental disorder had contact with primary healthcare ($p<0.001$), and primary and specialized MHS ($p=0.001$) prior to referral compared to the group referred for an emotional disorder. However, more children referred for a developmental disorder had contact with specialized educational services in the two years prior to referral ($p<0.001$).

The results from the systematic review of the content of referral letters in Study IV (Table 6) cannot be compared directly to the results from the Children's Services Interview in Study II, but they also show significant differences in descriptions of previous support and interventions in the referral letters associated with primary referral diagnoses. Psychosocial interventions aimed at the child were much more frequently described in referrals for emotional disorders (41.2% for affective disorders and 42.0% for anxiety disorder) compared to referrals for neurodevelopmental disorders (18.6% for ASD and 16.9% for ADHD). In contrast description of contact with educational psychologists, part time support teacher in class or enrollment in full time special needs educational programs (specialized educational services) were much more common in referrals for neurodevelopmental disorders than in referrals for emotional disorders. More than one in five (22.7% ASD, 22.0% ADHD/ADD) of referrals for neurodevelopmental disorders mentioned the child being in full time special needs educational programs compared to 12.3% for referrals for anxiety disorders and 7.1% of referrals for affective disorders.

Table 5: Help-seeking pathways' association with referral reason (Study II)

	Neurodevelopmental Disorders		Emotional disorders		P-value
	N 140[a]	%	N 67[a]	%	
Sociodemographic characteristics					
Age, median (IQR)	11.3	(9.0-14.0)	14.6	(13.1-16.6)	<**0.001**
Sex	112	(80.0)	14	(20.9%)	<**0.001**
Psychiatric history					
Referred child previously assessed by CAMHS	39	(27.9)	17	(25.4)	0.74
Parent reported SDQ score (above the norm)	N=134[b]		N=66[b]		
Emotional problem	86	(64.2)	51	(77.3)	0.06
Conduct problem	91	(67.9)	27	(40.9)	<**0.001**
Hyperactivity	98	(73.1)	22	(33.3)	<**0.001**
Social problem	110	(82.1)	54	(81.8)	0.96
Pro social (below the norm)	60	(44.8)	20	(30.3)	**0.02**
Total problem	122	(91.0)	53	(80.3)	**0.04**
SDQ impairment	119	(88.8)	53	(80.3)	0.13
Help-seeking pathways					
First contact	N=137[c]		N=67		
Educational services	92	(67.2)	30	(44.8)	**0.03**
Healthcare services	16	(11.7)	23	(34.3)	**0.03**
Social services and MHS	9	(6.6)	6	(9.0)	0.37
Other	20	(14.6)	8	(11.9)	0.96
Contacts in the previous 2 years	N=140		N=67		
Number of sectors contacted (mean, SD)	2.8	(0.9)	3.1	(0.9)	**0.01**
Number of sectors the family received specialized services from, mean (SD)	2.0	(0.8)	1.8	(1.2)	0.19
Educational services					
Primary	135	(96.4)	62	(92.5)	0.30
Specialized	118	(84.3)	38	(56.7)	<**0.001**
Healthcare services					
Primary	98	(70.0)	67	(100.0)	<**0.001**
Specialized	31	(22.1)	9	(13.4)	0.19
Mental Healthcare Services (MHS)					
Primary	6	(4.3)	14	(20.9)	<**0.01**
Specialized	43	(30.7)	37	(55.2)	<**0.01**
Social services					
Primary	81	(57.9)	32	(47.8)	0.18
Specialized	87	(62.1)	33	(49.3)	0.10
Referral	N=140		N=67		
Referral source					
- Healthcare Services	55	(39.3)	60	(89.6)	<**0.001**
- Educational Services	68	(48.6)	≤4	(≤6.0)	<**0.001**
- MHS or Social services	17	(12.1)	≤4	(≤6.0)	0.22

[a]The 9 participants with both neurodevelopmental- and emotional disorder as referral reason are not included in this analysis. [b]SDQ data missing for 7 participants. [c]3 missing, due to informant not knowing the child at the time of first help-seeking contact (children placed in care).

Table 6: Content of referral letters for the four most common primary referral diagnoses (Study IV)

	Affective disorder		Anxiety disorder		ASD		ADHD/ADD	
	N	%	N	%	N	%	N	%
	255	(14.0)	212	(11.6)	409	(22.4)	509	(27.9%)
Previous support/interventions								
Combined (school, psychosocial and healthcare)	173	(67.8)	159	(75.0)	385	(94.1)	457	(89.8)
In school								
- Extra attention from teacher	16	(6.3)	17	(8.0)	22	(5.4)	35	(6.9)
- Educational psychologist involved	37	(14.5)	41	(19.3)	193	(47.2)	206	(40.5)
- Part time support teacher in class	≤4	(≤1.6)	9	(4.3)	48	(11.7)	62	(12.2)
- Full time special needs education	18	(7.1)	26	(12.3)	93	(22.7)	112	(22.0)
Psychosocial								
- For the child	105	(41.2)	89	(42.0)	76	(18.6)	86	(16.9)
- For the parents	14	(5.5)	10	(4.7)	48	(11.7)	82	(16.1)
- For both the child and parents	5	(2.0)	6	(2.8)	9	(2.2)	18	(3.5)
Healthcare								
- Allied health professionals[a]	4	(1.6)	7	(3.3)	97	(23.7)	73	(14.3)
- Medical doctor	44	(17.3)	55	(25.9)	108	(26.4)	135	(26.5)
Description of cognitive level								
- Academic level	37	(14.5)	39	(18.4)	31	(7.6)	37	(7.3)
- Cognitive testing	11	(4.3)	32	(15.1)	281	(68.7)	321	(63.1)
Impact on schooling								
- Academic problems	12	(4.7)	6	(2.8)	83	(20.3)	138	(27.1)
- Absence on some days	46	(18.0)	37	(17.5)	48	(11.7)	68	(13.4)
- Complete school refusal	34	(13.3)	45	(21.2)	41	(10.0)	19	(3.7)
Self-harm and suicidal ideations								
- Self-harm	20	(7.8)	7	(3.3)	21	(5.1)	25	(4.9)
- Suicidal ideations	105	(41.2)	18	(8.5)	29	(7.1)	26	(5.1)
- Self-harm and suicidal ideations	51	(20.0)	4	(1.9)	9	(2.2)	14	(2.8)

[a]Allied health professionals included physiotherapist, occupational therapist, speech therapists, health visitors and dieticians

4.5. SYMPTOM SEVERITY AT THE TIME OF REFERRAL TO CAMHS

Parent reported SDQ scores at the time of referral were collected in Study II/III and Study V. In total, parent reported SDQ scores were available for 402 children referred to CAMHS. At the time of referral to CAMHS 86.2% (n=270) scored above the norm for total difficulties score and 87.6% (n=352) scored above the norm for the impact score.

As seen in Table 4, there was an association in Study II between symptom duration and parent reported SDQ scores, for several factor scores as well as for the total difficulties score and impact score. Longer symptom duration was associated with higher SDQ total difficulties scores with 62.5% (<1 years) vs. 86.9% (1-5 years) vs 90.8% (>5 years), p=0.003, scoring above the norm as well as a higher proportion scoring above the norm for impact 70.8% (<1 year) vs. 84.5% (1-5 years) vs. 90.0% (<5 years), p=0.04).

4.6. BARRIERS TO ACCESSING SERVICES FOR CHILD MENTAL HEALTH PROBLEMS

In Study III "reluctance to ask for help from professionals" was reported by 41.0% (n=100) of all participating parents. Prominent themes in the thematic analysis relating to this question were difficulties differentiating mental health problems from normal developmental problems and parents needing time to accept that they needed professional help for their child. Some parents expressed that the need to ask professionals for help, made them feel like they had failed as parents.

Figure 7: Percentage of parents reporting barriers to help-seeking for their child's mental health problems (Study III)

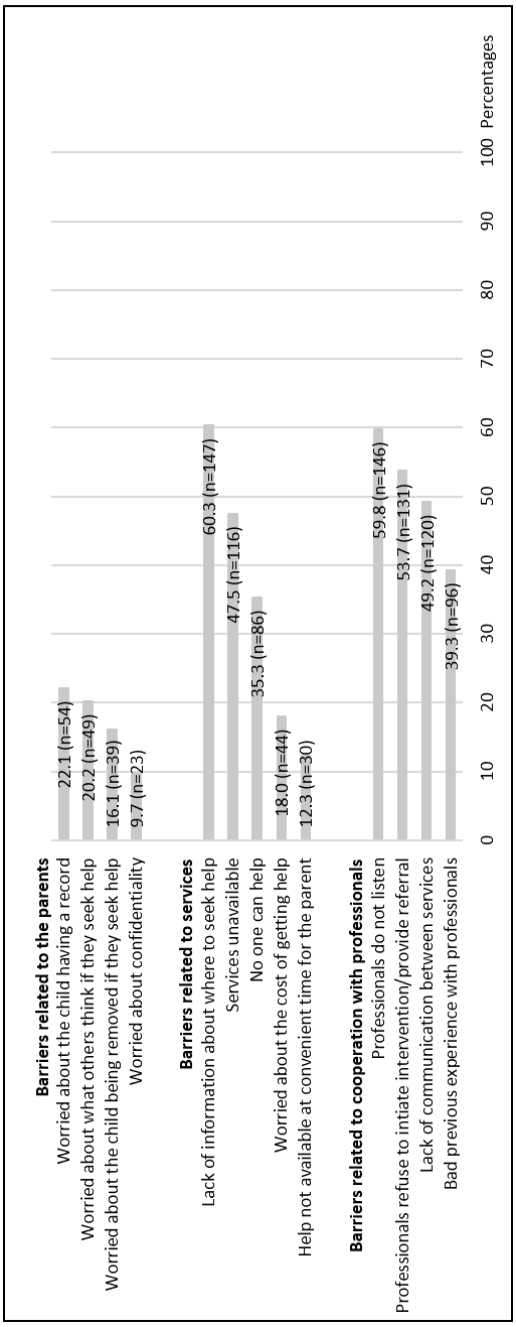


Figure 7 shows the percentage of parents who endorsed specific barriers related to their own worries as well as barriers related to services and cooperation with professionals.

A fifth of the participating parents endorsed the barriers "worried about the child having a record" (n=54, 22.1%) and "worried about what others think if they seek help" (n=49, 20.2%). These concerns were based on worries about the child being labelled and subsequent stigmatization and negative consequences of this stigmatization. Parents also worried that others would judge their parenting skills if they sought professional help.

