UiT The Arctic University of Norway

Faculty of Health Sciences

Functionally impaired children and their caregivers:

A study in a clinical neuropaediatric setting on validity and usefulness of screening instruments completed by caregivers, and caregivers' satisfaction with neuropaediatric assessment

Katarina Maria Smejda Kjærandsen

A dissertation for the degree of Philosophiae Doctor, Mai 2024

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Acknowledgements

First, I would like to thank my supervisor Dr. Per Håkan Brøndbo and co-supervisor Dr. Marianne Berg Halvorsen, for their input, suggestions, critical comments, and advice.
I want to thank Bjørn Helge Handegård for his support and patience in explaining statistical methods.

I appreciate all the help I have received from Prof. Monica Martinussen, who was always available and supportive, and gave me thoughtful comments.

I want to thank the neuropaediatric clinics at the Finnmark Hospital Trust in Hammerfest and University Hospital of North Norway in Tromsø for collecting data, and the patients and their families who contributed to the data collection.

Finally, I want to thank the Regional Centre for Child and Youth Mental Health and Child Welfare – North at UiT, The Arctic University of Norway in Tromsø, and the Northern Norway Regional Health Authority for financing my PhD project.

My thesis uses data that was already collected during the prosject: “Mental health and cognitive function: A multi-center study in neuropediatric clinics in Northern Norway” (grant number PFP1178-14; with Dr. Marianne Berg Halvorsen as post doc/project manager). This original research study was funded by The Norwegian Directorate of Health and the Regional Center for Child and Youth Mental Health and Child Welfare North at UiT The Arctic University of Norway in Tromsø.

Summary

This dissertation is based on a naturalistic multicentre study in the context of an interdisciplinary assessment in neuropediatric clinics. The general objective of this study was to broaden our knowledge about this assessment, focusing mainly on the role of screening instruments completed by caregivers and their satisfaction with the assessment. Following this general objective, three articles were written.

The validity and usefulness of the Everyday Feeling Questionnaire (EFQ) as a screening instrument for parental mental health, and the Impact supplement of the Strength and Difficulties Questionnaire (SDQ impact) in measuring functional impairment, were assessed. In addition, parental satisfaction and experiences with the assessment were measured using a short generic survey.

A particular focus was on parental mental health, as many previous studies have highlighted distress in parents of children with neurodevelopmental disorders. The results showed that the EFQ can be used to assess parental distress, and that parental distress was significantly related to the child's parentally evaluated functional impairment and continuous measures of symptoms, not necessarily diagnoses of neurodevelopmental disorders. An unexpected but interesting result was that parents of the patients in Norwegian neuropaediatric clinics scored no more distress/mental health problems on average than the general adult population.

Parentally evaluated SDQ impact was shown to be a sensitive tool in discovering general functional impairment in children with attention-deficit/hyperactivity disorder and autism spectrum disorder. In this severely functionally impaired neuropaediatric population, it was impossible to specify which diagnoses/symptoms caused functional impairment. However, the SDQ impact proved to be an easy-to-use tool, and the overall study results indicated that it was partly valid. Overall, as assessed by parents, the child's functional impairment was a good indicator of clinical significance and the child's symptoms, and was related to parental distress.

The conclusion about parental experiences with the assessment was that they were more satisfied when an assessment was suited to the child's situation, when they experienced good cooperation with other public services such as social/educational

services and primary health care, and when they were given adequate information about the child's diagnosis, in accordance with earlier studies on this field.

The overall conclusion was that screening instruments filled out by caregivers were valid and useful for screening in the neuropaediatric patient population. In fact, parents have an indispensable role in assessing child's problems and their opinions should be actively used to improve health service delivery.

List of papers

I. Kjaerandsen, K. S., Handegård, B. H., Brøndbo, P. H., & Halvorsen, M. B. (2021). Parental mental health screening in a neuropaediatric sample: Psychometric properties of the Everyday Feeling Questionnaire and variables associated with parental mental health. *Journal of applied research in intellectual disabilities: JARID*, *34*(2), 648–658. https://doi.org/10.1111/jar.12834

II. Kjærandsen, K.S., Handegård, B.H., Brøndbo, P.H., Halvorsen, M. (2023). Impact supplement of the Strengths and Difficulties Questionnaire in the assessment of functional impairment in children with ADHD or ASD: A partial validation study. *Journal of Mental Health Research in Intellectual Disabilities*, 16(1), 1-22. https://doi.org/10.1080/19315864.2022.2148788

III. Kjærandsen, K.S., Brøndbo, P.H., Halvorsen, M. (2021). Determinants of parental satisfaction with child neurodevelopmental assessment in neuropediatric clinics. *BMC Health Services Research*, 21, 139. https://doi.org/10.1186/s12913-021-06153-5

Abbreviations

ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism Spectrum Disorder
CAMHS	The Child and Adolescent Mental Health Services
CFI	The comparative fit index
CGAS	Child Global Assessment Scale
DAWBA	Development and Well-being Assessment
DSM	The Diagnostic and Statistical Manual of Mental Disorders
EFQ	The Everyday Feeling Questionnaire
GP	General practitioner
GS-PEQ	The Generic Short Patient Experiences Questionnaire
ID	Intellectual Disability
RMSEA	The root mean square error of approximation
SD	Standard deviation
SDQ	The Strengths and Difficulties Questionnaire
SES	Socioeconomic situation/status
TLI	The incremental fit index of Tucker and Lewis

Table of Contents

1. Introduction

1.1 Background of the thesis

This thesis is a part of a regional multi-centre study of «Mental health and cognitive function: A multi-center study in neuropediatric clinics in Northern Norway» carried out at two neuropaediatric clinics [in Norwegian: Habilitering for barn og unge] in Tromsø and Hammerfest that come under the specialist health service. The overall aim of this study was to provide new knowledge about the assessment and diagnosing of mental health problems in children and adolescents with complex cognitive difficulties, as this kind of research was lacking in the field of neuropaediatrics (Halvorsen et al., 2014).

«Action Plan for neuropaediatric patients» (The Norwegian Directorate of Health, 2009) pointed out that users should receive services of a high professional quality. This requires that the neuropaediatric services systematise their experiences and knowledge, ensuring that these are not only research-based but also based on users' experiences. In neuropaediatrics, both children and their parents play key roles in the treatment process, making parents essential partners. Therefore, understanding parents' experiences is vital for ensuring the quality of services provided to children and young people who require neuropaediatric care. Moreover, this understanding allows for the guidance given to parents, regarding caring for their child in daily life, to be better tailored to meet their specific needs. The thesis is also concerned with being able to screen parents' mental health and children's impairment more quickly and effectively in advance of a more extensive investigation.

1.2 Neuropaediatric clinics in Norway and the patient population

Neuropaediatrics, also called paediatric rehabilitation (Kaufman et al., 2017), is a complex field within somatic or mental health specialist services with patients having complex difficulties in the intersection of somatics, including neurology, and psychiatry (The Norwegian Directorate of Health, 2009). All health trusts in Norway

have such clinics for patients between 0 and 18 years in need of specialised health care due to conditions listed in Table 1 (The Norwegian Directorate of Health, 2015).

Target patient groups for the neuropaediatric clinics in Norway are children with congenital or early-acquired disabilities (e.g. epilepsy or cerebral palsy), syndrome conditions with impairment, neurodevelopmental disorders [NDD] (e.g. ASD), developmental delays, intellectual and developmental disabilities. The various health trusts differ with regard to neuropaediatrics and mental health care for children and youths. This applies to the responsibility for assessment, diagnosing and treatment, especially for children and adolescents with autism spectrum disorders [ASD] and children and adolescents in the neuropaediatrics target group with attention deficit/hyperactivity disorder [ADHD] as a comorbid condition (The Norwegian Directorate of Health, 2015).

Table 1. *Conditions qualifying for referral to neuropaediatric clinics in Norway.*

Acquired brain injury
Delayed development/delay in cognitive function
Pervasive developmental disorder / ASD - suspicion
Extensive behavioural difficulties in the target group
Extensive communication and language difficulties in the target group
Extensive motor developmental delay/disturbance - suspected or detected
Extensive and complex eating/nutrition difficulties in the target group
Extensive difficulties related to puberty, sexuality and identity in the target group
Progressive diseases of the brain, nervous system or muscles - suspected
Syndromes affecting function and development - suspected or detected

Note. Information obtained from The Norwegian Directorate of Health (2015).

The patient and the family are offered an interdisciplinary assessment, diagnostics, and follow-up carried out by paediatricians specialising in neurology, psychologists and neuropsychologists, special education therapists and

physiotherapists. In addition, neuropaediatric clinics collaborate *inter alia* with other specialist health services, general practitioners [GPs], municipal health and care services, kindergartens, schools, and educational psychology service (The Norwegian Directorate of Health, 2020).

Around 1% of the Norwegian child population is offered evaluation or treatment in neuropaediatric outpatient clinics every year (The Norwegian Directorate of Health, 2016, p.163). Data from 2015 (The Norwegian Directorate of Health, 2016) about patients in neuropaediatric clinics in Norway showed that the two most common main diagnoses in this patient population were ASD (15%) and cerebral palsy (13%). Other diagnoses included Asperger's syndrome (separately from autism), mild ID or hyperkinetic disorders/ADHD, Down syndrome and epilepsy, affecting between 3% and 4% of the patients. Unfortunately, detailed knowledge about all the diagnostic groups and characteristics of the patients in the respective regional neuropaediatric clinics is unavailable. This is due to diverse organisations, employees, patient groups and different methods of registering both appointments and diagnoses (The Norwegian Directorate of Health, 2009).

A high degree of comorbidity between these various disorders is well-described in the literature (Gillberg, 2010; Gillberg et al., 2004; Gillberg & Neville, 2010; Taylor, 2010; Turk, 2010; more about this subject in chapter 1.3.2). In addition, a significant proportion of the patient population in neuropaediatric clinics has weakened cognitive abilities that are associated with an increased risk of developing mental health problems (Emerson, 2003a; Einfeld et al., 2011; Linna et al., 1999; Whitaker & Read, 2006; more about this subject in chapter 1.3.3).

The symptom picture in neuropaediatric patients is often complex, and it requires a thorough and interdisciplinary assessment from a developmental perspective, particularly with regard to cognition, motor skills, language/communication and severe behavioural difficulties. Furthermore, the health conditions in these patients can affect their life quality, as well as their interaction with family and other networks. Therefore, their health condition should be clarified as early as possible, and relevant interventions and help should be initiated for both the child and the family (The Norwegian Directorate of Health, 2015, 2020).

1.3 Neurodevelopmental disorders

1.3.1 Definition and classification

The term "neurodevelopmental disorders" [NDD] had a long history (Bishop & Rutter, 2008) before it was officially included as a separate category in both DSM-5 (American Psychiatric Association [APA], 2013) and the ICD-11 (World Health Organisation [WHO], 2022) classification systems (Table 2). The range of developmental deficits in NDDs varies from specific limitations to control of executive functions or learning to global impairments of social skills or intelligence (APA, 2013). The narrowest concept of NDD comprises specific psychological development disorders (e.g., disorders involving language development, scholastic skills, or motor function) presented by the second axis of the ICD-10 classification (WHO, 2010). These disorders are characterised by (1) onset during infancy or childhood, (2) impairment or delay in the development of functions strongly related to biological maturation of the central nervous system, and (3) a steady course without remissions and relapses, unlike many mental disorders that are more episodic (WHO, 2010).

The term neurodevelopmental was also applied to a broader group of disabilities involving some form of brain development disruption, such as single-gene disorders or disorders having their origin in prenatal insults (Gathercole & Alloway, 2006; Thapar et al., 2017). These disorders are defined in terms of aetiology. In this way they belong to a different class than specific disorders of psychological development, which are defined in terms of specific impairments of linguistic, scholastic and motor skills and have a putative multifactorial aetiology (Bishop & Rutter, 2008; Thapar et al., 2017).