The most commonly endorsed barrier was "lack of information about where to seek help" (n=147, 60.3%). Parents felt it required a lot of resources from them to navigate the system to find the appropriate help and support. They missed information about who to contact to access help and what their rights were and often felt that services "passed the ball around".

Two barriers related to cooperation with professionals were also reported by the majority of parents namely "professionals do not listen" (n=146, 59.8%) and "professionals refuse to initiate intervention/provide referral" (n=131, 53.7%). Both barriers were reported across service sectors and different groups of professionals. Many parents specified that they felt blamed by professionals for their child's mental health problems and parents often felt like their observations were less valued than observations made by professionals.

Just under half of the interviewed parents reported "lack of communication between services" and "services unavailable" as barriers to accessing services. With regards to lack of communication, one challenge was information getting lost in transition between services. Many parents also reported that a large overturn of professionals involved in their child's case was a barrier, due to insufficient hand-over. There were also challenges related to professionals not having access to information collected by other services (i.e. GPs not having access to information from social services or educational services), leaving the parents with the responsibility of being carriers of information between different services. Unavailability of services was due to long waiting times for some services as well as lack of flexibility from services. Parents also reported access to some services being dependent on previous assessment by CAMHS, but referrals to CAMHS often being rejected.

Table 7: Association between parent reported barriers, symptom duration and parent reported impact (Study III)

	Symptom duration prior to referral[1]						Impact on the SDQ[2]			
	1-5 years			> 5 years			Above the norm			
	Crude		Adjusted	Crude		Adjusted	Crude		Adjusted	
Barriers related to the parents										
Worried about the child having a record	0.63	(0.19-2.02)	0.58 (0.14-2.37)	0.99	(0.34-2.88)	0.96 (0.26-3.49)	2.40	(0.77-7.47)	2.30	(0.70-7.59)
Worried about what others think if they seek help	0.99	(0.30-3.28)	0.70 (0.16-3.08)	0.93	(0.29-2.96)	0.91 (0.23-3.60)	**4.75**	**(1.50-15.06)**	**5.76**	**(1.79-18.48)**
Worried about the child being removed if they seek help	**4.79**	**(1.65-13.90)**	3.06 (0.91-10.28)	**4.85**	**(1.77-13.34)**	**3.32** **(1.03-10.76)**	3.26	(0.88-12.10)	3.08	(0.75-12.59)
Worried about confidentiality	-	-	- -	-	-	- -	**3.83**	**(1.44-10.15)**	**3.57**	**(1.15-11.10)**
Barriers related to services										
Lack of information about where to seek help	**3.44**	**(1.14-10.38)**	**3.35** **(1.03-10.93)**	**4.91**	**(1.64-14.69)**	**4.62** **(1.46-14.62)**	1.41	(0.62-3.17)	1.23	(0.55-2.74)
Services unavailable	1.14	(0.47-2.77)	0.72 (0.25-2.08)	1.42	(0.58-3.47)	1.09 (0.37-3.19)	1.83	(0.81-4.17)	1.81	(0.74-4.42)
No one can help	1.50	(0.55-4.09)	1.19 (0.38-3.70)	1.87	(0.70-4.99)	1.65 (0.49-5.52)	**2.87**	**(1.08-7.65)**	**2.91**	**(1.00-8.42)**
Worried about the cost of getting help	3.07	(0.91-10.35)	2.79 (0.64-12.11)	2.30	(0.68-7.78)	2.26 (0.57-9.83)	1.26	(0.38-4.21)	1.19	(0.38-3.72)
Help not available at convenient time	-	-	- -	-	-	- -	0.71	(0.20-2.49)	0.50	(1.44-1.75)
Barriers related to cooperation with professionals										
Professionals do not listen	**3.97**	**(1.37-11.49)**	2.91 (0.90-9.41)	**4.30**	**(1.44-12.80)**	2.85 (0.99-8.22)	**2.79**	**(1.29-6.06)**	**2.56**	**(1.14-5.72)**
Professionals refuse to initiate intervention/provide referral	1.56	(0.61-3.96)	1.14 (0.34-3.74)	2.52	(0.99-6.37)	1.86 (0.57-6.11)	**2.33**	**(1.03-5.26)**	2.16	(0.92-5.06)
Lack of communication between services	3.07	(0.96-9.85)	2.01 (0.61-6.60)	**3.33**	**(1.12-9.91)**	1.83 (0.56-5.98)	**2.65**	**(1.16-6.06)**	**2.50**	**(1.02-6.14)**
Bad previous experience with professionals	**3.88**	**(1.07-13.98)**	2.83 (0.70-11.48)	**6.11**	**(1.77-21.05)**	**4.78** **(1.17-19.45)**	1.90	(0.82-4.39)	1.62	(0.67-3.93)

[1]Reference: Symptom duration < 1 year;
Adjusted for sex, age, placement outside the home, previous psychiatric assessment, impairment score on SDQ and referral diagnosis
[2] Reference: SDQ impairment score within the norm (80th percentile);
Adjusted for sex, age, placement in care, previous psychiatric assessment, symptom duration and referral diagnosis
- Not possible to calculate OR for "Worried about confidentiality" and "Help not available at convenient time" according to symptom duration

There was no association between the age of the referred child and parent perceived barriers to help-seeking and only the barrier "worried about what others think if they seek help" showed an association with referral reason with an adjusted OR 0.21 (95%CI 0.05-0.88) for emotional disorders compared to neurodevelopmental disorders. As seen in Table 7 longer symptom duration prior to referral was associated with an increased risk of reporting several barriers (worried about the child being removed, lack of information about where to seek help and bad previous experience with professionals). Parent rated SDQ impact score above the norm was associated with an increased risk of reporting "worried about what others think if they seek help", "worried about confidentiality", "no one can help", "professionals do not listen" and "lack of communication between services" (Table 7).

4.7. FACTORS ASSOCIATED WITH REJECTION OF REFERRALS FROM CAMHS

Rejection rates from the study center varied over time. In 2005, 19.4% of all referrals were rejected, compared to 33.9% in 2010 and 24.0% in 2018 (Table 2).

Table 8 shows factors associated with rejection of referrals from CAMHS. Referrals for children placed in care were more likely to be rejected by CAMHS compared to referrals for children living at home (Adj. OR 2.54, 95%CI 1.61-4.00) and referrals from GPs had a 3.29 (95%CI 2.35-4.61) increased risk of being rejected. Several factors were associated with a decreased risk of rejection of referrals by CAMHS. Compared to first time referrals, children who had previously been assessed for a mental disorder had a decreased risk of having their referral rejected (Adj. OR 0.71, 95%CI 0.52-0.98). Being referred by an educational psychologist was also associated with decreased risk of rejection (Adj.0.30, 95%CI 0.21-0.45) as were several primary referral diagnoses. With regards to previous support/interventions described in the referral letter, only part time support teacher (Adj. OR 0.53, 95%CI 0.30-0.95), and healthcare interventions (Adj. OR 0.60, 95%CI 0.37-0.99 for allied health professionals and Adj. OR 0.41, 95%CI 0.18-0.89 for medical doctor) were associated with decreased risk of rejection. Lastly descriptions of previous psychological testing of cognitive level in the referral letter was associated with decreased risk of rejection by CAMHS (Adj. OR 0.34, 95%CI 0.23-0.50).

Table 8: Logistic regression model: Factors associated with rejection of referrals by CAMHS (Study IV)- *continued next page*

	Rejected (unadjusted)		Rejected (adjusted)*	
	OR	**95%CI**	**Adj. OR**	**95%CI**
Living situation				
Lives with parent(s)	Reference		Reference	
Placed in foster care or residential home	2.24	(1.56-3.21)	2.54	(1.61-4.00)
Previous contact for mental health problems				
First time referral	Reference		Reference	
Previously rejected	1.12	(0.81-1.57)	1.23	(0.85-1.78)
Previously assessed	0.74	(0.57-0.96)	0.71	(0.52-0.98)
Referral source				
General practitioner	3.35	(2.65-4.24)	3.29	(2.35-4.61)
Other medical doctor	0.67	(0.45-0.99)	0.64	(0.40-1.02)
Educational psychologists	0.26	(0.20-0.35)	0.30	(0.21-0.45)
Social worker	0.86	(0.54-1.39)	0.81	(0.48-1.38)
Primary referral diagnosis				
Affective disorder	0.54	(0.38-0.77)	0.37	(0.25-0.55)
Anxiety disorder	1.29	(0.94-1.76)	1.00	(0.70-1.45)
Reactions to severe stress and adjustment disorder	0.28	(0.14-0.57)	0.23	(0.11-0.46)
Eating disorder	0.84	(0.50-1.39)	0.52	(0.30-0.90)
Autism spectrum disorder	0.41	(0.31-0.56)	0.54	(0.38-0.76)
ADHD/ADD	0.93	(0.73-1.18)	1.18	(0.90-1.55)
Other	2.12	(1.52-2.94)	1.76	(1.22-2.54)
Previous support/interventions				
In school				
No support	Reference		Reference	
Extra attention from teacher	0.66	(0.41-1.04)	1.18	(0.65-2.15)
Educational psychologist involved	0.53	(0.41-0.68)	0.96	(0.68-1.36)
Part time support teacher in class	0.32	(0.20-0.54)	0.53	(0.30-0.95)
Full time special needs education program	0.50	(0.36-0.68)	0.86	(0.56-1.30)
Psychosocial				
No interventions	Reference		Reference	
For the child	0.61	(0.47-0.80)	0.83	(0.61-1.13)
For the family/parents	0.69	(0.48-0.99)	0.98	(0.65-1.49)
For both the child and the family/parents	0.79	(0.41-1.53)	1.56	(0.75-3.22)
Healthcare				
No support	Reference		Reference	
Allied health professionals	0.48	(0.30-0.77)	0.60	(0.37-0.99)
Medical doctor	0.67	(0.51-0.89)	0.41	(0.18-0.89)
Allied health professionals + medical doctor	0.31	(0.15-0.67)	0.70	(0.51-0.95)

Description of cognitive level of functioning				
None	Reference		Reference	
Cognitive testing	0.31	(0.24-0.40)	0.34	(0.23-0.50)
Impact on schooling				
No description	Reference		Reference	
Academic problems	0.49	(0.35-0.69)	0.81	(0.55-1.18)
Absence on some days	0.72	(0.52-0.98)	0.90	(0.63-1.27)
Complete school refusal	0.55	(0.37-0.82)	0.85	(0.54-1.35)
Self-harm and suicidal ideations				
No description	Reference			
Self-harm without suicidal ideations	1.04	(0.66-1.62)	0.83	(0.50-1.40)
Suicidal ideations	0.69	(0.49-0.98)	0.80	(0.54-1.19)

*Adjusted for age, sex, placement in care, previous contacts for mental health problems, referral source, primary referral diagnosis, previous support/interventions, description of cognitive level, impact on schooling and self-harm/suicidal ideations

Table 8: Logistic regression model: Factors associated with rejection of referrals by CAMHS (Study IV)- *continued from previous page*

4.8. THE EFFECT OF THE DAWBA ON REFERRAL DECISIONS

In Study V the effect on referral decisions by CAMHS of the DAWBA as an adjunct to referral letters was tested in a randomized feasibility trial. At baseline the DAWBA group differed from the SDQ group only with regards to fewer children being placed in care (≤% vs. 11.8%, p=0.03) and statistically significantly fewer having "other" as their primary referral reason (6.0% vs. 17.1%, p=0.04). Most participating parents in the DAWBA group, completed the entire DAWBA interview (90.5%, n=76) whereas only 65.4% (n=40) of participating children≥11 years completed the entire DAWBA interview.

Study V found that almost all (95.9%, n=118) of children referred to CAMHS fulfilled the diagnostic criteria for a mental disorder and 79.7% (n=98) fulfilled criteria for two or more disorders based on the KSADS-COMP interview. This finding was true both for children accepted and rejected by CAMHS. When comparing primary referral diagnosis with KSADS-COMP diagnoses 88.2% of children referred for a neurodevelopmental disorder and 82.9% of children referred for an emotional disorder fulfilled criteria for a matching disorder on the KSADS-COMP.

Combining mental disorder with report of high impact on functioning on the SDQ as a measure for clinical need of assessment, 82.1% of the referred children had a clinical need. The proportion of referrals with one or more mental disorders and high impact did not differ when analyzed by referral source (83.1% for referrals from GPs vs. 80.4% for referrals from other sources, p=0.71)) or by placement in care (77.8% for children placed in care vs. 82.5% for children living at home, p=0.66).

Rejection rates in the DAWBA group were lower than in the SDQ group (21.2% vs. 32.9%, p=0.11) but the difference was not statistically significant. For referrals from GPs specifically there was also no statistically significant difference in rejection rates between the two groups (46.7% (SDQ) vs. 28.3% (DAWBA), p=0.09).

Table 9: Sensitivity, specificity, PPV and NPV for CAMHS referral decisions with and without the DAWBA (Study V)

	Full sample		**Referred from GP**		**Other referral source**	
	SDQ N=58	DAWBA N=65	SDQ N=35	DAWBA N=42	SDQ N=23	DAWBA N=23
Sensitivity	0.63	0.83	0.53	0.76	0.78	0.95
Specificity*	0.30	0.42	0.50	0.50	-	0.14
Positive predictive value	0.81	0.86	0.89	0.87	0.74	0.86
Negative predictive value*	0.14	0.36	0.18	0.33	-	0.50

*Specificity and negative predictive value could not be calculated for referrals from other referral sources

As seen in Table 9 sensitivity for referral decisions by CAMHS showed that in the SDQ group only 63% of those with a clinical need for assessment were accepted compared to 83% in the DAWBA group. When analyzing the result by referral source there were higher sensitivity for the referral decision regardless of referral source in the group randomized to the DAWBA. However, sensitivity for both groups was lower for referrals from GPs compared to referrals from other sources. Specificity of the referral decision was also higher in the DAWBA group compared to the SDQ group, but overall specificity for the referral decision was lower than the sensitivity. PPV for the referral decision was generally high and only marginally higher in the group randomized to the DAWBA. However, for the NPV there were higher values in the DAWBA group than the SDQ group and results indicate that this was mainly due to higher NPV for referrals from GPs when the DAWBA was used as an adjunct to standard referral letters.

CHAPTER 5. DISCUSSION

In order to efficiently plan service provision and tailor child mental health policies to the needs of children with mental health problems there is a need for current knowledge of which children are seen by CAMHS. User involvement in service planning and development has been a focus point in health policies for years[130,131] and when investigating pathways to care to CAMHS it is highly relevant to include perspectives of parents, as they are the main gateway providers for children with mental health problems[34]. Parents are in a unique position to offer insight and valuable perspectives relevant to child mental health service planning, due to their experiences with seeking help for their child's mental health needs[132].

The aim of this thesis was to provide current knowledge on referral patterns to outpatient CAMHS and pathways to care including parental perspectives on barriers to timely access to appropriate services with the aim of providing data to inform future child mental health policies. Child mental health services are multi-agency collaborations involving several service sectors. This reflects the complex needs of families with a child suffering from mental health problems[133]. One cannot investigate service use for CAMHS without considering the organizational context that CAMHS is a part of. The main findings from this PhD project are discussed with this idea in mind. At the end of this chapter, the strengths and limitations of the PhD project are addressed.

5.1. REFERRAL PATTERNS TO OUTPATIENT CAMHS

5.1.1. REFERRAL RATES

Increasing referral rates to outpatient CAMHS have been found across high-income countries in the last decades[5] sparking public debate about the need for preventative initiatives to halt the deteriorating of children's overall mental health[5,134,135]. What is often neglected in this discussion is the fact that less than a third of children with mental disorders in Europe are in contact with specialized services[12]. There is also evidence of poor provision of evidence-based treatment for childhood mental disorders[58,135].

In 2005 only 0.4% of children aged 0-17 years in the catchment area for the study center were referred to assessment by CAMHS[115] and the percentage across all hospital based CAMHS in Denmark was 0.6%[115]. The increase in referral rates from 2005-2018 corresponds to 1.7% of children in the catchment area being referred in 2018, and with almost a quarter (24.0%) being rejected, 1.3% were seen for assessment by the study center in 2018. In a report from 2001, the Danish Health Board estimated that 1-2% of children under 18 would require referral to CAMHS[136]. The same report also concluded that there were no epidemiological data at the time to base the estimates of how many children would require referral to CAMHS on[136].

Following this report, two Danish epidemiological studies in representative population samples have reported prevalence rates for mental disorders in 5-7 year-olds of 5.7%[99] and of 11.8%[137] in 8-9 year-olds. The meta-analysis of world-wide prevalence by Polanczyk et al. from 2015 reported a prevalence of 13.4% for children and adolescents[2] and epidemiological data from the UK from 2017 found a prevalence of 12.8% for 5-19 year-olds[24].
Evidence does not suggest that the current number of children in contact with CAMHS exceeds the number of children with a need for contact with specialty mental health services[2,12]. It is possible that the current referral rates do not reflect an increase in prevalence of childhood mental disorders. They might instead indicate a closing of an existing treatment gap. This could at least partly be explained by a combination of increased public awareness of child mental health problems and an increase in the capacity of CAMHS[5,13,26,28].
When investigating changes in referral patterns to CAMHS it is not only relevant to look at the absolute number of referrals, but also to look at changes in referral patterns.

5.1.2. CHANGES IN REFERRAL PATTERNS

For affective and anxiety disorders there was a decrease in proportion of referrals from 2005-2010 followed by an increase from 2010-2018. For DF80-89 and DF90-98 disorder the opposite was true, with an increase from 2005-2010 followed by a decrease in proportion of referrals from 2010-2018.

Temporal changes in the diagnostic distribution among children referred to CAMHS may be reflective of changes in diagnostic practice[138,139] or changes in the prevalence of childhood mental disorders in the background population. They might also be a result of changing priorities in different sectors and new mental health policies influencing which children are prioritized in referral to specialized services[28]. ICD-10 has been used in Denmark since 1994[139] so any changes in diagnostic practice between 2005-2018 is not a result of changes in diagnostic criteria, but there might have been changes in how the diagnostic criteria are interpreted. To examine for temporal changes in prevalence it is necessary to compare representative population samples using equivalent assessments of mental disorders or symptoms over sufficiently long time periods[5,14]. In addition, the instruments used for assessment must be applied in the same way across the different timepoints. Two recent systematic reviews by Bor et al (2014) and Collishaw (2015) have investigated whether there have in fact been changes in prevalence of childhood mental disorders[5,14]. Following these two reviews NHS digital also published updated data on prevalence and trends in childhood mental disorders from the UK in 2018[24]. Bor et al. did not find any evidence of increasing prevalence of mental health problems in children or of externalizing mental health problems in adolescents, but did find evidence of increasing prevalence of internalizing symptoms in adolescents, particularly for girls[14]. This finding was supported by Collishaw and recent data from NHS digital[5,24]. Thus, the increase in

referral rates for affective and anxiety disorders found in Study I, might in part be explained by an increase in prevalence, but this cannot fully explain this change.

Although changes in diagnostic practice or increasing prevalence of childhood mental disorders might in part explain the temporal changes in referral patterns to CAMHS, changes in public awareness and priorities are probably also a contributing factor. Previous studies investigating changes in referral pattern have found an association between increased media attention and increases in referrals for specific disorders like ADHD[26] and depression[140]. A systematic search of all major daily newspapers in Denmark using the national database www.infomedia.dk for articles on specific childhood mental disorders and childhood mental disorder in general showed a 2.2 times increase in published news articles on childhood mental disorders from 2005-2018. In 2005 almost half (48.7%) of the published articles on specific childhood mental disorders were on ASD, in 2010 ADHD was the most frequently referenced disorder (43.6%) and in 2018 it was anxiety disorders (45.1%) illustrating that the public attention shifts among specific disorders. However, it is not possible to conclude whether increased media attention is a result of improvements in public knowledge or if the media attention itself is a contributing factor in creating an increased public focus. If parents and professionals working with children become increasingly aware of symptoms of a specific disorder, then that might affect referral rates for the specific disorder. This might also apply to gender differences for specific disorders. Although some studies in clinical samples from the Nordic countries have found increasing proportion of girls diagnosed with neurodevelopmental disorders over time[20,21,141] which is in line with the findings from Study I of increasing proportion of girls among referrals for neurodevelopmental disorders, this finding was not replicated in the worldwide review by Fombonne et al. from 2021[23]. Previous research has pointed to these disorders being underdiagnosed in girls[142], and that the increase in referrals might reflect an increased public awareness leading to increased recognition in girls[142,143], but Fombonne et al. also did not find support for the hypothesis of underdiagnosis in girls in their recent review[23]. Public awareness of new treatment options for specific disorders might also affect referral patterns[26,140].