ASD and ADHD belong to the NDD category primarily due to these disorders having a multifactorial aetiology, and are characterised by both abnormal and impaired functioning, which are present from the early stage of life, and tend to improve with increasing age. Males have an overrepresentation of these disorders. Finally, both are characterised by neuropsychological impairments in some aspects of executive function in ADHD, and in social cognition, central coherence and executive function in ASD (Bishop & Rutter, 2008).

When diagnosing NDDs, as with psychiatric disorders, one has to fulfil certain criteria including specific symptoms, and significant distress or functional impairment (APA, 2013). In the current study, DSM-IV (APA, 1994; APA, 2010) and ICD-10

(WHO, 2010) classification systems were applied, as the Norwegian health care system still uses ICD-10. However, NDDs are classified into separate categories in the most recent diagnostic classification systems DSM-5 (APA, 2013) and ICD-11 (WHO, 2022).

Table 2: *Major categories of neurodevelopmental disorders in the most recent classification systems: DSM-5 (APA, 2013) and ICD-11 (WHO, 2022).*

Neurodevelopmental disorders, main categories	
DSM-5	**ICD-11**
Intellectual Disabilities	Disorders of intellectual development
Autism Spectrum Disorder	Autism spectrum disorder
Attention-Deficit/Hyperactivity Disorder	Attention deficit hyperactivity disorder
Specific Learning Disorder	Developmental learning disorder
Communication Disorders	Developmental speech or language disorders
Motor Disorders	Developmental motor coordination disorder Stereotyped movement disorder Primary tics or tic disorders

1.3.2 Coexisting neurodevelopmental disorders

The focus on comorbidities between NDDs implies that there are some morbid conditions. However, some researchers emphasised the importance of using other terms, such as coexistence/coexisting disorders and problems (Gillberg, 2010; Gillberg et el., 2004) or co-occurrence (so-called concurrent comorbidity, Angold et al., 1999a; Kaplan et al., 2006; Thapar & Rutter, 2015) to express high overlapping rates known to exist between NDDs (Carlsson et al., 2013; Gillberg, 2010; Gillberg et al., 2004; Gillberg et al., 2013; Gillberg & Neville, 2010; Gilger & Kaplan, 2001; Kaplan et al. , 2001; Kantzer et al., 2018; Taylor, 2010; Turk, 2010). For example, among children with NDD who were referred to mental health services, around 22% had another NDD (Hansen et al., 2018). ADHD and ASD are the most commonly registered co-occuring conditions to intellectual disability [ID] in clinical studies (Strømme & Diseth, 2000). These disorders also coexist with ID in population-based studies (Dykens, 2000; Emerson, 2003a). In a study by Bryson et al., (2008), 28% of children with ID had co-occuring autism. In a meta-analysis (Buckley et al., 2020) based on 19 studies, the mean percentage was 30% of children and adolescents with ID who also had ADHD. Children with ASD often have problems with hyperactivity (Maskey et al., 2013), and in a study on children with ASD for co-occurring psychiatric diagnoses, over half of the sample met the criteria for ADHD (Salazar et al., 2015).

A full-blown or sub-threshold condition coexisting with a NDD can worsen functional impairment and treatment and can be confusing both in research and clinical practice (Thapar & Rutter, 2015). Children with coexisting NDDs, unlike those with a single NDD, have different cognitive and adaptive skills profiles. For example, ADHD coexisting with ID increases the impairment of some cognitive skills in children with ID (Di Nuovo & Buono, 2007).

Gillberg (2010) coined the acronym ESSENCE from Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examination to emphasise the complexity of NDDs and the coexistence of, *inter alia,* ADHD, ASD, oppositional disorder, and tic disorder. As Rutter et al. (1970) or Gillberg et al. (2014) noticed, these children usually have complex, impairing developmental symptoms already in early childhood in the areas of general development and specific fields such as

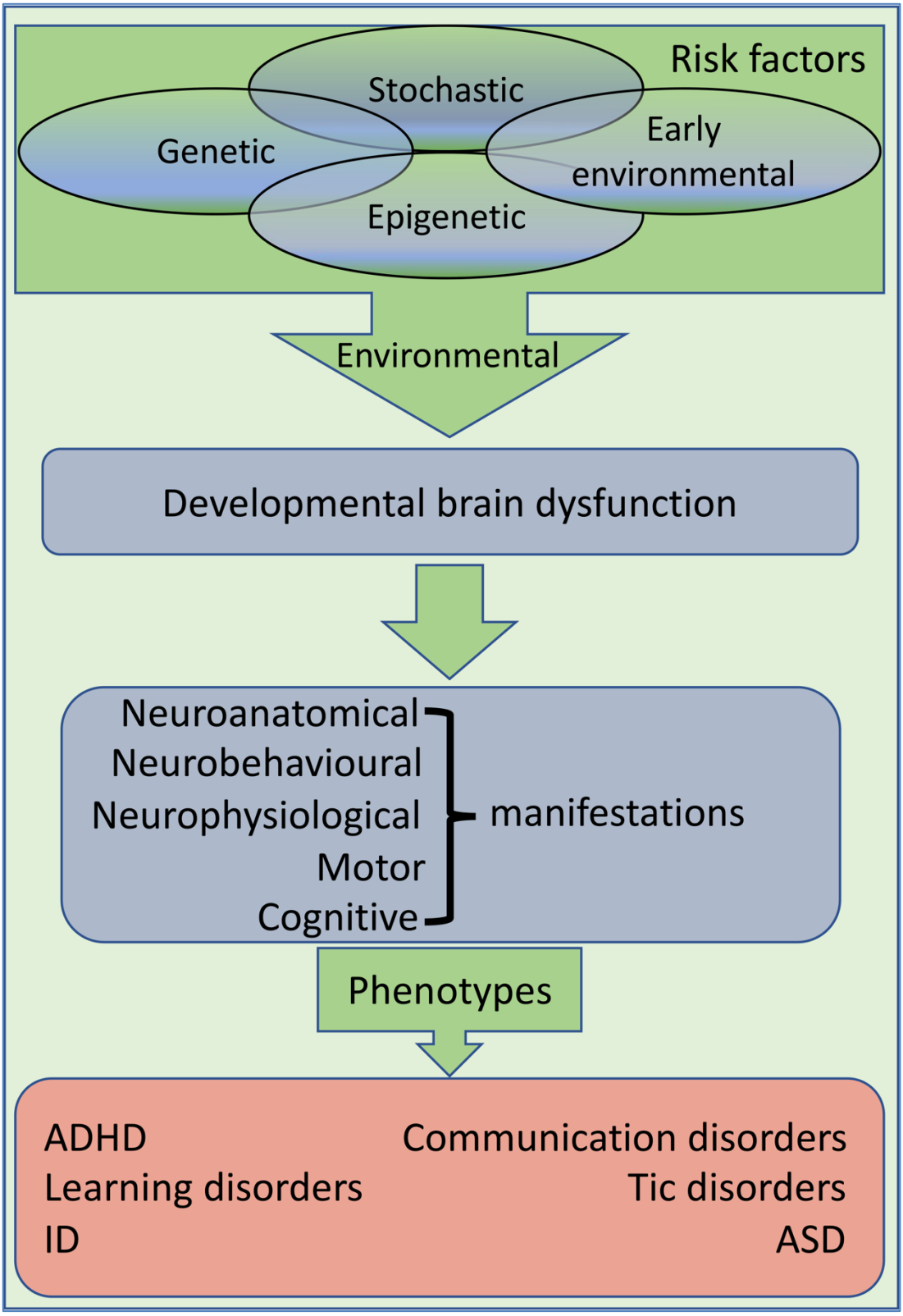

Figure 1. *Model illustrating potential contributions to the overlap between neurodevelopmental disorders. The model is based on models proposed by Thapar and Rutter (2015), and Moreno-De-Luca et al. (2013).*

communication and language, social interactions, motor coordination, attention, activity, behaviour, mood and sleep.

The observed coexistence between different NDDs can result from shared genetic, early environmental (e.g. teratogenic, traumatic), epigenetic (e.g. caused by maternal undernutrition, prenatal stress, early deprivation/neglect), and stochastic risk factors, which interact with later environmental factors. Together these can result in developmental brain dysfunction showing diverse cognitive (e.g., intelligence quotient [IQ], language, memory), motor (e.g. coordination), neurobehavioural (e.g., problems with attention, impulse control, social reciprocity, aggression), and neuroanatomical/neurophysiological manifestations (e.g. structural abnormalities, seizures) that form some phenotypical patterns identified as NDD diagnoses (Meaney & O'Donnell, 2015; Moreno-De-Luca et al., 2013; Thapar & Rutter, 2015; see Figure 1).

1.3.3 Mental health difficulties in children with neurodevelopmental disorders

A specific subject in studies on neurodevelopmental and neurological disorders includes mental health problems in persons diagnosed with/or having symptoms of NDDs. An extensive amount of literature highlights that NDDs coexist with some mental health problems more often in this group than in the general population.

Having an ID is associated with an increased risk of developing mental health problems (Buckley et al., 2020; Emerson, 2003a; Einfeld et al., 2011; Linna et al., 1999; Whitaker & Read, 2006). Research indicates a significant prevalence of mental health disorders among young patients with ID or special educational needs, ranging between 30% and 50% (Dekker & Koot, 2003a; Emerson, 2003a; Einfeld & Tonge, 1996; Einfeld et al., 2011; Emerson & Hatton, 2007; Linna et al., 1999; Strømme & Diseth, 2000; Tonge & Einfeld, 2003). This is notably higher compared to the general child population in Europe, where the prevalence is estimated to be between 7% and 10% (Emerson, 2003a; Emerson & Hatton, 2007; Ford et al., 2003; Heiervang et al., 2007; Linna et al., 1999; Wichstrøm et al., 2012). Furthermore, the worldwide prevalence of mental disorders among children stands at approximately 13.4% (Polanczyk et al., 2015). Children with ID, developmental delays, or borderline

intellectual functioning (i.e. with IQ between 70 and 85) have also higher rates of dimensionally-measured total difficulties or difficulties in special areas (i.e. emotional symptoms, conduct problems, hyperactivity/inattention or peer problems) compared to typically-developing children (Baker et al., 2002; Bjorgaas et al., 2013; Dekker et al., 2002; Emerson et al., 2010; Goodman et al., 2007; Kaptein et al.,2008).

Generally, children with NDDs have the same types of mental health problem as children in the general population (Einfeld & Emerson, 2008; Szymanski, 2009). However, those with milder delay/mild ID may be more likely to have disruptive and emotional disorders than the general child population. Those with more severe delay/severe ID may have higher rates of severe and pervasive disorders such as hyperactivity and autism with more symptoms of stereotypy, self-harm and social isolation (Chadwick et al., 2005; Dykens, 2000; Scott, 2002; Witwer & Lecavalier; 2008). Presentation of mental health problems in persons with severe ID can be challenging to determine (Scott, 2002), particularly where there are severe communication limitations and problems with expressing pain or discomfort (Tang et al., 2008).

The prevalence rates of specific psychopathology in children with ID depend on the population studied and the kind of instruments or procedures used for the assessment. For example, diagnoses taken from medical records in clinics or hospitals can result in elevated rates in relation to non-referred (e.g. population-based or community) samples (Buckley et al., 2020; Dykens, 2000; Reardon et al., 2015). Rojahn and Meier (2009) listed possible reasons for variations in reported prevalences of coexisting mental health problems in individuals with ID, such as uncertainty related to definitions and classifications of some psychiatric disorders in those individuals, their limited capacity to understand and report thoughts, feelings and experiences, and diverse samples and screening instruments used across the studies.

NDDs such as ADHD and ASD also have a high risk of coexisting emotional and behavioural problems (Hansen et al., 2018; Kopp & Gillberg, 2003). Several studies have found an elevated incidence of mental health problems in persons with ID and concomitant ASD, compared to persons with ID alone (Bakken et al., 2010; Bradley et al., 2004; Eisenhower et al., 2005; Tonge & Einfeld, 2003). High rates of coexisting anxiety and depression in ASD (Bakken et al., 2010; Hossain et al., 2020; Leyfer et al., 2006; Salazar et al., 2015; Simonoff et al., 2008; White et al., 2009) and

ADHD (Gillberg et al., 2004; Gümüş et al., 2015; Mayes et al., 2009; Mitchison & Njardvik, 2019; Taylor, 2010) are reported. High coexistence rates of behavioural problems are also reported, both in children with ADHD (e.g., Mitchison & Njardvik, 2019; Taylor, 2010) and ASD (e.g., Bakken et al., 2010; Hossain et al., 2020; Giovagnoli et al., 2015; Maskey et al., 2013). More impaired executive functions in ADHD and ASD predict more severe depression or anxiety (Dajani et al., 2016).

Children with other disorders assessed and treated in neuropaediatric clinics have increased concurrent mental health problems as well. Both children with cerebral palsy (Bjorgaas et al., 2012; Eisenhower, et al., 2005; Hysing et al., 2009; Parkes et al., 2008) and epilepsy (Alfstad et al., 2011; Hysing et al., 2009) have elevated rates of psychiatric disorders or simply behavioural problems. These difficulties are more common in these children than in children with Down syndrome (Eisenhower et al., 2005) or chronic somatic illnesses (Hysing et al., 2009).

All these data highlight the need for tailored mental health support and interventions for children with NDDs.

1.3.3.1 Explanatory model for mental health problems in children with neurodevelopmental disorders

There is no simple, direct explanation for the high incidence of concomitant mental health problems in children with lower IQ or NDD. Broadly there are two possibilities: either there are common factors for both cognitive impairment and mental health problems, or cognitive impairment leads to some consequences that contribute to the development of mental health problems (Goodman & Scott, 2012; see Figure 2).

The increased risk for development of psychopathology in children with NDD can be attributed to disproportionate exposure to a whole range of psychological, familial, social, environmental, and cultural risk factors for mental health problems, such as being a child of a single parent, unemployed parents and simply coming from a poorer family (Meltzer et al., 2003). In the general population, a poor family economy is associated with worse mental health and behavioural problems in children (Bøe et al., 2012; Heiervang et al., 2007). Similarly, a socioeconomic disadvantage may be related to an increased risk of worse mental health and contribute to the experience of a greater number and a wider array of adverse life

events in children and adolescents with ID (Emerson & Hatton, 2007; Hatton & Emerson, 2004). This is particularly important since children with lower intellectual functioning are significantly more likely to be exposed to socioeconomic disadvantage (Emerson et al., 2010). As Wallander et al. (2006) revealed in their longitudinal study, family dysfunction and parental mental illness are other essential factors associated with child psychopathology.

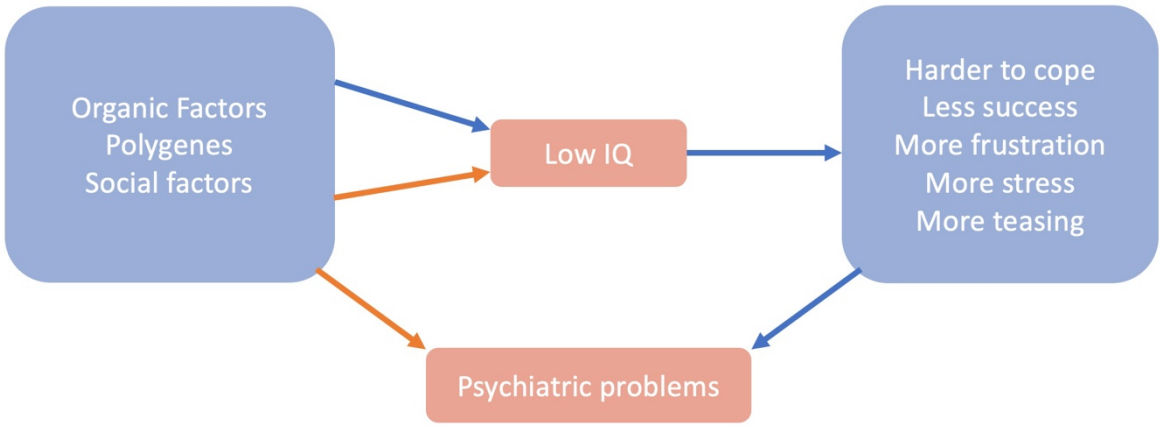

Figure 2. *A model showing two possible ways of associating low IQ and mental health problems. Adapted from Goodman and Scott (2012).*

Much of the risk can depend on the person's intellectual impairment (Sheerin et al., 2019). Neurodevelopmental impairments can also create or influence adverse life events or stressors such as peer rejection, social isolation, academic failure or parental hostility that can contribute to the onset of mental disorder (Thapar & Rutter, 2015). In addition, due to cognitive and adaptive barriers, individuals with ID or NDD may have limited skills to cope with stressors (Dykens, 2000; Hartley & MacLean, 2005; Hartley & MacLean, 2008; Tang et al., 2008).

Dykens (2000) reviewed several bio-psycho-social hypotheses on factors mediating the expression of psychopathology in children with ID, including biological vulnerabilities such as brain conditions or common genetic status (Barnett, et al., 2006). Certain syndromes/specific genetic disorders underlying ID may be associated with behavioural phenotypes, i.e., patterns of behaviour and

psychopathology (Dykens, 1995; Dykens et al., 2000; Mæhle & Houge, 2011; Szymanski, 2009; Tonge & Einfeld, 2003).

1.3.3.2 Diagnostic overshadowing

Symptoms such as depression, anxiety or lack of motivation are not apparent reasons for referring children with ID/NDD for mental health consultation, unlike more visible reactive behavioural problems (Szymanski, 2009). A Norwegian population-based study found out that only one-third of children with low cognitive ability and concurrent mental illness had received help for their mental health problems in the specialist health service (Strømme & Diseth, 2000). In a study by Mason and Scior (2004), clinicians were more likely to recognise a range of symptoms in those with an IQ in the normal range than those with ID. Other studies confirmed that children with ID or other developmental disorders and comorbid mental health problems did not receive sufficient professional help (Dekker & Koot, 2003a; Einfeld & Tonge 1996; Kaptein et al., 2008; McCarthy & Boyd, 2002; Reilly et al., 2014); however, comorbidities and impairment in everyday functioning increased the likelihood of referral (Dekker & Koot, 2003a).

Children with coexisting NDDs and mental health difficulties may have a problem receiving adequate treatment due to ascribing their mental health symptoms to other causes or due to difficulties in diagnosing mental health problems (Sheerin et al., 2019). Attributing mental health difficulties in the NDD population to the primary NDD is a process called diagnostic overshadowing (Einfeld et al., 2011; Halvorsen et al., 2014; Reiss et al., 1982; Simonoff, 2015; White et al., 1995). The reasons for this situation may be that underlying physiological mechanisms in some neurodevelopmental mechanisms in some neurodevelopmental and psychiatric conditions are common or shared (Goodman & Scott, 2012; King, 2016), and symptoms between NDDs and mental difficulties may overlap, making it difficult to distinguish between conditions (Helverschou et al., 2011).

Diagnostic criteria for mental health disorders might not be easily transferable to persons with impaired cognitive functions (White et al., 2005). An atypical presentation of mental health problems in persons with ID can lead to misdiagnosing or under-diagnosing when using standard classification systems (Cooray et al., 2015). The other problem can occur when adult psychiatric diagnostic criteria are

applied to children. For example, depression has a different phenomenology for children and adults. However, both ICD-10 and DSM-IV had few specific childhood categories of emotional disorders (Scott, 2002). The situation improved with DSM-5 (APA, 2013) which updated disorder criteria to capture more adequately the symptoms in children.

Buckley et al. (2020) showed a possible solution for difficulties in capturing mental health comorbidities. They stated that mental health problems could be better detected using symptom phenotypes rather than psychiatric disorders phenotypes. For example, the National Institute for Health and Care Excellence (NICE, 2016) recommends using tools such as the Developmental Behaviour Checklist – parent version (DBC-P) or the Strengths and Difficulties Questionnaire (SDQ) when assessing children and adolescents with learning disabilities. The results of a systematic review by Halvorsen et al. (2023) supported the use of standardised ID instruments as the first choice in an initial assessment of mental health in children with ID.

1.3.4 Functional impairment

The functional impairment criterion is used in a majority of the disorder definitions and is one of the crucial criteria for clinical significance in diagnosing neurodevelopmental disorders, in both DSM and ICD diagnostic systems (APA, 2013; WHO, 2022).

Clinical diagnosis is best predicted by both clinical symptoms and their impact (Goodman, 1999). Assessment of the impact is based on whether symptoms result in (1) social impairment/interference in family life, classroom learning, friendship and/or leisure activities, (2) distress for a child, such as being anxious or depressed, (3) disruption for others (Goodman & Scott, 2012). Distress refers to a subjective discomfort and is an emotional reflection of experienced problems. Distress is a core component of some psychiatric disorders like depression or anxiety, but in neurodevelopmental disorders it is a consequence of the disorder (Rapee et al., 2012). The construct of functional impairment has more noticeable and objective aspects than does the concept of distress, and generally refers to interference with the adequate performance of important and desired aspects of a child's life due to the symptoms of the disorders (Rapee et al., 2012).

Functional impairment comprises specific deficits in multiple domains of functioning, as the opposite of adaptive functioning defined as an adjustment to life's demands (Rapee et al., 2012; Winters et al., 2005). Common conceptualisations of functional impairment indicate three areas of impairment: within family, school and social domain (Achenbach & Edelbrock, 1979). In the same way, home life, friendships, classroom learning and leisure activities are the main areas of "social impairment" that need to be considered when rating psychosocial disability using the World Health Organisation's multiaxial classification of child and adolescent psychiatric disorders (Rutter & WHO, 1996). Previous measures of social impairment have also focused mainly on these areas (Bird et al., 1996; Shaffer et al., 1983).

Functional impairment is distinguishable from symptoms of a disorder (Barkley et al., 2006), and is a real-life consequence of a clinical disorder manifested by these symptoms (Weiss et al., 2018). There is no perfect relation between symptoms and the impairment caused by them, and we cannot predict impairment with precision from the breadth or intensity of symptom manifestation alone (Lewandowski et al., 2006). For example, a correlation between symptoms and impairment in ADHD was .30-.50 in a study by Gordon et al. (2006). The relationship between symptoms and impairment is not rigidly strict for a range of developmental conditions, especially when corrected for IQ and age (Gathje et al., 2008; Klin et al., 2007; Ray-Subramanian et al., 2011). Symptoms might exist without impairment and vice versa (Lewandowski et al., 2016). As a result of the lack of a strict operationalisation and inconsistency in functional impairment's importance across the diagnoses, Ustün and Kennedy (2009) proposed disentangling disability/impairment from disorder in DSM.

Defining disorders solely in terms of symptoms results in high case rates, with cases not significantly socially impaired by their symptoms, not in need of treatment, and not corresponding to what clinicians would typically recognise as cases (Bird et al., 1990). Recognising impairment in addition to core symptoms of disorders helps assess the clinical significance, and is a necessary threshold criterion for many diagnoses in order to prevent high case rates (Bolton, 2013; Canino et al., 2013; Costello et al., 2005; Goldstein & Naglieri 2016; Rapee et al., 2012; Regier et al., 1998; Shaffer et al., 1996; Spitzer & Wakefield, 1999). Clinically significant impairment can be based on relative discrepancies between presumed potential and actual performance or absolute abnormality relative to the general population (Lewandowski et al., 2006).