Changes in child mental health policies between 2005-2018 most likely also influenced referral patterns. In 2008 the Danish Health Board reported that waiting times to CAMHS had been steadily rising in the last decade[144]. Long waiting times might deter some professionals from referring children to CAMHS. In 2014 an assessment guarantee was introduced in Denmark for CAMHS[49] giving patients the right to be assessed within 60 days, if the referral was accepted and from 2015 the assessment guarantee was lowered to 30 days. This new national policy has resulted in a lowering of waiting time for CAMHS. In 2005 71.8% of accepted referrals to the study center were seen within 60 days[115], compared to 96% being seen within 30 days in 2018[50]. Another policy change that most likely has influenced referral patterns to CAMHS is the guideline from 2011 regarding pharmacological treatment of childhood mental disorders, which specifies that assessment of indication and

initiation of pharmacological treatment for all childhood mental disorders is a specialist task[145], thus all children that GPs suspect of having a need for psychopharmacological treatment now have to be referred to CAMHS. In December 2017 the Danish National Health Board published disease management programs[146] for childhood mental disorders[43,48,147] which are currently in the process of being implemented, but it is doubtful that they already had an effect on referral patterns to CAMHS in 2018.

5.1.3. RE-REFERRALS

More than a third (37.6%) of referrals in 2018 had previously been assessed for a mental disorder and an additional 9.1% had previously had a referral rejected by the study center. A large proportion of re-referrals (44.0%) were for treatment of an existing disorder, primarily pharmacological treatment of ADHD, but 25% of children referred for assessment of new psychopathology had also previously been assessed. The proportion of re-referral to CAMHS found in this research project is slightly higher, but comparable to previous findings from the UK and Canada which found re-referral rates of 30%[82,148]. Studies investigating in-patient CAMHS have found one-year re-admission rates between 10 and 38%[149–152]. Whereas re-admission rates to inpatient services is frequently used as an indicator of the quality of care[153] less attention has been awarded to investigating if re-referral rates to outpatient CAMHS could reflect quality of services.

Most childhood mental disorders are either ongoing or have high recurrence rates[154]. There is also evidence of heterogeneity in childhood psychopathological development[155] and co-morbidity rates are high for most childhood mental disorders[156]. This could at least partly explain the high proportion of children in need of re-assessment by CAMHS, but there might also be other explanations. When assessing re-admission to inpatient services the time from discharge to re-admission is often taken into consideration[153]. This would probably also be relevant when investigating re-referrals to outpatient services. Re-referral rates within a short timeframe, such as within a year, might to a higher extent be reflective of the quality of services than re-referrals years later. Quicker re-referrals may reflect deficiencies in the initial assessment by CAMHS resulting in misdiagnosis, overlooked co-morbid disorders or failure to realize the severity of the problems causing a need for re-assessment. Re-referral within the first year could also be a result of insufficient follow up by other services following contact with CAMHS. It is perhaps less likely that re-referral years after initial contact with CAMHS reflect the quality of services and these might better be explained by the developmental nature of childhood mental disorders. However later re-referral could still be a result of the child not receiving appropriate help and support from other services following assessment by CAMHS. Currently there is not enough research within this field to determine what proportion of re-referrals could potentially be prevented by improving the quality of service provision.

Based on this PhD project it is not possible to determine the intervals between re-referrals. Reid et al. investigated time between service contacts with community CAMHS and found a median duration between first and second service contact of 638.8 days (SD 377.6)[154] while another study found a median time to renewed contact of 13 months[148]. For in-patient clinical populations demographic, clinical, family and treatment characteristics have been found to predict re-admission[151]. Fontanella found that adolescents discharged to lower levels of care were more likely to be re-admitted[151] and Yampolskaya et al. found that timing of services was crucial in preventing re-admission[152]. The only existing study examining predictors of re-access to out-patient CAMHS found that younger age at first contact, a medium level of care from CAMHS, and high parental burden, was associated with higher odds of re-access to CAMHS[148]. These findings indicate that part of the high re-referral rate may be explained by suboptimal service provision either by CAMHS or by services in primary settings following initial CAMHS assessment.

5.2. HELP-SEEKING PRIOR TO REFERRAL TO CAMHS

When investigating referral patterns to CAMHS, it is also relevant to investigate the help-seeking pathways leading to referral. For children with mental disorders it is relevant to investigate not only if they encounter services but also which services and the timing of service contacts.

5.2.1. HELP-SEEKING CONTACTS PRIOR TO REFERRAL

The findings from this clinical sample that families are in contact with multiple services prior to referral to CAMHS is similar to findings from epidemiological studies from the US and the UK[35,40] as well as clinical samples from Canada[33,157]. This is also in line with the view that help-seeking for childhood mental disorders is not linear[34,36]. The high rates of contacts with different service sectors in the help-seeking process reflect the global impact mental disorders have on children and their families. In the absence of a single coordinating entry point into child mental health services this underscores the importance of good multi-agency collaboration to coordinate care and prevent families from getting lost in transition between services.

Although the majority of families had educational services as their first help-seeking contact in Study II, referrals to CAMHS came predominantly from GPs and educational services only played a prominent part in referrals for neurodevelopmental disorders. Help-seeking patterns might differ within and among countries as a result of differences in the organization of child mental health services and policies. Knowledge of primary help-seeking contacts and primary referral sources is relevant when designing interventions with the purpose of improving early problem recognition or improving the referral process to CAMHS, as these might need to be targeted at different professionals/different services.

There are several potential explanations for educational services playing a very small role in referrals for emotional disorders. It may be that because emotional disorders are less disruptive in the school setting, specialist educational services are less likely to be involved in the care pathway. However, school absent, either partly or completely, is described in a third of all referrals for affective disorders and anxiety disorders, so emotional disorders do often have an impact on functioning in school. Another potential explanation for this referral pattern in a Danish context may be that CAMHS services are more focused on children with neurodevelopmental disorders having a cognitive assessment prior to referral despite this recommendation also being present in the disease management program for emotional disorders[43]. This may make GPs more reluctant to refer children for neurodevelopmental disorders in anticipation of the referral being rejected. It could also reflect parents' preconceptions of where to seek help for different symptoms. Emotional disorders are more common among adults, than neurodevelopmental disorders, and for the adult populations GPs are the gatekeeper to specialized mental health services and this might also lead parents to more frequently consult a GP about referral to CAMHS for childhood emotional disorders. However, educational services were still the most common first help-seeking contact for families of children referred for emotional disorders. The findings from Study II highlight the key role educational services have in parents help-seeking pathway, in line with the family network-based model for help-seeking and lends support to an increased focus on testing and implementing evidence-based interventions for childhood mental health problems in school settings.

5.2.2. DELAY IN TIME-TO-REFERRAL TO CAMHS

Study II showed substantial delays in time-to-referral for almost all primary referral diagnoses, but most pronounced for children referred for neurodevelopmental disorders who had a median delay in time-to-referral of 6 years and only 10.1% of the referred children were referred to CAMHS within the first year of symptoms. Interestingly the delay in time-to-referral was also very long (6.8 years) for boys referred for emotional disorders who also had an earlier median onset of symptoms (5.0 years) compared to girls. These results are in line with previous findings from Canada and the Netherlands[33,60] who also found treatment delays to be most pronounced for disorders with early onset of symptoms. There are several potential explanations for this finding. As highlighted by the family network-based and the Gateway provider model help-seeking for children is dependent upon mental health literacy of key adults like parents and teachers[34]. If key adults do not recognize the child's symptoms as a mental disorder or do not know how or where to seek help, then that will lead to delays in accessing the right services. A review by Hurley et al. found that despite improvements in mental health literacy at the population level the level of parental mental health literacy continues to be inadequate[158]. In Study III 60% of parents reported lack of information on where to seek help as a barrier to help-seeking and there was an association between lack of information on help-seeking and symptom duration prior to referral. In other studies up to 75% of parents have reported

this barrier[72]. This supports the notion that poor mental health literacy plays a role in causing delays in time-to-referral to CAMHS. Studies have also found that teachers, who are often the first help-seeking contact, have limited knowledge of mental disorders and appropriate help-seeking[159,160]. Another challenge is that symptoms that are present from a very early age might be perceived more as a personality trait of the child than as symptoms of a mental disorder[161]. This is in part supported by findings from Study III, where some parents reported that they had been reluctant to ask for help, because they found it hard to differentiate normal development from mental health problems. With 41% of parents in Study III reporting that they had been hesitant to seek help for their child for different reasons, part of the delay in time-to-referral to CAMHS can most likely also be attributed to delays in parents actively seeking help. Another potentially contributing factor is the stepped care approach in child mental health care, which emphasizes that referral to CAMHS should generally be preceded by interventions in primary settings (i.e. schools, social services or primary healthcare) and should only take place if interventions in primary setting do not yield satisfactory improvements in the child's functioning[41,43]. Other barriers encountered by parents in the help-seeking process might also contribute to the delay in time-to-referral for children in need of CAMHS assessment.

5.2.3. BARRIERS TO HELP-SEEKING

Stigmatization of mental disorders continues to be a barrier to help-seeking[72] and for childhood mental disorders the parents also frequently experience stigmatization by association[162,163]. One of the reasons that parents stated for their hesitation to seek help in Study III was that needing professional help for their child made them feel like they had failed as a parent. A fifth of the participating parents also worried about what others would think if they sought professional help. This was both due to worries about stigmatization of the child and stigmatization of the parents themselves. Perceived negative attitudes by others is the most common parentally reported barrier related to concerns about help-seeking[88]. Studies have also shown that there is a higher degree of attribution of parental blame by the public for mental disorders compared to physical disorders in children[164], especially for neurodevelopmental disorders[164]. Parents in Study III also reported feeling blamed by professionals for their child's mental problems when asked about barriers related to cooperation with professionals. Negative experiences with help-seeking, like feeling disrespected by professionals have been shown to be negatively associated with future help-seeking intentions by families[165]. A previous study by Johnson et al. among professionals working in child mental health services (social workers, psychologists and psychiatrist), reported that one in five professionals agreed that the child's mental problems could be attributed to poor parenting and half of the participating professionals agreed to some extent that the child's problems could be attributed to the parent[166]. Parental attribution of blame was less frequently reported by professionals with higher level of training within child mental health[166]. Johnson et al. also found that professionals who assigned responsibility for the child mental health problems to deficient parenting were less

likely to refer the child to services[166]. This was a barrier reported by more than half the parents in Study III. Due to the design of this study, it is not possible to say if there was any association between professionals refusing to provide services or refer a child and attribution of parental responsibility for the child's difficulties. However, if too much focus is given to parenting skills as opposed to the child's mental health problems, then this could contribute to delays in accessing relevant services for the child.