Table 3. *Functional impairment in diagnostic criteria in ICD-11 and DSM-5 for the chosen NDDs: ID, ASD, and ADHD.*

Examples of NDDs	ICD-11	DSM-5
ID	Adaptive behaviour measured by standardised tests is significantly below the average – severity defined by standard deviations below the average.	Deficits in adaptive functioning in conceptual, social and practical domains – different depending on the severity level. Criterion B
ASD	"Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context".	"Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning." Criterion D
ADHD	The core symptoms have "a direct negative impact on academic, occupational, or social functioning".	"There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning." Criterion D

Note. Adapted from ICD-11 (WHO, 2022) and DSM-5 (APA, 2013).

Both ICD-11 and DSM-5 define neurodevelopmental disorders in terms of symptoms and their impact; neurodevelopmental disorders are characterised by developmental deficits that produce distress and impairments of personal, family, social, academic, or occupational functioning (APA, 2013, WHO, 2022). Diagnosing ID requires deficits in both intellectual functions and adaptive functioning; here limited functioning is present in at least one domain of adaptive functioning (conceptual, social or practical) in various settings, such as home, school, work, and community (APA, 2013; WHO, 2022). Other NDDs diagnostic criteria do not rely on "adaptive behaviour"; however, they include some descriptions of functional impairment, emphasising the severity of the symptoms in ICD-11, and being an explicit part of diagnostic criteria in DSM-5 (examples in Table 3).

ICD's explicit goal was to avoid using social role functioning as diagnostic criteria (Wakefiled, 2009); however, social disability enters many ICD criteria sets (Table 3). There is a stipulation that symptoms must be severe enough to result either in substantial distress for the child or in significant impairment in the child's ability to fulfil normal role expectations in everyday life.

1.4 Assessment

1.4.1 Clinical assessment of neurodevelopmental disorders

1.4.1.1 Clinical assessment

Diagnostic assessment involves information gathering and clinical reasoning aimed at determining a patient's health problem following specific diagnostic criteria (Balogh et al., 2015). Health services for patients with mental health problems or developmental disabilities have gradually incorporated evidence-based practice characterised by a systematic and structured approach, which integrates research evidence and standardised data with clinical expertise, and includes patient involvement (Achenbach, 2017; APA, 2006; Bornstein, 2017; Spring, 2007; Sturmey, 2014; Youngstrom, 2013). Standardised assessment methods were developed to go beyond the weaknesses of subjective clinical assessment problems and are intended to be part of routine clinical practice (Angold & Costello, 2009; Cashel, 2002).

The use of structured interviews is known to improve diagnostic accuracy in a mental health setting (Basco et al., 2000; Miller et al., 2001), particularly since clinical experience is only weakly associated with judgment accuracy (Spengler et al., 2009). Rating scales and diagnostic instruments are attempts to create objective measures of mental health symptoms. Tools can be clinician-rated, self-rated by a patient, or by important informants such as parents. Standardised assessment methods also simplify communication between researchers and increase comparability between studies (Borsboom, 2008). Clinical assessment emphasises the importance of assessing the social context and individual resources such as cognitive ability, level of functioning, socioeconomic situation, or quality of parenting (Achenbach, 2017). Meyer et al. (2001) suggested in their review that a multimethod assessment battery provides a structured means to maximise the validity of individualised assessments.

A specialist makes the final diagnosis; however, it is first and foremost parents, health centres, kindergartens or schools that detect signs of neurodevelopmental problems in children and young people. Sheldrick et al. (2019) studied the effectiveness of a clinical decision rule for children with suspected ASD. They concluded that parents' concerns, providers' clinical judgment, and shared decision-making were significant in detecting and diagnosing ASD and, consequently, providing appropriate treatment. They also concluded that concerns reported by parents could be stronger predictors of referral completion than positive screening scores.

1.4.1.2 Clinical assessment in neuropaediatric clinics in Norway

Guidelines comprising professional recommendations based on knowledge obtained from research, clinical experience and user experience are used for diagnostic assessment of ID and ASD in neuropaediatric clinics (RHABU, 2019; RHABU, 2023). In Tromsø and Hammerfest, the standard assessment and diagnosing process in cases of suspected ASD is based on guidelines published by Regional Professional Network for Autism, ADHD and Tourette's Syndrome, Health South-East [in Norwegian: Regionalt Fagnettverk for Autisme, ADHD og Tourettes syndrom, Helse Sør-Øst], (R-FAAT, 2019), which serves as national guidance. Diagnostic assessment for ID is also based on regional guidance published by Oslo University Hospital (RHABU, 2019; RHABU, 2023); this also functions as national

guidance. Assessment of attention-deficit/hyperactivity disorder is usually secondary to other developmental diagnoses and is not a primary activity at neuropaediatric clinics. Traditionally, there has been less focus on mapping and diagnosing mental health in neuropaediatric clinics, while somatic health, cognitive, linguistic and motor skills are mapped more thoroughly (The Norwegian Directorate of Health, 2009; Halvorsen et al. 2014). Apart from assessment and follow-up of children and adolescents with ADHD, ASD and severe behavioural disorders, the clinics do not focus on patients with psychological difficulties (The Norwegian Directorate of Health, 2015).

Assessment of ID. It is important to mention that the purpose of diagnosing ID is to give the child and its environment an understanding of the cognitive, social and practical difficulties the child has, and what causes them. In addition, the assessment reveals the child's and family's needs for adjustments, interventions and follow-up (RHABU, 2019; RHABU, 2023). Somatic causal explanations, environmental conditions and signs of cognitive overload should always be considered. Clinical assessment is an important complement to standardised testing, and clinical factors inform instrument selection, administration and interpretation. The severity of ID is determined by both the extent of adaptive impairment and the level of required support. Significantly impaired intellectual functioning (indicated by an IQ score that is two standard deviations or more below the mean, usually <70) is a necessary component in ID diagnosis. However, standardised IQ testing is no longer the key feature for classifying ID severity. Most children with an IQ <70 have adaptive impairments, yet their adaptive functioning may improve with appropriate interventions, such that some persons will no longer meet the criteria for an ID diagnosis. Although ID severity is not solely classified according to an IQ score, intellectual impairment may be regarded as being in the ranges of mild (IQ between 50 to 55 and 70), moderate (IQ between 35 to 40 and 50 to 55), severe (IQ between 20 to 25 and 35 to 40), and profound (IQ less than 20 to 25).

Assessment of adaptive functioning is included in standard neuropaediatric assessment (RHABU, 2019; RHABU, 2023). It is recommended that adaptive functioning should be mapped using a questionnaire or interview, and diagnostic interviews Vineland Adaptive Behaviour Scales (VABS-II/III) or Adaptive Behavior Assessment System (ABAS-II/3). VABS-II/III is recommended to be used as a first

choice. The informant should know the child well, and have observed the child's typical behaviour in different contexts. It may be necessary to supplement the diagnostic assessment with a systematic observation of the child in kindergarten, at school or at home. A diagnosis of ID is not warranted in the absence of significant adaptive impairment (even if IQ is <70). The nature and extent of adaptive limitations are crucial to defining ID and its severity. Diagnosing ID requires impaired functioning in at least one of the domains - conceptual, social or practical - impacting participation across diverse everyday settings (e.g. the child's home, community or school) and demanding ongoing support.

Assessment of ASD. If ASD is suspected, an assessment should be carried out following the guidelines for assessing and diagnosing ASD (R-FAAT, 2019). In diagnosing ASD it is recommended to use structured clinical interviews Autism Diagnostic Interview - Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS), as well as observation in the child's environment. For children with severe developmental disabilities or other additional difficulties, using adapted or separate mapping forms may be necessary when assessing ASD. Diagnosis of possible ID should be made after adapting the environment to meet the needs of the child with the ASD diagnosis. Standard procedures in diagnosing ASD comprise cognitive assessment including adaptive skills, paediatric neurological examination, sensory examination, medical examination using MRI, metabolic screening and genetic analyses, in addition to the assessment of communication, language and motor skills (The Norwegian Directorate of Health, 2015). There can be some differences in the diagnostic approach between regional guidelines for diagnosing ASD.

Assessment of ADHD. The diagnosis of ADHD is the result of an overall assessment and is only made if symptoms/difficulties appear in multiple areas, such as at school, in the workplace, at home or among friends. When ADHD is suspected, standard ICD-10 diagnostic criteria are used.

If ADHD is suspected as an additional condition in children and young people with ID, the assessment should be made in accordance with the national professional guideline for assessment and diagnosis of ADHD (NICE, 2018; The Norwegian Directorate of Health, 2016). When mapping ADHD symptoms, behaviour and results from tests related to attention should be considered in the context of cognitive level. In case of uncertainty related to the validity of the cognitive assessment,

neuropaediatric clinics should make a new assessment for possible ID after the facilitation for/treatment of ADHD symptoms has been established (RHABU, 2019).

Assessment of mental health. Assessment of children's mental health should be included in an overall assessment when assessing possible ID, and if necessary, a diagnostic assessment of additional mental difficulties should be made. As a rule, children with mild or moderate ID who also have a mental illness, will be offered a referral to Child and Adolescent Mental Health Services (CAMHS). A new assessment of possible ID should be made after treatment and adjustments of/for the mental illness (RHABU & RBUB, 2022).

1.4.2 Screening

Screening instruments can be used both for research and for clinical decision-making. Their main property is that they are short and reduce the time needed by the researchers or clinician to obtain the respondent's perceptions. Screening for mental health problems provides an opportunity to reach more people and can maximise the appropriate identification of mental health problems (Lavigne et al., 2016). Screening instruments are essential for monitoring and evaluating health care delivery outcomes as well (Groth-Marnat, 2009; Lavigne et al., 2016). The majority of screening tools are self-reporting measures, but they also exist in the form of brief, clinician-administered interviews. A significant other person in the patient's life, such as a parent, can be an informant and can complete the form (Groth-Marnat, 2009; Lavigne et al., 2016). Parental concern is crucial, in addition to mental health screening tools, in providing information about a child's mental health (Hacker et al., 2006). For example, a simple score indicating the cumulative childhood burden of psychopathology can be the best predictor of adult health, and legal, financial and social outcomes (Copeland et al. 2015). In another study, Hacker et al. (2014) showed that adolescents who screen positive on a psychosocial screen designed to facilitate the recognition of cognitive, emotional, and behavioural problems, were significantly more likely to be referred for mental health care.

Validating screening tools in a specific context and for a specific population in which they will be employed is significant, as screening tools tested in multiple settings and populations give different results between studies (Ali et al., 2016).

Before a screening tool can be applied in clinical settings, it is crucial to evaluate its accuracy compared to gold-standard tests used for diagnostic assessment (Li & He, 2018). In addition to being reliable and valid, screening instruments should have high levels of sensitivity and specificity. Essential for all screening instruments are their psychometric properties that enable detecting the possibility of being in a group/having a problem, or being excluded from a group/not having a problem, which helps in further decision-making. The greater the sensitivity of the instrument, the greater the probability that the tool will identify a person who actually has a problem that the tool tries to capture. A test with high sensitivity is useful for “ruling out” a disease if a person tests negative. The greater the specificity of a tool, the greater the probability of not identifying a person who does not have the problem. A test with high specificity is useful for 'ruling in' a disease if a person tests positive (Lavigne et al., 2016; Shreffler & Huecker, 2023). The aim is to identify the most persons with the particular problem and, at the same time to yield the fewest false positives. However, few screening instruments are both highly sensitive and specific. Thus, it would be useful to choose a highly sensitive and moderately specific tool to identify patients with symptoms that might meet diagnostic criteria, while still excluding many who clearly do not have a problem (Lavigne et al., 2016).