It has previously been reported that the majority of children in contact with CAMHS also receive specialized services from other sectors[167] and this is in line with the findings from Study II. This highlights the need for integration of CAMHS with other forms of specialized care[167]. Although multi-agency collaboration is generally perceived as important and helpful by both professionals and parents[39] several of the barriers reported by the participants in Study III point to challenges with the multi-agency nature of child mental health services in line with previous research[39,168]. Even when parents knew what services were available many found it difficult to navigate the system and know whom to contact when. About half the parents also reported lack of communication between services as a barrier and services being unavailable- both barriers to successful multi-agency collaboration[39,51,169]. Inadequate resourcing, resulting in unavailability of services is the most commonly cited barrier for multi-agency collaboration[39]. Perceived unwillingness from professionals to refer the child to other services could also be a result of lack of resources. It could also stem from legislation and practices within the different service sectors not always being aligned[170] which can be an obstacle for professionals referring a child to specific services. For multi-agency collaboration to work well, it is important for all services involved in the care pathway of a child to possess adequate resources and competencies to provide relevant services within their field and to know when and how to refer a child on to more specialized services. Research has highlighted the importance of good interagency communication and mutual understanding between professionals to succeed with stepped-care multiagency collaboration[168]. Joint training in child mental health for all professionals working within services could contribute to a better understanding between professionals[39,170]. Cooper et al. also suggest that co-location of services and a named link person for families involved with multiple services could improve multi-agency child mental health services for the families using these services[39].

Based on the results from Study III the delay in time-to-referral could be a result of a cumulative delay across all steps of the help-seeking process (problem recognition, deciding to seek help, selecting where to seek help and accessing care) and interventions to minimize the delay could be aimed at all four steps. In relation to the Gateway Provider Model[34], the findings from Study III points to barriers related both to structural characteristics and gateway provider knowledge and perception both with regards to the parents as the primary gateway providers and with regards to professionals in the primary sector acting as gateway providers.

5.3. REFERRAL DECISION PROCESS

Uncertainty about referral criteria[171] and high rejection rates[82] for CAMHS represent another challenge for multi-agency child mental health services as they may deter parents and professionals from referral to CAMHS.

5.3.1. FACTORS ASSOCIATED WITH REJECTION BY CAMHS

In Study IV only three factors were found to be associated with increased risk of a referral being rejected- 1) being placed in care, 2) having "other" as the primary referral diagnosis and 3) being referred by a GP.

Children placed in care have been found to have almost a four-fold higher prevalence of mental disorders compared to the background population[2,172]. A study from Denmark found that half of children placed in care reported mental health problems compared to less than five percent of children not in contact with social services[173]. In their systematic review Kääriälä and Heikki found that as young adults children placed in care had an increased risk of mental health problems, suicidal behavior and higher mortality compared to the general population [174]. This finding emphasized the need to detect and treat mental disorders in this high-risk group. In Denmark only around 1% of children are placed in care[175], but in the systematic review of referrals in Study I, they accounted for 8.2% of all referrals. This is in line with previous findings that more children placed in care are in contact with CAMHS compared to the background population[176]. However, previous research has also shown that a high proportion of children with impairing mental disorders who are placed in care are not in contact with CAMHS[173,176]. In the relatively small study sample in Study V, there were no statistically significant differences in the proportion of referred children places outside the home who fulfilled the criteria for clinical need of assessment by CAMHS compared to children living at home that could explain the higher rejection rate.

The reason that "other" as a primary referral diagnosis was associated with higher rejection rate, could potentially be explained by some of the referral diagnoses included in this category not having a treatment offer within CAMHS in Denmark. While there is no question that children with psychotic experiences are within the target group for CAMHS, attachment disorder and conduct disorder, are typically treated within educational and social services.

The finding that referrals from GPs have a 3 times higher risk of being rejected by CAMHS is in line with previous findings from the UK by Hinrichs et al.[82]. This finding is relevant, because GPs are responsible for most of referrals to CAMHS. The high rejection rates by CAMHS and lack of clarity about the multi-agency organization of child mental health services cause frustration for GPs[85]. Lack of skills, knowledge, tools, time and resources have been identified as barriers for GPs in the

referral process to CAMHS[84] and GPs have expressed a wish for more feedback on referrals from CAMHS[84]. The high rejection rates for referrals from GPs could be due to several issues. GPs might refer children before interventions have been attempted in primary settings in accordance with the stepped care policies[43,48]. GPs are placed on Step 1 in the Danish graduated care model (Figure 2) for child mental health services, as opposed to all other referral sources (educational psychologist, case worker from social services and medical doctors in secondary healthcare services) who are placed on Step 2. Hence all referrals from other sources than GPs indicate previous Step 2 interventions and might therefore be more likely to be accepted by CAMHS in accordance with existing policies. Other issues contributing to the higher rejection rates could be that referrals from GPs do not include sufficient information about the child's symptoms and impairment or that GPs refer children not fulfilling the established criteria of moderate-to-severe mental disorders[82]. Although based on a small study sample, the findings in Study V do not support that GPs refer a higher proportion of children who do not have a clinical need for assessment by CAMHS. The results from Study V do however give an indication that insufficient information in referral letters is part of the explanation for the increased risk of referrals from GPs being rejected. If this is the case, then interventions aimed at increasing the quality of information in referrals should lead to a decrease in rejection rates for referrals from GPs.

5.3.2 APPROPRIATENESS OF REFERRALS TO CAMHS

Generally, the literature pertaining to issues regarding referrals and rejection rates from specialized healthcare services tend to focus on appropriateness of referrals[83] and not on potential inappropriateness of decisions to reject referrals by specialist services. This is relevant because, despite research documenting a high level of agreement between GPs and specialists on the content of referral letters[177], a recent Norwegian survey regarding adults with mental disorders found that there was a lack of shared understanding among two thirds of GPs and specialists regarding which patients should be accepted by specialist mental health services[178]. Appropriateness of referrals is generally assessed by the three dimensions 1) necessity or clinical need, 2) correct destination of referrals and 3) quality of the referral[179]. Discussion of appropriateness of referrals is complicated by several factors. There is no clear definition of when referral to CAMHS is needed[180] and the definition of need is politically influenced by how many resources society allocates to child mental health services and how these resources are allocated. The concept of clinical need is a complex concept of overlapping constructs including symptoms, disease burden, treatment effectiveness, user perspectives and factors related to the overall healthcare system[180–182]. Also there is not sufficient evidence on what the appropriate referral rate should be[183]. Another issue regarding appropriateness of referrals pertains to timeliness. In this regard, rejection of referrals for children with a clinical need for assessment by CAMHS due to poor quality of referral letters could further contribute to delays in accessing appropriate evidence-based assessment and treatment. The

complex nature of assessing appropriateness of referrals might to some extent explain the scarcity of studies investigating interventions aimed at improving the referral process.

5.4. INTERVENTIONS TO IMPROVE THE QUALITY OF REFERRALS TO CAMHS

A Cochrane review examining interventions to improve outpatient referrals to specialist care found that although there is substantial evidence to indicate that the referral process can be improved there is a limited number of studies that have tested interventions to improve appropriateness of outpatient referrals[79]. Several of these interventions only focused on the effect of interventions on the quantity of referrals and not on the quality[79]. The only interventions found to lower referral rates from primary care settings were active local educational interventions involving specialists and structured referral sheets[79]. Within CAMHS specifically there are very limited numbers of studies investigating interventions to improve the quality of referrals[89]. Two small studies have investigated the effect of joint consultation between GPs and either a primary care mental health worker[90] or a CAMHS specialist[89] and they both report that joint consultation resulted in fewer and more adequate referrals.

The intervention with the DAWBA as an adjunct to standard referral letters did not aim at evaluating if the use of the DAWBA would result in fewer referrals but rather if it led to more accurate referral decisions regarding clinical need for assessment being made by CAMHS. In this way it differs from previous studies in the field and to the PhD candidate's knowledge no previous study on improvement of referrals to CAMHS has included a measure of clinical need as a guide for correct referral decisions. The results from Study V indicate that the use of the DAWBA as an adjunct to referral letters mainly leads to fewer children with a clinical need for assessment being rejected, without leading to an increase in the proportion of accepted referrals for children without a clinical need. Thus, the DAWBA could be a useful tool in helping to judge which children should be assessed by CAMHS. However, the reference standard in Study V did not account for the second dimension of appropriateness of referrals since a measure of correct destination was not included in the reference standard. This most likely explains why specificity and NPV of the referral decision measured against the reference standard remained relatively low despite being higher in the DAWBA group compared to the SDQ group. Some children might have an impairing mental disorder, without CAMHS being the most appropriate specialized service to refer to. The DAWBA could potentially also aid in making the decision of appropriate destination for a referral in addition to aiding in assuring the appropriate quality. For the DAWBA to aid with appropriateness of both destination and quality, it would need to be applied earlier in the referral process, prior to a GP (or another referral source) deciding whether to refer a child to CAMHS. If GPs had the opportunity to ask the family of a child consulting on mental health problems to fill out the DAWBA and have it rated by a CAMHS specialist, then the

clinical DAWBA rating could help guide the GP on how to proceed. In case a referral is needed, the information in the DAWBA would contribute to an appropriate quality of the referral. This is essentially a hybrid between the previously tested joint consultations[89,90] between GPs and CAMHS specialists and the intervention tested in Study V and might be more feasible within the current organization of CAMHS in Denmark than physical joint consultations as it is more flexible with regards to time and place and is less time consuming for the CAMHS specialists involved in the intervention.

5.5. IMPLICATIONS FOR CHILD MENTAL HEALTH POLICY AND CLINICAL PRACTICE

Although all five studies in this Ph.D. project were conducted at a single regional CAMHS in Denmark, the findings from the studies overall echo findings from other high-income countries with regards to pathways to care and barriers to accessing services[72]. However, the results should be interpreted with regards to the health care policy system in Denmark and might not be directly applicable to other countries with a different organization of services. Ideally child mental health policy should continuously be evolving based on assessment, political priorities and changes in the knowledge base, including feedback from patients and carers on what works and what does not[184]. The findings from this research project adds to the existing knowledge base on service provision for child mental health problems in Denmark and offers parental perspectives on the functioning of the current system. In the time-period from 2018-2021 national funds have been allocated to test interventions aiming at increasing the availability of consulting CAMHS specialists for primary care services[185] and implementation of graduated disease management programs for specific childhood mental health disorders (ADHD, eating disorders, depression and anxiety) across social services, educational services, primary healthcare and CAMHS[43,48,147]. It will be relevant to assess if these interventions have an effect on the barriers to accessing services identified in Study III, as the interventions may tackle some of the parent perceived problems with the multi-agency nature of child mental health services.