Another indicators of test accuracy are the positive predictive value (PPV) and the negative predictive value (NPV). The PPV of a test result is the likelihood that a person with a positive test result has the predicted attribute or problem. The NPV of test results is the likelihood that a person with a negative test sign does not have the problem. The predictive values of tests with cutting scores vary as a function of their sensitivity and specificity values and the population base rate of the problem of interest (Glaros & Kline, 1988).

The sensitivity and specificity of a screening tool do not allow estimation of the probability of a problem in a patient. However, when they are combined with a measure called likelihood ratio, and given the prevalence of the problem, they can be used to estimate an individual's probability of having a problem (Akobeng, 2007). Therefore, the usefulness of the results of a test is best described in terms of ratios of probabilities based on sensitivity and specificity, known as likelihood ratios (Deeks & Altman, 2004; Warner, 2004). There are two types of likelihood ratios: the likelihood ratio for a positive test (LR+) and the likelihood ratio for a negative test (LR−). LR+ is defined as the probability of an individual with a problem having a positive test

divided by the probability of an individual without problem having a positive test. LR− is defined as the probability of an individual with problem having a negative test divided by the probability of an individual without problem having a negative test (Warner, 2004).

Table 4. *Definition of sensitivity, specificity, predictive values and likelihood ratios (LR).*

	Case	Non-case	Total	
Positive test result	a	b	a + b	*Positive predictive value*: a/(a+b)
Negative test result	c	d	c + d	*Negative predictive value*: d/(c+d)
Total	a + c	b + d	a + b + c + d	
Sensitivity: a/(a+c)		*Specificity*: d/(b+d)		*LR*+: sensitivity/(1-specificity) *LR*-: (1-sensitivity)/specificity

Screening information may be useless without some form of cut-off or clear diagnostic threshold (Lavigne et al., 2016). Scales are useful when the information about their mean value or clinical decision threshold "cut-off point" for selected subjects is available. Cut-off points allow separation of cases from non-cases. The chosen cut-off score is determined by maximising sensitivity (i.e. including all true cases) without minimising specificity (i.e. excluding all true non-cases) (Warner, 2004). Most screening instruments, particularly for scores near the cut-off point, have modest negative and positive predictive values (Sheldrick and Garfinkel 2017).

The effectiveness of screening can depend on the severity of a health condition or the cost of missing “true” patients (Rah et al., 2022). A decision threshold that is optimal regarding the total error rate is not necessarily a decision threshold that is optimal regarding the risks and benefits of the decision. The appropriateness of a judgement method for a specific clinical condition hinges on the relative benefits and harms associated with true positive and false positive diagnoses (Sanders et al., 2015). Ideally, screening tools should identify patients early enough to provide treatment and reduce symptoms and their negative consequences, thus improving health outcomes and keeping the costs low (Iragorri & Spackman, 2018).

Since sensitivity and specificity refer to the tool's accuracy in identifying "cases", they are not likewise important accuracy criteria for treatment outcome measures. For an outcome measure, it is more important that it measures what it should measure, and that the approach is appropriate in the given context (Wright & Bufka, 2020).

1.4.3 Parents as informants

Due to a child's difficulties with communication, introspection and atypical symptoms in the neuropaediatric population, assessment of child’s problems and obtaining information important for diagnosis relies largely on parental reports.

The way parents perceive a child's difficulties can influence their decisions about looking for help and how they report their child's problems. Parental problem recognition and help-seeking are dependent on the amount of distress or burden parents experience in raising their child (Angold et al., 1998; Farmer et al., 1997). Thus, parental evaluation of a child's problematic behaviour is one of the most potent predictors of later referral to child health services and further professionals' assignment of NDD diagnoses (Bussing et al., 2003; Sacrey et al., 2018; Sourander et al., 2001).

Ratings of child problems may be affected by factors such as the expectation of the "correct" answer, knowing a child's problems from a specific context, denial of problems, strained relationship between child and informant, or exaggeration of the child's behaviour (Wender, 2004). A review article about parental help-seeking for emotional and behavioural problems in children and adolescents showed that the presence of parental mental health problems increased child problem recognition but

did not increase the use of mental health services, while parents or relatives who themselves received mental health care were more likely to seek help for child psychopathology (Zwaanswijk et al., 2003).

Achieving informant agreement among multiple informants on a broad spectrum of child mental health issues has been a persistent methodological challenge (see De Los Reyes & Kazdin 2005, for a review). Such low agreement may be explained by the different expression of symptoms in different environments, and the emphasis placed on different aspects of behaviour by each informant (Breton et al., 1999). Generally, informant agreement appears to be higher for externalising behaviours (e.g. aggression and hyperactivity) as compared to internalising behaviours (e.g. depression and anxiety; Duhig et al., 2000; Müller et al., 2011), as externalising behaviours are more overt and therefore more observable (De Los Reyes & Kazdin, 2005). Adolescents' internalising problems are not consistently recognised by their parents, especially anxiety in children, and internalising problems in boys are difficult to recognise by parents (Davidsson et al., 2017). Parents may have limited access to young people’s intrapsychic processes; therefore, self-reports are the best source for identifying emotional problems such as depression and anxiety (Aebi et al., 2017; Lagattuta et al., 2012). On the other side, parents' reports are better suited for identifying behavioural problems/disorders and specifically for conduct disorder and oppositional defiant disorder in adolescents (Aebi et al., 2017; Lagattuta et al., 2012). Overall, self-ratings were more closely associated with parents' reports than with teachers' reports (Becker et al., 2004), once again indicating the importance of the information obtained from parents.

The correspondence of parental reports with professional evaluation is crucial for clinical practice. However, some child- and family characteristics may play a role in an assessment, for example a poorer agreement between parents and clinicians was observed when children had higher IQ scores or when a child came from lower SES-families (Lin et al., 2011; Neuhaus et al., 2018). Substantial disagreement between caregivers and clinicians could lead to inadequate intervention services, leading to negative experiences for families (Neuhaus et al., 2018). Therefore, questionnaire reports from different informants should be treated as complementary in diagnosing and act as a supplement to clinical evaluation (de Ruiter et al., 2007; Wender, 2004).

1.4.4 Evaluation of the clinical assessment by parents

Patient satisfaction surveys capture patient evaluations across various services functioning as indicators of health care quality or as outcome measures (Crow et al., 2002). When assessing the quality of mental health services for children and adolescents, it is essential to explore the perspectives of their parents (Garland et al., 2007; Riley et al., 2005).

Patient satisfaction surveys are often utilised to enhance quality in health care; however, it's worth noting that assessments of overall patient satisfaction may offer limited value in the context of quality improvement processes (Jenkinson et al., 2002). (Jenkinson et al., 2002). Even if the treatment outcomes are poor, satisfaction with the service can still be high (Norman et al., 2016). High reported satisfaction does not necessarily indicate the achievement of an optimal health outcome; conversely, reported dissatisfaction may be used as an indicator of a negative experience (Williams et al., 1998). Asking about patient-reported experiences, and not satisfaction, results in more reliable reports on the quality of the treatment (Bjærtnes et al., 2016; Garratt et al., 2008; Sjetne et al., 2011). Hence, measuring patient experiences is increasingly employed as a quality indicator in the health care sector (Garratt et al., 2008; Danielsen et al., 2010). Measuring patient experiences with health services can have different purposes, including describing achieved health care from the patient's point of view, measuring the care process, and evaluating the outcome of care (Sitzia & Wood, 1997; Pettersen et al., 2004). The results can help to identify problem areas, improve care, meet patients' expectations, and effectively manage and monitor health care performance (Al-Abri & Al-Balushi, 2014; Bjertnæs et al., 2012). Positive associations have been reported between patient experience, patient safety, and clinical effectiveness across a wide range of disease areas, settings, outcome measures, and study designs (Doyle et al., 2013).

Patient satisfaction is a function of the multi-dimensional components of health care delivery, including, for example, accessibility of services, interpersonal aspects of care, technical aspects of care, and information given to patients (Sitzia & Wood, 1997). Patient experiences identify specific health care aspects crucial as measures of service quality from the patients' perspective, contributing to their overall satisfaction (Danielsen et al., 2010). The concepts "experiences with health care" and "satisfaction" are positively related (Bjertnæs et al., 2012). While experiences

with health care components form the foundation for patient satisfaction, they represent only a portion of the overall satisfaction concept. Patient satisfaction is a complex concept influenced by various variables, such as social standards, context, needs, values, previous experiences, future expectations, information, education, health, medical care, treatment, and psychological factors (Carr-Hill, 1992; Crow et al., 2002; Nathorst-Böös et al., 2001; Sitzia & Wood, 1997). Thus, patient satisfaction can be understood as the fulfilment of expectations (Williams et al., 1998).

Information about caregiver experiences with neuropaediatric health services or services for disabled children is increasingly gathered and serves as an important indicator of the quality of health care provided to those children (Bodin et al., 2007; Chilvers et al., 2013; Farmer & Brazeal, 1998; Kirkwood et al., 2017). The survey results are thought to support organisational patient-centeredness (Reeves & Seccombe, 2008) and can be expected to be a crucial factor in justifying clinical services (Kirkwood et al., 2017; Shirley & Sanders, 2013). Family-centred services emphasise a partnership between parents and service providers so that families are involved in every aspect of services for their child, which in turn is associated with higher parental satisfaction with services, decreased parental stress, and positive child outcomes (Law et al., 2003).

Patient-practitioner relationship is the most important health service factor affecting patient satisfaction (Crow et al., 2002). Greater satisfaction with the treatment is also associated with receiving the expected medical help (Rahmqvist & Bara, 2010), individualised treatment (Bates et al., 2020), getting broad and suitably adapted information (Danielsen et al., 2010; Hasnat & Graves, 2000), good communication with practitioners (Hasnat & Graves, 2000), and professionals' concern and competence (Farmer & Brazeal, 1998).

The essential elements for satisfaction in paediatric rehabilitation/neuropaediatric services are processual elements such as respectful and supportive care (feeling being listened to), and the most critical elements for dissatisfaction with the paediatric rehabilitation services are both structural elements (lack of access) and process elements (lack of respectful and supportive care, lack of continuity and coordination of care) (King et al., 2001). In addition, results from many studies showed that parents emphasised positive expectations of treatment outcome and feeling supported as factors related to their involvement and further success of

the treatment (Baker-Ericzén et al., 2010; Delaney & Engles-Scianna, 1996; Gerkensmeyer & Austin, 2005; Resendez et al., 2000).

Communication with parents who realise their child is disabled is a difficult task for professionals, especially since parents experience great emotional stress during the diagnostic process. In a qualitative study on this subject (Graungaard & Skov, 2007), the certainty of the diagnosis was central to parents' experiences, in addition to the need to be met with empathy and to be treated as equal partners in communication and cooperation with professionals. A study on satisfaction with paediatric neuropsychological evaluations by Bodin et al. (2007) revealed four dimensions of satisfaction: general satisfaction, clinician acceptance/empathy, provision of help, and facilities/administrative assistance. Particularly important is receiving post-diagnostic support, e.g. getting information about educational and social services, informal and formal social networks, and support groups (Crane et al., 2016; Rahi, 2004). Parents tend to experience higher satisfaction with the first communication of a diagnosis of developmental disability when the professional communicates directly, understands parental concerns, and shares a large amount of information about the diagnosis (Hasnat & Graves, 2000). In a study by Arffa and Knapp (2008), parents evaluated the usefulness of their child's neuropsychological evaluation, particularly obtaining knowledge that helped them to understand their child's strengths, weaknesses, cognition, and behaviour, and refining the diagnosis, were seen as more beneficial.

Health status and health outcomes affect patient satisfaction – sicker patients, except for chronically-ill groups and those experiencing psychological distress, have lower satisfaction rates (Crow et al., 2002; Danielsen et al., 2010; Rahmqvist & Bara, 2010). This also applies to parental evaluations, e.g. distressed parents were less satisfied with the parent training sessions in preventive health services (Bairati et al., 2011), and parental mental health was a significant predictor of satisfaction in paediatric neurology clinic (Mah et al., 2006). In addition, more demanding symptoms in children can create more need for treatment, and parental satisfaction with the health care for their children can be lower if children have more complex health and developmental problems, simply because their needs for help are not being met (Law et al., 2003; Zablotsky et al., 2015).

1.5 Parents of functionally impaired children

The role of parents of children with disabilities is irreplaceable. As described earlier, patients in neuropaediatric clinics suffer from complex neurodevelopmental and/or neurological conditions. Overlapping difficulties in many areas are the rule rather than the exception. This population often suffers from mental health problems, and their behavioural problems are particularly pronounced. All in all, these children have a comprehensive need for help, and their parents are central to their assessment, further treatment and rehabilitation. The situation for these parents is in no way simple, and they carry great responsibility, exceeding typical parental care for typically developing children. Obviously, many of them adapt well to the situation; however, there is evidence that they experience more everyday stress, parenting stress, burden, social isolation and last but not least mental health problems such as depression. These parents are the main voice for their children, and they are broadly used as the informants; in addition, they deliver all the necessary help for their children. Therefore, their mental health should be given proper attention. The well-being of families raising children with disabilities is an important study area. Among the most-researched areas of well-being in these families are parenting stress (Most et al., 2006; Plant & Sanders, 2007) and parental distress/depression (Bailey et al., 2007; Baker et al., 2011; Glidden & Schoolcraft, 2003).

1.5.1 The concept of well-being and distress

Mental health is more than the absence of mental illness (WHO, 2020, p.1) and can be defined as «a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community» (WHO, 2004, p.10). Well-being has no global definition, but two perspectives are specifically worth mentioning – hedonic and eudaimonic well-being (Deci & Ryan, 2008; Tov, 2018). Hedonic well-being (also called subjective well-being) includes positive affect (emotional component) and life satisfaction (cognitive component) (Diener, 1984; Diener et al., 1999). Eudaimonic well-being (also called psychological well-being) is conceptualised as optimal functioning that enables a person to reach their full potential, including meaning, growth and autonomy (Ryff, 1989; Waterman, 1993).

Psychological distress is an unpleasant subjective state that exists in major forms of depression and anxiety. These distress forms take further two forms of mood (sadness of depression and worry of anxiety) and malaise (somatic states related to depression and anxiety) (Mirowsky & Ross, 2003).

Well-being and psychopathology can exist on two distinct continua. These continua can be independent (Huber et al., 2016), i.e., with the definition of health as "the ability to adapt and to self-manage, in the face of social, physical and emotional challenges" (Huber et al., 2011) it is possible to be ill and healthy at the same time. Another eventuality is the lack of assumed independency between these continua, i.e., people with low well-being are at risk of developing illness (Kendler et al., 2011; Keyes, 2005; Westerhof & Keyes, 2010;). These models are best applicable to the general population, where well-being is moderately negatively correlated with distress/psychopathology (Massé et al., 1998).

Another approach to the relation between well-being and psychopathology is situating well-being at the opposite end of a spectrum of the common mental disorders such as depression and anxiety (Huppert & So, 2013). In a study by van Erp Taalman Kip and Hutschemaekers (2018) on a population with clinically significant psychopathology, well-being and psychopathology correlated much more strongly than in the general population. In this population, the distinction between well-being and psychopathology should be questioned. A two-dimensional model, best for a general population, is not particularly beneficial when screening for psychiatric disorders (Hu et al., 2007). The reason can be that many mental health disorders, such as anxiety or depression, are defined by a lack of well-being (subjective distress is an explicit criterion) (APA, 2013). For instance, deficits in psychological well-being and quality of life in depression are severe (Krieger et al., 2014; Nierenberg et al., 2010). Such results confirm an approach that emphasises the bipolar structure of positive and negative affect (Green et al., 1993), existing on the continuum and being conceptualised as a normally distributed one dimension with two ends, from emotional well-being to symptoms of depression and anxiety (Uher & Goodman, 2010; Figure 3). Many mental health problems can be understood as one end of bipolar continua, with well-being on the other end. Interestingly, reducing some psychiatric symptoms decreases the risk of several other psychiatric symptoms (Siddawaya et al., 2017).

Parental mental health has been variously described and measured as parental emotional well-being (Bøe et al., 2014; Eisenhower et al., 2005; Olsson & Hwang, 2008), as depression in parents (Baker et al., 2005; Olsson & Hwang, 2001), as mental health status (Emerson, 2003b) or as maternal mental health/emotional disorder (Totsika et al., 2011a). Different measurement methods were used, (e.g. the General Health Questionnaire measuring psychiatric morbidity among parents, Emerson, 2003b, or the Beck Depression Index-2r measuring depressive symptoms, Olsson & Hwang, 2008). Regardless of the name or measurement method, the relation between parental mental health and diverged expressed psychopathology of their children is established in the literature.

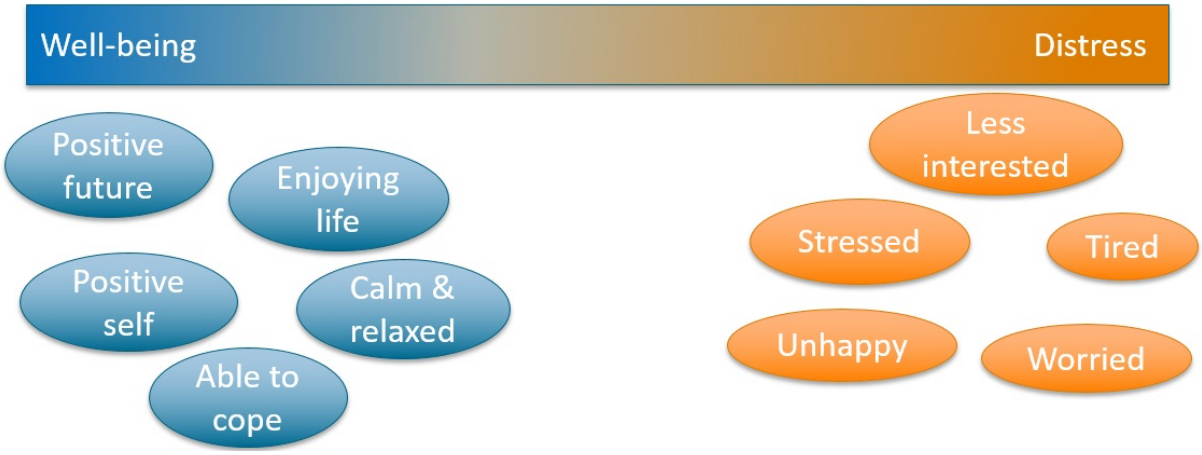

Figure 3. *Graphical presentation of the dimension from symptoms of well-being to distress (symptoms from the Everyday Feeling Questionnaire; Uher & Goodman, 2010).*

1.5.2 Parenting stress and parental mental health

Many studies show elevated parenting stress levels in parents of children with NDDs (Almogbel et al., 2017; Craig et al., 2016; Esbensen, 2010; Hayes & Watson, 2013; Totsika et al., 2011a; Totsika et al., 2011b). In a study by Almogbel et al. (2017), parents of children with NDDs classified as functionally impaired increased the risk of clinically significant parenting stress scores by a factor of 5.5. Some results pointed out that parents of children with NDDs were more depressed, more distressed and experienced less well-being than parents in the control group (Olsson

& Hwang, 2001). The main result from a meta-analysis by Singer (2006) was that the prevalence of depression in mothers of children with NDDs was 10% higher than in mothers in control groups.

Overall, lower IQ levels and emotional and behavioural problems are associated with higher levels of parenting stress (Craig et al., 2016). The psychological well-being of parents of young people with NDD seems to be more strongly associated with the severity of mental disorder in these children, particularly their behavioural and emotional problems, than with the severity of their intellectual or developmental disability (Baker et al., 2002; Baker et al., 2005; Emerson, 2003b; Farmer et al., 1997; Giovagnoli et al., 2015; Langley et al., 2020; Nalavany et al., 2009; Olsson & Hwang, 2001; Raina et al., 2005; Ricci & Hodapp, 2003; Tonge & Einfeld, 2003).

Different outcomes for parents can be related to the differences in behavioural phenotypes for children with different diagnoses, e.g. higher level of adaptive behaviour exhibited by individuals with Down syndrome, and behavioural problems among children with autism (e.g., Tosika et al., 2011a). Parents of children with ASD in particular report higher levels of parenting stress than parents of typically developing children or parents of children with cerebral palsy, Down syndrome or ID (Craig et al., 2016; Dąbrowska & Pisula, 2010; Eisenhower et al., 2005; Hayes & Watson, 2013). Behavioural problems in children with ASD cause many parents to feel particularly stressed and burdened (Bromley et al., 2004; Lecavalier et al., 2006). Parenting stress and emotional burden are known to be high among families of children with ADHD as well, and are related to the severity of symptoms and behavioural problems (Corcoran et al., 2017; Craig et al., 2016; Harrison & Sofronoff, 2002; Theule et al., 2013).

In a study by Faust and Scior (2008), participants expressed that stress and difficulties in families increased as a child with ID developed mental health problems. According to these parents, obtaining appropriate help for a child with an ID background was difficult, and parents experienced stigma, shame and isolation. Emotional and behavioural problems in children and young people with ID influence family functioning and parental well-being more negatively than in the normative sample (Tonge & Einfeld, 2003). Child psychopathology is a huge stressor for families that affects parenting abilities, increasing parental negativity and various forms of ineffective disciplining practice (Berg-Nielsen, et al., 2002).

High parenting stress has been associated with parental depression (e.g. Farmer & Lee, 2011; Hastings et al., 2006). Obviously, some parents are resilient in their reaction to stressful life conditions (Olsson & Hwang, 2008). Resilience is about overcoming stress or adversity (Rutter, 2006). According to this theory, adaptation is dependent on the interplay between risk and protective factors. For example, self-esteem and emotional support protect the psychological health of parents (Cantwell et al., 2015), and some coping strategies such as escape-avoidance are related to less well-being and more depression in mothers (Glidden et al., 2006).

Well-being plays an essential role in mothers' and fathers' ability to parent their children successfully (Belsky, 1984). Parents who have to cope with their own symptoms of depression or anxiety may have more difficulty providing care for their child compared to parents with good mental health, especially when they struggle with a lack of resources and support (National Research Council and Institute of Medicine, 2009).

Parental mental health problems have been found to negatively affect children's social, cognitive, emotional and behavioural development (Bauer & Webster-Stratton, 2006; Choe et al., 2013; Division of Behavioral and Social Sciences and Education Staff et al., 2009; Goodman & Gotlieb, 1999; Manning & Gregoire, 2006). Children of parents who struggle with mental health are likely to experience violence, family disruptions including divorce, or living in poverty (Wolicki et al., 2021). Negative consequences of having a parent with depression are well-reviewed in a book by the National Research Council and Institute of Medicine (2009), where the authors pointed out significant relations between parental depression and more hostile, negative and disengaged parenting and less positive parenting, independently of the child´s age, as well as parental depression associated with children’s stress-related health conditions, poorer physical and mental health and maladaptive patterns of health care utilisations. Parenting stress and maternal caregiving strains are negatively associated with parental satisfaction with mother–adolescent relations as well (Mitchell & Hauser-Cram, 2010; Orsmond et al., 2006).