The steep increase in demand for CAMHS services world-wide[5] coupled with well-documented unmet need for mental health services among children[12] has raised the question of whether the role of CAMHS will remain the same in the future[11,186,187]. There is a worldwide shortage of CAMHS specialist[188] and it has been argued that it will be a Herculean task to train enough CAMHS specialist to close the treatment gap[187]. Some of the strategies that have been suggested are a reorientation of CAMHS towards not only playing a part at the final step of the stepped care model, but to increasingly play a part at earlier steps of the care model, by serving as consultants offering a bio-psycho-social perspective on prevention efforts[186,187]. This approach may also help to tackle the issue of high re-referral rates to CAMHS, found in Study I by also providing relevant consultation to primary sector services after initial

CAMHS assessment, which may lead to more effective service provision in the primary sector for children with mental health needs. It could also potentially help to identify children in need of CAMHS assessment at an earlier point, and thereby help to reduce the long delay in time-to-referral found in Study II for those in need of specialized services.

It will also be relevant to focus on developing efficient evidence-based interventions, which can be delivered in primary settings, like schools and social services. One example of such in Denmark, is the recently developed Mind my Mind intervention, which is a transdiagnostic manual based therapeutic intervention delivered by school mental health services[45].

Another strategy could be to focus on implementing new digital health interventions, as a way to minimize the strain on ressources[186,187]. The DAWBA used in Study V, serves as one example of a web-based assessment tool, which could be implemented in clinical practice as an inexpensive and time-efficient aid for assessment of psychopathology[94]. Digital solutions like telepsychiatry and virtual reality are also increasingly being utilized for therapeutic purposes[187].

5.6 STRENGTHS AND LIMITATIONS

One of the main strengths of this research project was that it investigated the full spectrum of children referred to a hospital based CAMHS and as such the findings are applicable to everyday clinical conditions. The systematic review of referral letters allowing more detailed knowledge of referrals than what is possible in studies based solely on administrative data was also a strength.

Delivery of patient centered care is a central goal for healthcare services and including patient perspectives and/or caregivers perspectives on service delivery and organization is highly relevant[189,190] and another strength of this research project.

Also, it was possible to investigate for representativeness of participant in the studies with limited participation rate (Study II, III and V) by comparing the included referrals to all referrals to the study center in 2018. There were only minimal differences with regards to child characteristics and referral characteristics when comparing samples from Study II, III and V to all referrals from 2018 (Study I). Participants in Study II/III differed from all referrals with regards to fewer of the referred children having previously been assessed by CAMHS, fewer being referred by a GP and a higher number being referred by educational psychologists. These three differences are most likely all linked as GPs are more often responsible for re-referrals which are rarely carried out by educational psychologists. The implication of the difference is that the results from Study II and Study III might not fully represent the help-seeking pathways and barriers encountered by families of children with recurrent referrals to CAMHS. Study IV differed from the other studies in that children referred for

treatment of an existing disorder were excluded from the analyses. This explains why this study population differed from all referrals with regards to primary referral reason. A large proportion of re-referrals (44%) were for treatment of an existing disorder, primarily ADHD, and this would explain the lower proportion of referrals for neurodevelopmental disorders in this study population. However, despite minimal differences between study populations with regards to child characteristics and referral characteristics there might still be selection bias in Study II, III and V. As there is no socioeconomic data for the non-participating parents it is not possible to rule out that there could be a selection bias regarding which parents chose to participate. Generally participants in research studies tend to come from higher socioeconomic background than non-participants [191] and if that is the case in these studies, then the results are not necessarily generalizable to children of families from lower socioeconomic background. This is relevant as these children have a two to three times increased risk of developing mental health problems[192]. Although there are no strong associations between economic status and CAMHS service use[193], there might be differences with regards to help-seeking patterns prior to accessing CAMHS and encountered barriers. There may already be an increased focus on these families across sectors due to risk factors associated with lower socioeconomic status, resulting in contact with more services prior to referral. However, there may also be a risk that mental health problems in children from socioeconomically disadvantaged families are more often attributed to social circumstances and therefore overlooked, resulting in parents from lower socioeconomic backgrounds encountering different barriers to help-seeking than families from higher socioeconomic background. An indicator that this could be a problem is the findings of higher odds of rejection for referrals to CAMHS for children placed in care.

For Study II and III specifically it was a strength that the Children's Services Interviews were conducted by interviewers with clinical experience in CAMHS compared to using lay interviewers to ensure that the collected information was correlated to help-seeking for mental health problems. Another strength was that the sample sizes were large enough to allow for subgroup analysis, which provided knowledge on differentiating help-seeking patterns.

In Study V it was a strength that we were able to test the effect of the DAWBA as an adjunct to standard referral letters in a randomized feasibility study using a reference standard based on well-validated instruments (the KSADS and the SDQ). To the PhD candidate's knowledge, this has not previously been done. It was also a strength that all raters of both the DAWBA and the KSADS-COMP had several years of clinical experience in CAMHS.

However, there are a number of limitations to this research project. With regards to study design, four out of five studies were cross-sectional observational studies, and therefore do not allow for the possibility to conclude anything about causality of the findings in the studies but only about associations. Although cross-sectional studies

are placed lower in the hierarchy of evidence pyramid[194] than randomized controlled trials, cohort studies and case-control studies they still play an important role in developing hypotheses for future research[195]. The definition of health service research from the Institute of Medicine from 1995 reads ''Health services research is a multidisciplinary field of inquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes, and effects of health services for individuals and populations''[196]. The cross-sectional studies in this research project provide knowledge on what children are accessing services and their different pathways to care which can inform policies on organization of child mental health services. They also provide more detailed knowledge on rejection patterns from CAMHS, which can help inform future research aiming to minimize inappropriate referrals to CAMHS for children with mental health problems. This could potentially lead to improved timeliness in access to appropriate services for children with mental health problems.

The studies only focused on a clinical population of children referred to outpatient CAMHS. Therefore, it is not possible to deduce anything from the results about service use for the large proportion of children with mental health problems who are not referred to CAMHS[12] nor are the results applicable to children admitted directly to in-patient services. With regards to reported barriers to help-seeking, Sayal et al. (2015) found that non-service users reported similar barriers to service-users, but to a lesser extent[62] and it is therefore plausible that the barriers identified in Study III also applies to help-seeking families who have not been referred to CAMHS.

Another limitation was that study participants for all the studies were recruited from a single CAMHS and therefore might not be representative of referrals to other CAMHS nationally and internationally. The age and sex distribution as well as distribution of referral source and primary referral diagnosis at the study center did not differ largely from the overall distribution of all referrals made to hospital based CAMHS in Denmark[86,115] and was similar to clinical populations from studies on help-seeking and referral patterns from other European countries[26,47,78]. However, across individual CAMHS in Denmark considerable variation in referral source and primary referral diagnoses has been observed[86,115] which might in part reflect differences in resources across municipalities in services in primary care settings. Geographical differences in incidence of diagnosed childhood mental disorders have previously in part been explained by regional differences in accessibility to services[197]. There are also regional differences with regard to the percentage of children that are referred to CAMHS across Denmark[29,109]. As a result, the findings from this research project might not be generalizable to other CAMHS centers. However, the increase over time in the proportion of children referred to CAMHS found in Study I is observed across all regions in Denmark[29,109,115] and internationally[14,22].

It was also a limitation to all studies in this research project that the primary referral diagnoses were not verified CAMHS diagnoses. Previous studies have only found a modest correlation between referral diagnosis and final CAMHS verified diagnoses[140]. Although primary referral diagnosis could not be compared to final diagnosis after CAMHS assessment in this project, broader primary referral diagnosis categories were compared to KSADS-COMP verified diagnoses in Study V. In this study 88.2% of children referred for a neurodevelopmental disorder and 82.9% of children referred for an emotional disorder fulfilled criteria for a matching disorder on the KSADS-COMP. The agreement between referral diagnosis and subsequent KSADS-COMP diagnosis for the broader diagnostic categories found in Study V was higher than the 68% agreement between referral diagnosis and clinical diagnosis previously reported for emotional disorders by Sørensen et al.[140].

The telephone interviews conducted in Study II and III were not recorded and transcribed verbatim, which is a weakness with regards to the thematic analysis of specifications of barriers in Study III. However, it would not have been possible to transcribe interviews from such a high number of informants within the timeframe of this project.

The studies investigating user perspectives only included parents as informants, and it would be relevant to also explore the views of the referred children. It would also be relevant to investigate the views of professionals in primary settings with regards to help-seeking for child mental health problems to get a more complete picture of barriers to efficient service provision.

There were also several limitations to Study V. Firstly the constructed reference standard for correct referral decision, was a simplification and did not account for current Danish child mental health policies stipulating that referral to CAMHS for certain disorders should preferably only take place after relevant interventions in primary settings have been tested. Secondly, due to the tight timeframe and the timing of eligibility for the study, randomization to the two groups had to be done prior to families consenting to participate. Although families were blinded to what group they were randomized to prior to accepting to participate, we cannot rule out that there was some selection bias in what families consented to participation. It was also not possible to blind the clinical raters of the DAWBA or the KSADS-COMP interviews to the randomization. The smaller percentage of children placed in care in the DAWBA group might indicate that completing the more extensive DAWBA interview was a challenge for this group. The timing of the intervention also made it impossible to include the teacher's version of the DAWBA and possibly contributed to the low participation rate. As a result of the low participation rate the sample size for the study was also smaller than intended and this might have affected the statistical power of the study with regards to showing an effect of the DAWBA on rejection rates. It was a limitation to Study V, that a sample size calculation was not conducted prior to the study. However due to the sparsity of literature on interventions aimed at

improving referrals to CAMHS, it was not possible to make accurate assumptions on how large an impact the use of the DABWA would have on CAMHS referral decisions. However, the results from Study V, provide relevant data to base sample size calculations on for a future randomized controlled trial. Assuming that the use of DAWBA as an adjunct to standard referral letters gives a minimum of 15% reduction in rejection rates for referrals from GPs, a future randomized controlled trial with a power of 0.80 and a significant result at the 5% level would require inclusion of 138 participants in each group to show a statistically significant effect of the DAWBA on rejection rates by CAMHS.

CHAPTER 6. CONCLUSIONS

The aim of this research project was to contribute to knowledge on referral patterns to CAMHS and to investigate help-seeking patterns and barriers to accessing timely and appropriate services for children and adolescents referred to CAMHS. The PhD project contributes to the existing international literature by adding new knowledge on care pathways for a clinically referred population in a Scandinavian setting. In addition, this research project is the first to investigate if the use of a web-based diagnostic interview as an adjunct to standard referral letters improves the accuracy of referral decisions made by CAMHS by improving the quality of information available when making the referral decision.