Children´s mental health difficulties in addition to their intellectual disability may result in increased pressure and extra responsibilities for parents. At the same time, children with special needs are more prone to develop mental health difficulties and need parental care that is adjusted to cope with such difficulties. Given that parental

well-being is crucial for their ability to deliver good care for their children, it is important that parents can cope effectively with diverse life difficulties and get extra support in situations that are beyond their coping abilities.

A holistic family perspective should be a way to ensure quality in neuro-paediatric clinics (Bjerre et al., 1999; Lerdal & Sørensen, 2008). This holistic perspective should include particular attention on parental well-being, especially in the light of the presented research literature that highlights the fact that parents of functionally impaired children experience worse mental health. As Phoenix et al. (2022) highlighted in their review, there are few studies indicating how children's service providers in rehabilitation settings can identify parental needs and enable families to get more support (Phoenix et al., 2022). Hunt et al. (2022), in their review on parental depression screening in paediatric health care settings, were clear that a broad screening for parental depression across different clinical settings has the potential to identify families in need of additional resources or support.

1.6 Summary of the introduction

Children referred to neuropaediatric clinics present with complex difficulties, not only restricted to neuropsychological problems, but also mental health problems, and all of them struggle with functional impairment. Therefore, finding out if functional impairment can be screened or measured more effectively compared to more comprehensive clinical interviews is of major importance.

The other issue is the burden on the child's parents and their mental health, including distress and well-being. With the relation between child difficulties and parental mental health outcomes in mind, screening for parental mental health issues can help in a quicker implementation of supportive solutions for parents once the problems are detected, and thus prevent the escalation of untreated mental health difficulties. Parental mental health is crucial for a child's well-being, and good support is particularly important when a home situation with impaired children demands more complexity and flexibility in coping with the demands of everyday life. Providing effective methods for screening of parental mental health status should be prioritised.

Parents are important in providing information about their children, and including parents in the assessment helps to ensure good quality evaluation and treatment. Therefore, it is necessary that they evaluate the treatment that is given.

This thesis emphasises the importance of finding the right, time-efficient and acceptable instruments for additional evaluations around neuropaediatric assessment. These issues are addressed in this thesis as described in “aims”.

2. Aims of the thesis

The general objective of the thesis is to broaden knowledge about the interdisciplinary assessment of neurodevelopmental disorders in two neuropaediatric clinics. The overall focus of the thesis is on the validity and usefulness of the screening instruments completed by caregivers in the context of the assessment, and caregivers' satisfaction with the assessment.

Thus, the aims of this thesis are as follows:

1. To examine the usefulness of the Everyday Feeling Questionnaire as a screening instrument for parental mental health in a neuropaediatric clinical population. We specifically aimed to check the relationship between parental mental health and child neurodevelopmental disorder diagnoses, child mental health symptom scores, and child functional impairment in a neuropaediatric clinical sample. This aim is addressed in article 1.
2. To examine the validity and usefulness of the Impact supplement of the Strength and Difficulties Questionnaire in measuring functional impairment in children and adolescents diagnosed with ADHD or ASD in neuropediatric clinics. This aim is addressed in article 2.
3. To examine which parental experiences with the neuropaediatric clinics are crucial for satisfaction with and perceived benefit of the service, and which background variables are associated with these outcome variables. This aim is addressed in article 3.

3. Methodology

3.1 Study design and data collection

The thesis is based on a multicentre study in a naturalistic clinical setting. A cross-sectional design is used. The data collection took place in the two northernmost neuropaediatric outpatient clinics at the University Hospital of North Norway (UNN), Tromsø and the Finnmark Hospital Trust, Hammerfest. The clinics in Tromsø and Hammerfest are specialised health care service units in the Northern Norway Regional Health Authority and cover the county municipalities of Troms, Finnmark, Ofoten (northern Nordland) and Svalbard, with a population of 266,000.

These facilities provide services for children and adolescents with neurodevelopmental and neurological disorders or early-acquired disabilities. Assessment teams are interdisciplinary, including specialists such as paediatricians, neuropsychologists/ psychologists, special education therapists, occupational therapists and physiotherapists.

The inclusion criterion for this study was a referral to these clinics between October 2012 and July 2016 at UNN, or between January 2014 and July 2016 at the Finnmark Hospital Trust. The exclusion criterion included age below four years due to a lack of suitability of one or more of the instruments for that age group. These criteria resulted in 518 children and adolescents eligible for the study. Nevertheless, 30% of them were excluded from the study due to time constraints, lack of parental motivation, or insufficient knowledge of the Norwegian language. Overall, 365 children and adolescents participated in the study.

3.2 Participants

The total sample (N = 365) involved children aged 4–18 years (M = 10.11, SD = 3.81) with a predominance of boys (65.2%). A total of 310 patients were included at UNN and the remainder at the Finnmark Hospital Trust. The patients were referred by a general practitioner (n = 247) or a medical specialist in the specialist health services (n = 118). They were referred with suspected neurological or neurodevelopmental disorders. In the articles, the number of participants ranges from N = 299 to N = 337 due to varying response rates on the different instruments.

Detailed demographic and clinical descriptions of the sample can be found in the respective articles.

Table 5. *Prevalence of the disorders (ICD-10) in the patients admitted for a developmental/neurological assessment (N = 365) in the neuropaediatric outpatient clinics at the University Hospital of North Norway (UNN) and the Finnmark Hospital Trust (2012/2014 – 2016).*

Diagnoses	N	%
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	40	11.0
Diseases of the nervous system (G00-G99)	52	14.2
Intellectual disability (F70-F79)	80	21.9
Specific developmental disorders (F80-F83)	156	42.7
Pervasive developmental disorders (F84)	56	15.3
Hyperkinetic disorders (F90) and ADD (F98)	50	13.7
Disorders of social functioning with onset specific to childhood and adolescence (F94)	19	5.2
Tic disorders (F95)	3	0.8

Patients referred to the neuropaediatric outpatient clinics were characterised by below-average full-scale intelligence quotient (FSIQ) score (M = 76.22, SD = 17.19) and adaptive functioning score as assessed by Vineland Adaptive Behaviour Scales II (VABS-II; Sparrow et al., 2011; M = 67.10, SD = 15.15). The most frequent

diagnostic groups among the participants were specific developmental disorders (41.5%), ID (21.8%), ASD (15.8%), diseases/disorders of the central nervous system such as epilepsy and cerebral palsy (14.8%), ADHD (13.7%) and congenital malformations, deformations and chromosomal abnormalities such as Down Syndrome (11%). The diagnoses were not mutually exclusive, so a specific patient could have more than one diagnosis. Two coexisting disorders were registered for 31.5% of the patients, and further 9.3% had three or more diagnoses. Patients with hyperkinetic disorders had coexisting disorders almost without exception. More single-diagnosis patients are among those with a specific learning disability (57%), ID (39%) or pervasive developmental disorders (55%). Coexisting medical disorders in these groups belong in almost all cases to congenital malformations, deformations and chromosomal abnormalities, or diseases of the nervous system such as epilepsy or cerebral palsy. A total of 11.2 (n = 41) of children were not given any neurological or neurodevelopmental disorder diagnosis. More detailed diagnostic characteristics of the studied population are listed in table 5.

Patients' caregivers (N = 315) were aged between 24 and 71 years (M = 41.5, SD = 7.4). We have information about their role in relation to a child (N = 330); 70.3% were mothers, 20.9% were fathers, whereas mothers and fathers who filled the questionnaires together constituted 3%, and caregivers having another role made up 5.8%. Most of them had Norwegian as their mother tongue (89.7%). About half were married, and 19% lived without a partner. Of the responding caregivers, 47.6% were educated to college or university level, as were 34.4% of the second caregivers. In addition, 74.2% were in employment. More sociodemographic information regarding the caregivers is included in Tables 1 in articles 1 and 3.

3.3 Measures

For an overview of the instruments and variables included in articles 1 to 3 see Table 6.

Table 6. *Overview of measures/variables in the articles.*

Measures	Variables	Article 1	Article 2	Article 3
WPPSI, WISC and Raven's Coloured Progressive matrices	Intellectual function, Intelligence quotient	X	X	
DAWBA	Child mental health diagnoses	X		
EFQ	Parental mental health	X		X
SDQ	Child mental health symptoms	X	X	
VABS-II	Adaptive behaviour/ functional impairment		X	
SDQ Impact Supplement	Functional impairment and distress	X	X	
CGAS	General functioning/ functional impairment		X	X
Family Stresses	Socio-economic status	X		X
DAWBA – background	Age, gender, employment…	X		X
GS-PEQ	User satisfaction, user experiences			X

Note: WPPSI, WISC: Wechsler intelligence tests; DAWBA: The Development and Well-Being Assessment; EFQ: Everyday Feeling Questionnaire; SDQ: Strengths and Difficulties Questionnaire; CGAS: The Children's Global Assessment Scale; Family Stresses: one subscale related to a socioeconomic situation; GS-PEQ: Generic Short version of Patient Experiences Questionnaire.

3.3.1 Assessment of intellectual function

Full-Scale Intelligence Quotient (FSIQ) expresses children's intellectual function. Children were individually assessed with a standardised Wechsler intelligence test appropriate for their age (WPPSI, WISC; Wechsler, 2007, 2008a, 2008b, 2009, 2012). A small number of children were assessed with Raven's Coloured Progressive Matrices (CPM; Raven, 2004) because of insufficient completed subtests on the Wechsler test to estimate FSIQ. The Wechsler intelligence test provides a strong measurement of general intelligence through its FSIQ-score (Canivez et al., 2016; Watkins, 2010). The reliability of the WISC-IV is presented in its Technical and Interpretive Manual (Wechsler, 2003). The average internal consistency coefficient for FSIQ is .97. The WISC-IV is a stable instrument with an average test-retest coefficient of .93 for the FSIQ (Wechsler, 2003). A test-retest reliability coefficient of the FSIQ was .82 (Watkins & Smith, 2013). The average internal consistency for the CPM scale was determined as .83 – .88 (Bildiren, 2017; Kazem et al., 2007). Detailed reviews of the intercorrelations between the CPM and full-length "intelligence" tests are found in Court and Raven (1995) and Raven et al. (1998). For English-speaking children and adolescents, correlations between the Standard Progressive Matrices and Wechsler scales range from 0.54 to 0.86. Kluever et al. (1995) reported a correlation of r = .67 between the WISC-III FSIQs scaled score and CPM percentiles. In a study by Wilkes and Weigel (1998), the mean IQ was 10 points higher on the CPM than on the WISC-R.

The score ranges for intellectual function levels include: high (130 and above), moderately high (115-129), adequate (86-114), moderately low (71-85), and low (70 and below). For *n* = 30 children, the FSIQ scores were missing due to administering a test appropriate for chronologically younger children.

3.3.2 Assessment of mental health

3.3.2.1 Child mental health diagnoses

The Development and Well-Being Assessment (DAWBA; Goodman et al., 2000) was used to determine diagnoses of mental health disorders based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders,

Version IV (DSM-IV; American Psychiatric Association, 2000) (www.dawba.info). The present study used a web-based DAWBA, which included a detailed psychiatric interview for parents (N = 299), an adolescent interview (n = 103), and a short questionnaire for teachers (n = 220 teachers). The DAWBA contains modules for diagnoses related to common emotional disorders such as anxiety and depression, conduct /oppositional disorders, and other, less common disorders, as well as modules for background information (more about the child's health, the Family Stress Scale, and parental distress/well-being) and the child's strengths. The DAWBA discriminates between population-based and clinical samples and between different diagnoses (Goodman et al., 2000). The DAWBA generates realistic estimates of the prevalence of mental illness and has shown high predictive validity when used in public health services in Norway (Brøndbo et al., 2013; Heiervang et al., 2007). Good to excellent agreement between diagnoses from clinical practice and diagnoses based exclusively on the DAWBA has been reported, with Kappa values between .57 and .76 for different diagnoses (Foreman & Ford, 2008; Foreman et al., 2009). Inter-rater reliability was reported in British and Norwegian studies, with Kappa values of .86 – .91 for any disorder, .57 – .93 for internalising disorders, and .98 – 1.00 for externalising disorders (Ford et al., 2003; Heiervang et al., 2007). After completion of the DAWBA interview, two expert raters (BM and PHB), both of whom are senior clinical specialists in neuropsychology with at least 15 years of experience in the field and who are trained in the DAWBA ratings (Brøndbo et al., 2012), generated diagnostic ratings based on the answers provided by the parents, teachers and adolescents (Halvorsen et al., 2019b).