6.1. REFERRAL PATTERNS

Although there has been a steep increase in referral rates to CAMHS in Denmark from 2005-2018, the current referral rates have not exceeded previous estimates of how many children have a clinical need for contact with CAMHS. The results from Study I and IV showed that a high proportion of children with mental disorders have a recurrent need for referral to CAMHS.

GPs were responsible for the majority of referrals to CAMHS, but there was an increase of 9.1% from 2005 to 2018 in the proportion of referrals coming from educational services and in 2018 educational psychologists were responsible for more than a quarter of all referrals to CAMHS. Although neurodevelopmental disorders remained the most common primary referral reason, there was a decrease in the proportions of referrals for neurodevelopmental disorders from 2010-2018. At the same time there was an increase in the proportion of referrals for emotional disorders, most pronounced for anxiety disorders. For neurodevelopmental disorders proportionally more girls were referred in 2018 compared to 2005, but the referral age for the girls was significantly higher than for the boys.

6.2. HELP-SEEKING

Study II found that educational services were the most frequent first help-seeking contact. Educational services played a more prominent part in the help-seeking pathways for children referred for neurodevelopmental disorders. However, more than half of children referred for emotional disorders were also in contact with specialized educational services in the two years prior to referral to CAMHS, yet educational psychologists were only responsible for around 5% of referrals. When investigating service use across education, health care, mental health and social services sectors in the last two years prior to referral, parents reported contact with services from 2.9 different sectors and receiving specialized services from 1.9 sectors. Primary educational services and primary health services were the most common service

contacts, but almost three quarter of the referred children also received specialized educational services, and more than half were in contact with social services.

More than half of children referred to CAMHS had parentally recognized mental health problems for more than five years prior to referral and the delay in time-to-referral to CAMHS was more pronounced for disorders with earlier onset of symptoms. Total difficulties scores and impact scores on the SDQ were associated with symptom duration, with a higher percentage of parents reporting scores above the norm for children with longer symptom duration.

Lack of knowledge of where to seek help and challenges with the multi-agency collaborations of services involved in child mental health appear to be the main barriers to timely access to services for families in need. In addition, dismissive professionals and continuous stigmatization of childhood mental disorders are also important barriers to help-seeking. Parent reported barriers showed little to no association with the age of the child or type of symptoms, but several barriers were more frequently reported by parents of children with longer symptom duration and even more barriers were negatively associated with parent reported impact of the child's symptoms on the SDQ.

6.3. REFERRAL DECISIONS

High rejection rates by CAMHS also pose a barrier to parents help-seeking. In 2018 almost a quarter of referrals at the study center were rejected. Referrals for children placed in care and referrals from GPs were more likely to be rejected. Based on results from Study V the higher rejection rates for these two groups cannot be explained by fewer children among these referrals having a clinical need for assessment by CAMHS.

The intervention in Study V of adding the DAWBA as an adjunct to standard referral letters only tackled the issue of evaluating to what extent rejections by CAMHS were due to insufficient information in the referral letters. The use of the DAWBA resulted in higher sensitivity, specificity, PPV and NPV of the referral decision with regards to which children fulfilled a clinical need for assessment. Thus, it can be concluded that the DAWBA could be a useful aid in judging which referrals have a need for assessment by CAMHS. The use of the DAWBA resulted in fewer referrals being rejected, but the difference compared to the SDQ group was not statistically significant. The continued relatively low specificity and NPV of the referral decision when the DAWBA is used as an adjunct indicate that a substantial proportion of rejections could also be due to CAMHS specialists assessing that CAMHS is not the appropriate destination for the referral. The DAWBA might therefore be even more useful in mitigating inappropriate referrals, if it is utilized in primary settings in consultation with CAMHS, prior to referral decisions being made.

CHAPTER 7. CLINICAL IMPLICATIONS AND FUTURE RESEARCH

The public debate regarding increasing referral rates to CAMHS have tended to focus on the increase in absolute numbers of referrals and how to explain and halt the increase. However, research findings do not indicate that we have exceeded previously estimated need for CAMHS and evidence on what an appropriate referral rate should be is lacking[183]. In addition, unmet need continues to be a well-documented problem[12].

There could be a need to shift the discussion for child mental health care to increased focus on provision of evidence-based treatments by all services involved in graduated child mental health care, systematic evaluation of effects of interventions and appropriate timing of services for children with mental disorders. If children are receiving timely effectful evidence-based treatments in primary care settings, then long delays in time-to-referral to CAMHS should not present a problem as the children are receiving appropriate support in close proximity to their everyday life in accordance with stepped/graduated care models. However, this is not the case for most children with mental disorders[58,198,199] and findings from this research project also support the need to assess the functioning of the current model of care in delivering timely and effectful treatment to children with a clinical need.

The graduated disease management programs for children with mental disorders[43,48,147] published in 2017 by the Danish National Health Board, recommend that referral to CAMHS is preceded by family oriented and social and/or special educational interventions as well as consultation with professionals with specific knowledge of children with special needs. It will be relevant in upcoming years to continuously evaluate what effect this policy has on services involved with child mental health, in order to ensure that adequate knowledge and resources are available in different services involved in the care pathway for children with mental health problems. When evaluating care pathways for children with mental health problems it is important to remember that access to services does not necessarily translate into the need of the child or the family being met. Access to evidence-based treatments should not be delayed by services that do not have a documented effect on severity of symptoms or the child's functioning. Therefore, there is a need for further research on the efficacy of primary setting interventions for children with mental health problems. One potential model for improving interventions in primary settings could be to provide frontline professionals with the opportunity of consulting with CAMHS experts. In Denmark funds have been allocated to test such interventions[185] and the initiated projects are set to conclude at the end of 2021. If they result in improved quality of care for children with mental health problems, it will be relevant to secure funding for their continued implementation.

For referrals for assessment of anxiety disorders[43], depression[43] and ADHD[48] an evaluation of the child's level of cognitive functioning prior to referral is also specifically recommended in the Danish model which often requires access to educational psychologists. In contrast to clear regulations on accepted wait time following referral to specialized healthcare services[49], policies on how quickly families should gain access to specialized services in other sectors are less clear cut and this could contribute to delays in provision of relevant services. To prevent this a political focus on ensuring appropriate resources across services involved in child mental health care as well as on developing appropriate channels for sharing relevant information across service sectors is needed.

Another factor that potentially contributes to delays in timely access to relevant services is that the current disease management programs do not clearly stipulate how or when to evaluate the efficacy of interventions in primary settings or how long it is appropriate to wait before referring a child to CAMHS[43,48,147]. There is currently a lack of evidence of appropriate timeliness of access to different services for children with mental health problems. The median delay in time-to-referral to CAMHS for children with onset of mental health problems in early childhood found in Study II was 6 years and long symptom duration showed an association with severity of symptoms. This is an indicator that there needs to be a clearer focus on optimal timing of referral to more specialized services for children who continue to display symptoms of a mental disorder.

Targeted training in child mental disorders for professionals working with children could help to tackle this issue and might also help to resolve the issue of parental perception of dismissive professionals and parental blame which was found to be a barrier in help-seeking. A way of approaching this could be to increase the availability of consulting child mental health specialists in primary healthcare, educational and social service setting to increase the knowledge base of professionals in these settings. This approach might also help to facilitate better multi-agency collaboration. In designing intervention aimed at improving mental health literacy for professionals in primary setting it is important to remember that the first help-seeking contact is mostly teachers, whereas GPs is the group of professionals most often responsible for referrals to CAMHS, but also that the help-seeking patterns differ according to type and duration of the child's symptoms.

The high re-referral rates to CAMHS also calls for attention from commissioners and policy makers. Based on the data from this PhD project, it is not possible to say if the proportion of re-referrals has increased since 2005, but it would be relevant to investigate how large a percentage of the increase in referral rates can be explained by more children being referred more than once. This could be done using data from the Danish national registries. It would also be relevant to further investigate the reasons for re-referral and the interval between referrals, as some re-referrals might be possible to prevent. This was not possible within this PhD project. In contrast to

the extensive research on predictors of initial service contact, there is a paucity of research investigating predictors of recurrent use of outpatient CAMHS[148]. The high proportion of re-referrals is probably partly explained by the natural history of child mental health problems[155,200]. Both depression and anxiety disorders tend to be episodic with 50-70% of adolescents with depression experiencing another episode within three years[201] while other conditions, such as ADHD, often persist for years[202,203]. However, there is a lack of research on the optimal organization of services for children with repeated need for referral to CAMHS[200]. Research on predictors of in-patient CAMHS re-admission[151,152] as well as the few studies conducted on outpatient services[148,200] suggest that factors related to services and the timing of service provision after contact with CAMHS might be associated with re-referral to outpatient CAMHS. If this is true, then optimization of service provision following initial contact with CAMHS could potentially contribute to lowering referral rates to CAMHS. More research is needed to assess what proportion of recurrent use of CAMHS could potentially be prevented by ensuring timely and relevant services for children following initial diagnosis and what barriers currently exist for children accessing relevant professional support following CAMHS assessment. It is essential that this research includes both user perspectives as well as the perspectives of professionals.

Further research into help-seeking pathways for children following rejection from CAMHS is also warranted. For referrals rejected due to inappropriate destination, we need research on actions taken by the referral source following rejection. and knowledge on the subsequent help-seeking pathways for the families. For children who fulfill criteria for a moderate mental disorder but are rejected due to lack of previously attempted interventions in primary setting, it would be relevant to investigate to what extent interventions in primary setting subsequently remove the need for re-referral and to identify predictors for continued need for assessment of CAMHS.
The results from this research point to referrals for children placed in care having a higher risk of rejection. Due to the design of Study IV it was not possible to determine the reason for the higher rejection rates but it would be relevant for future studies to investigate if this is generally true for CAMHS across different centers and if so, to further investigate the reason behind this finding.

Lastly, the intervention of using the DAWBA as an adjunct to standard referral letters proofed useful in improving CAMHS specialists' ability to correctly identify referrals with a clinical need for assessment by CAMHS. However, it would be relevant to test the use of the DAWBA in conjunction with consultation by CAMHS specialist in aiding GPs decision-making on how to proceed when they see a child with mental health problems in their practice. It is not realistic for GPs to make clinical ratings of the DAWBA in their everyday practice. However, if they had the option of having families complete the DAWBA interview online after a consultation and having the DAWBA rated by a CAMHS specialist who could send written feedback to the GP,

then GPs would have a better foundation for making referral decisions and this could potentially reduce the amount of inappropriate referrals from GPs. In addition to quantitative research on the effect of the intervention it would be relevant to also include qualitative aspects investigating the perspective of both GPs, CAMHS professionals and families on this approach of consultative work by CAMHS. Preparations are currently in place to conduct a trial testing this application of the DAWBA in the referral process in collaboration with researchers within the field of primary health care.

This research has demonstrated a series of current suggestions of challenges to a hardworking system that is dealing with an ever-escalating demand. This calls for an evidence-based challenge to the current organization of services as well as to the components of provision to improve its user face and its effectiveness. This will most likely best be achieved by further research that it co-created with families and professionals across the different service sectors involved in provision of child mental health care services.

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APPENDICES

Appendix A: Ad hoc form for the systematic review of referral letters

Appendix B: The Children's Services Interview (modified)

Appendix A. Ad hoc form for the systematic review of referral letters

Record ID	
Personal identification number (CPR number)	
Is it indicated that the child is placed in care	O Yes O No
Date of referral	
Referral source	O Educational Psychologist O Case worker, social services O General practitioner O Pediatric hospital department O Private practicing medical doctor O Unit for suicide prevention O CAMHS department O Other
Previous diagnoses (as stated on referral)	O DF1X.X Substance use O DF 2X.X Psychosis O DF 3X.X Affective disorder O DF40-42.X Anxiety disorder O DF43.X Reactions to severe stress/adjustment O DF 50.X Eating disorder O DF 51.X Non-organic sleep disorder O DF 60.X Personality disorder O DF 7X.X Mental retardation O DF 84.X Autism spectrum disorder O DF 90.X+DF98.8c Attention deficit disorder O DF91-92 Conduct disorders O DF93.X Emotional disorders onset in childhood O DF94.X Disorders of social functioning O Other O Unknown
If “other”, specify which	
Purpose of referral	O Assessment O Treatment of existing disorder O Not possible to determine

Referral diagnosis (check all relevant)	O DF1X.X Substance use O DF 2X.X Psychosis O DF 3X.X Affective disorder O DF40-42.X Anxiety disorder O DF43.X Reactions to severe stress/adjustment O DF 50.X Eating disorder O DF 51.X Non-organic sleep disorder O DF 60.X Personality disorder O DF 7X.X Mental retardation O DF 84.X Autism spectrum disorder O DF 90.X+DF98.8c Attention deficit disorder O DF91-92 Conduct disorders O DF93.X Emotional disorders onset in childhood O DF94.X Disorders of social functioning O Other O Mental disorder unspecified O No diagnosis indicated
If "other", specify which	

Description of symptoms in the referral

	Specifically described as NOT being a problem	Specifically described as a problem	No information
Emotional problems (headache/stomachache, worried, sad, nervous, scared)	O	O	O
Conduct problems (temper tantrums, oppositional, bullies/gets in fights, lies/cheats, steals)	O	O	O
Inattentiveness problems (restless, hyperactivity, easily distracted, impulsivity, inattentiveness)	O	O	O
Social problems (loner, no good friends, not well-liked, bullied, gets along better with adults)	O	O	O

Descriptions of impact on functioning

	Is NOT described in the referral	Is described in the referral
Bad academic performance	O	O
School absence due to symptoms (missed days, but on average attendance several days a week)	O	O
School refusal (no attendance currently)	O	O

Social difficulties	O	O
High conflict level (with peers, parents or other adults)	O	O
Physical complaints associated with mental health problems (headache, stomachache, eczema from handwash, physical complaints due to low weight, etc)	O	O
Problems with mastering age appropriate activities of daily living (getting dressed, eating, getting to school, etc).	O	O
Bizarre behaviors that influence daily functioning	O	O
Continuous low mood, sadness or low energy affecting daily functioning	O	O
Low self-esteem/negative self-image	O	O
Disturbed sleep	O	O
Other	O	O

Specify “other”

Previous support and help mentioned in the referral letter

	Is NOT described in the referral	Is described in the referral
Special attention and/or special considerations in daycare/school (no extra resources)	O	O
Extra support person in daycare/ school some hours every week	O	O
Full time specials need educational program	O	O
Contact with educational psychologist	O	O
Therapeutic intervention aimed at the child (psychologist or other professional)	O	O

Family intervention (parenting courses, family therapy, support person in the home)	O	O
Respite care	O	O
Foster care	O	O
Residential home	O	O
Treatment by pediatric services (related to referral reason)	O	O
Interventions by general practitioner (not including simply referring to other services)	O	O
Contact with volunteer services	O	O
Other	O	O
Specify “other”		

Referral decision	O Rejected O Outpatient service O Inpatient service O Redirected to private practicing CAMHS
Diagnoses assigned by CAMHS specialist based on referral	O DF1X.X Substance use O DF 2X.X Psychosis O DF 3X.X Affective disorder O DF40-42.X Anxiety disorder O DF43.X Reactions to severe stress/adjustment O DF 50.X Eating disorder O DF 51.X Non-organic sleep disorder O DF 60.X Personality disorder O DF 7X.X Mental retardation O DF 84.X Autism spectrum disorder O DF 90.X+DF98.8c Attention deficit disorder O DF91-92 Conduct disorders O DF93.X Emotional disorders onset in childhood O DF94.X Disorders of social functioning O Other O Unknown

Appendix B. The Children's Services Interview (modified)

Informant

O Mom
O Dad
O Foster mom
O Foster dad
O Other

If other, specify who_____

Section a: semi-structured interview about services accessed

What problems have led to_____(*name of the child*) being referred to CAMHS?

1. For approximately how long has your child had these difficulties? (how old was s/he when they started?)

2. Have these changed a lot during the past 2 years?

If no, continue to question 3.
If yes, would you tell me a little about how s/he was previously?

3a. How old was_____(*name of the child*) the first time you sought help for these problems?

3b. Who did you initially contact to get help for the mentioned mental health problems?

4a**. <u>Over the past 2 years</u>- can you tell me about any help that you have got for these difficulties?**

Prompts:

Over the past 2 years- can you tell me about any help that you have got for these difficulties?
Prompts

- Where did s/he go?
- Who did s/he see?
- What happened there?
- How many times did you or s/he see x?
- How long were these appointments?

- What happened at the appointments?
- Was s/he seen alone or did you or other family members go too (how many for each)?
- Was s/he prescribed drugs for these problems?

4b. **Do you think what _____ did made any difference to him/her or to you as a family?** (ask for each service)
Prompts

- In what way?
- Did they make things worse in anyway?
- How was that?

Section b: perception of services

1. Who suggested/initiated referral to CAMHS?
2. Are you interested in receiving a specific type of help or treatment from CAMHS?

If yes, would you tell be what specific type of help you are hoping to receive?

3. Some parents have told us that they were put off asking for help or advice about their child's emotions, behaviour or concentration, even though they themselves or those around them think that they should. Have you felt reluctant to ask for help for your child?

If yes - can you tell me a bit about how you felt?

4. Have you or your child been offered any help that was unwanted?

if yes – can you tell me a bit about how you felt? (what was offered, why was it unacceptable, what did they do about it -specify child or parent)

I am going to list some reasons that people find it hard to get help for these worries and I want to know if any of them made it harder for you to ask for help or advice?

Present each as "some parents have complained that ------- made it harder to get help, did this bother you**? If yes …**
Can you tell me a bit about it**?**

Obstacle	**Response (yes/no/don't know)**	**Comment**
Lack of information about who can help?		
Services aren't available		
The professionals don't listen		
Professionals refuse to provide service or refer		
Available service unacceptable to parent/child (specify)		
No one can help		
Worries about what people will thing if seek help		
Worry about the child being removed if seek help		
Bad previous experience with professionals (specify)		
Help not available at a time when parents can get to it		
Worry about the costs of getting help (travel and time off)		
Lack of communication within/between agencies involved with your child		
Worry about privacy/ confidentiality		
Worry about the child having a record and how it might affect the future		
Other (specify)		

Section c: Screening for other contacts

Because it is very easy to forget, I am going to finish by screening through a list of places where children and their parents might get help for difficulties with emotions, behaviour and concentration. If you or ---------- have been to one of them over the last 2 years please let me know, otherwise I move onto the next one. And please bear with me as we ask the same screen of everyone and so I am not implying that we think that you ought to have seen any of these people.

SELF-HELP AND VOLUNTARY GROUPS

Over the 2 last years have you contacted any of the following types of support?

Person contacted	**Suggestion**	**Number of contacts**
Telephone		
helpline		
Self help group		
Voluntary agency (specify)		
Internet		
Religious minister		
Record any other categories mentioned		

HEALTH SERVICES

Over the last 2 years have you or your child visited any of the following health services about their_____?

Health service	**Reason**	**Number of contacts**
General practitioner		
Accident and emergency department or out-of-hours services		
Any outpatient clinic? Specify child or adolescent psychiatry, private practicing paediatrician, outpatient clinic at the paediatrics ward		
A private therapist (specify)		
An alternative therapist		
Has _____ had to go to a day hospital or stay in hospital Specify psychiatric/pediatric		
Record any other categories if mentioned		

EDUCATION SERVICES

What kind of school or college does (s)he attend?

Does s/he have any extra help at school? – **If yes** specify (support in class, small group outside class, 1:1 help outside class, special unit or school, and whether from teacher or learning support assistant)

Over the past 2 years has s/he had recognized special educational needs?

Are these special educational needs related to problems with emotions, behaviors or concentration?

Over the past 2 years have you or s/he seen any of the following people because of his/her emotional / behavioral difficulties or concentration?

Professional	**Number of contacts**	**What they did?**	**Since when**
Teachers, including behavioural support teacher			
Social worker associated with the School			
Student counsellor/youth guidance counsellor			
Learning support teacher or resource teacher			
Educational psychologist			
School nurse/doctor			
Other			

SOCIAL SERVICES

Over the past 2 years has there been any involvement with social services due to his/her difficulties with
emotions, behaviour or concentration?

If yes, what kind of involvement?

Services to prompt for	**Reason**	**Number of contacts**
Allocated social worker		
Respite care (specify)		
Temporary foster care		

Long term foster care		
Therapeutic community		
Individual or family-based treatment (specify)		
Substance abuse treatment		
§50 child assessment		
Involuntary placement outside the home (note only if mentioned)		
Other		

LEGAL SYSTEM

9a. Has s/he been in contact with the police or the legal system within the past 2 years?

If no - End of interview
b. If yes - was this related to his/her_____?
If no - End of interview
c. If yes, what did it involve?

Contacts to prompt for	**Reason**	**Number of contacts**
Contact with the police		
Criminal charges		
Social services involved		
Placement in open institution		
Placement in secured institution		
Other		

Thank you very much for your help.

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