3.3.2.2 Child mental health symptoms

The parent version of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1999) was also part of the web-based DAWBA (Goodman et al., 2000). The SDQ consists of 25 items that measure symptoms in four problem domains (emotional difficulties, hyperactivity-inattention, conduct problem, and peer problems) and one area of strength (prosocial behaviour). There are three response alternatives: “not true”, “somewhat true”, and “certainly true”. Scales for problem scales are added together to generate a total difficulties score. The SDQ has

satisfactory to good psychometric properties, and has been used in clinical and non-clinical child and adolescent populations (Emerson, 2005; Goodman, 2001; Smedje et al., 1999; Stringaris & Goodman, 2013). In the present study, the scales used had the following Cronbach's alphas: .75 for emotional difficulties, .68 for conduct problems, .79 for hyperactivity, .71 for peer problems,.80 for prosocial behaviour, and .85 for total difficulties score.

3.3.2.3 Parental mental health

Parental mental health was assessed with the self-administered version of the Everyday Feeling Questionnaire (EFQ; Uher & Goodman, 2010), which is a part of the DAWBA (Goodman et al., 2000). The scale consists of 10 items that measure symptoms related to depression and anxiety (e.g., "tired or lacking in energy", "worried or tense"), as well as items on psychological well-being, such as optimism, self-esteem, and coping (e.g., "positive about yourself", "able to cope with what life brings"). There are five response options reflecting the frequency with which the respondent experienced these symptoms in the last four weeks (from "none of the time" to "all of the time"). Positively worded questions regarding psychological well-being were reversed, and all the items were summarised into a total score. Higher scores represent higher levels of distress and lower levels of well-being. The EFQ has been validated in epidemiological (Uher & Goodman, 2010) and clinical populations (Mann et al., 2013). Factor analyses demonstrated that distress and well-being existed on a single continuum (Mann et al., 2013; Uher & Goodman, 2010). The EFQ has good internal consistency, with Cronbach's α .89 reported in a non-clinical population (Uher & Goodman, 2010) and Cronbach's α .90 (test) and .97 (retest) reported in a clinical population (Mann et al., 2013).

3.3.3 Assessment of functional impairment

3.3.3.1 Adaptive behaviour

The VABS-II (Sparrow et al., 2011) measures a child's adaptive abilities. This is a semi-structured interview with a parent that examines four adaptive functioning

domains with related subdomains: communication (receptive, expressive, and written), daily living skills (personal, domestic, and community), socialisation (interpersonal relationships, play and leisure time, and coping skills) and motor skills (gross and fine). In this study, we used an Adaptive Behaviour Composite score (ABC) with a mean of 100 and a standard deviation of 15, condensed from communication, daily living skills, and socialisation subscales. The score ranges for adaptive levels include: high (130 and above), moderately high (115-129), adequate (86-114), moderately low (71-85), and low (70 and below).

3.3.3.2 Functional impairment and distress

The extended version of the SDQ (Goodman, 1999) includes an Impact Supplement of eight questions focusing on a child's functional impairment in everyday activities. The first question asks whether the parent believes that the child has a problem. If the parent answers "yes" to this question, the remaining questions assess chronicity, overall child distress, social impairment, and burden on others. Functional impairment is calculated from the evaluation of overall child distress and impairment related to family, friends, classroom learning, and leisure activities. Answers to these items of "not at all" and "only a little" were scored as 0; the answer "quite a lot" was scored as 1, and "a great deal" was scored as 2 points. The scores were combined to give a total impact score, which ranged from 0 to 10. A total impact score of 0 is considered normal, 1 is defined as borderline, and 2 is defined as abnormal. The burden on others is not included in the total impact score. In the present study, Cronbach's alpha for impact score was .79.

3.3.3.3 General functioning

Children's Global Assessment Scale (CGAS; Shaffer et al., 1983) is a clinician-rated tool to assess the global psychosocial functioning of the child, taking into account all available information. The score on this scale reflects the lowest overall level of the child or adolescent's psychosocial functioning (at home, at school and with peers) during the preceding month. The scale is separated into 10-point intervals headed with a description of the level of functioning followed by examples of

matching behaviour and life situations suitable for children and adolescents. The scoring ranges from 1 (the most impaired level) to 100 (the best level of functioning). Scores above 70 on CGAS indicate functioning within the range of typically-developing children of the same age as the child who is being rated (Mendenhall et al., 2011).

CGAS score <51 indicates major impairment, and CGAS scores 70-51 indicate mild impairment. In the original study by Shaffer et al. (1983) the intraclass correlation coefficient (ICC; inter-rater reliability) was .84, and the consistency over time ICC was .85. However, in a large Norwegian study of clinicians in outpatient child and adolescent mental health services (Hanssen-Bauer et al., 2007), the interrater reliability of the routine use of the CGAS was found to be moderate (intraclass correlation coefficient =.61). Generally, ICC can vary from .53 to .90 (Dyrborg et al., 2000; Rey et al., 1995).

3.3.4 Sociodemographic and socioeconomic factors

Children's age and gender were taken from electronic medical records. Information on parental age, gender, partnership status (married, cohabiting, or without a partner), mother tongue, education level, and occupational status were taken either from the background section of the DAWBA (Goodman et al., 2000) or from an appendix from The Parent Experience Questionnaire for Outpatient Child and Adolescent Mental Health Services (Garratt et al., 2011). These data were used to describe the sociodemographic status of participants. A single scale from The Family Stress Scale (i.e., socioeconomic/housing score; included in DAWBA, Goodman et al., 2000) was employed to assess parents' subjective experience of their socioeconomic situation in the last 12 months. The variable included questions about individually-assessed stressors related to unemployment, financial difficulties, their home being inadequate for their needs, and neighbours/neighbourhood. The parents rated the items on a 3-point scale (from 0 = "no" or "doesn't apply" to 2 = "a lot"). A dummy variable was created, where scores equal to two or higher were categorised as lower socioeconomic status (socioeconomic disadvantage; score = 0).

3.3.5 Health service evaluation

The Generic Short Patient Questionnaire (GS-PEQ; Sjetne et al., 2011), created by The Norwegian Knowledge Centre for the Health Services, is a generic set of 10 items on user experience with specialist health care in general. The GS-PEQ is based on the previous testing of six group-specific questionnaires, including parents' evaluation of user experiences for somatic inpatients (Garratt et al., 2007) and psychiatric outpatients (i.e. CAMHS patients; Garratt et al., 2011). The GS-PEQ included items regarding clinical services, user involvement, information, organisation, accessibility (waiting time), incorrect treatment, and items on the outcome (satisfaction and perceived benefit). In addition, the questionnaire's authors added three additional items relevant to CAHMS patients to the generic questions: one additional question regarding clinical services; information about the examination, and experienced cooperation, thus "Generic short version – caregivers about CAMHS" of the GS-PEQ (Sjetne et al., 2009) was used in this study. Items are in a question format. Twelve of them could be answered on a 5-point scale from "not at all" (0) to "to a great extend" (4). Each of these questions could also be answered as "not applicable". One question regarding waiting time to get an appointment at the institution could be answered on a 4-point scale from "not" (0) to "way too long" (3). Two of the questions about waiting time and wrong treatment did not correlate or correlated weakly with the other scores in the questionnaire, and they were used for comparison with administrative data, respectively in the Parent Assessment of Outpatient CAMHS (Bjertnæs et al., 2008; Garratt et al., 2011), and the Parents Experiences of Paediatric Care (Garratt et al., 2007).

3.4 Procedures

The children underwent clinical treatment as usual, with the standard interdisciplinary developmental/neurological assessment typically carried out over two consecutive days. In addition, they were screened for mental health problems (Halvorsen et al., 2019a, 2019b), and their caregivers evaluated satisfaction and experiences with the overall assessment. Paediatricians specialising in neurology examined children for the presence of a neurodevelopmental/neurological disorder;

the examinations included, for instance, MRI Caput, EEG and/or genetic testing if indicated. Children with muscle disease or motor delays were also examined by a physiotherapist. All children were examined by a clinical psychologist/neuropsychologist; these examinations included a standardised intelligence scale and the VABS-II (Sparrow et al., 2011). Participants' neurodevelopmental/ neurological diagnoses were provided at the interdisciplinary assessment at the neuropaediatric clinics and recorded in electronic medical records. International Classification of Diseases, Revision 10 criteria were applied to code the diagnoses (WHO, 2010). The presence of an ID was operationalised as a score below 70 on both a standardised Wechsler Intelligence Test and VABS-II (Halvorsen et al., 2019b). The parents completed the GS-PEQ (Sjetne et al., 2011) immediately after the neuropaediatric assessment.

3.5 Ethical considerations

The study was approved by the appropriate Ethics Committee for validating mental health instruments and examining user participation/satisfaction in a neuropediatric population. The data protection officer at University Hospital of North Norway and Finnmark Hospital Trust approved the use of de-identified data for research purposes.

The study was conducted in line with the Helsinki Declaration of ethical principles for medical research involving human subjects published by the World Medical Association (WMA, 2008).

Special consideration to the vulnerable child population was given. Harms and benefits balance was considered in undertaking this research; harms were minimised by using clinical assessment as usual without additional procedures directly involving the children. Children’s rights to privacy and confidentiality were respected by gathering only the crucial information for both clinical assessment and related research, and by keeping all records from the study confidential with only the researchers involved in the study having access to them. Electronic information was secured using password-protected files/pendrives.

Written informed consent was obtained before the participants were included in the study. For participants who were younger than 12 years, their parents gave consent. For participants between 12 and 16 years, written consent was obtained

from both the parents and the participants. Finally, according to Norwegian legislation, participants who were older than 16 gave their own consent.

3.6 Statistical analyses

Statistical analyses were mainly computed using the Statistical Package for the Social Sciences (SPSS) version 25 for Windows (IBM Corp., 2017; articles 1 and 3), SPSS version 26 for Windows (IBM Corp., 2019; article 2) and MPlus v. 7.4 (Muthén & Muthén, 1998–2017). A 5% significance level was adopted for all statistical tests.

SPSS was used to calculate/analyse:

- Descriptive statistics, e.g., percentages, means, standard deviations, missing values, ceiling effect.
- Cronbach's alpha to assess the internal consistency of the scales used in the studies (EFPA, 2013).
- Bivariate associations using the Pearson correlation coefficient.
- Hierarchical logistic regressions; the overall model was tested using a chi-square statistic/test ($\chi 2$).
- Hierarchical linear regression analyses; the significance of a change in explained variation (R^2) was assessed by applying a conventional R^2 change of 2% as a small effect, a change of 13% as a medium effect, and a change of 26% as a large effect (Cohen, 1988).
- Receiver-operating characteristic curve analysis (ROC-analysis; Ogilvie & Creelman, 1968); the area under the curve (AUC), and sensitivity, specificity, and diagnostic likelihood ratio [DLR = sensitivity/(1-specificity)] were also calculated.

MPlus v. 7.4 was used in article 1 to:

- Explore the internal structure of the EFQ through confirmatory factor analysis of the polychoric correlation matrix for the 10 EFQ items. Goodness-of-fit for the factor models was assessed using the chi-square test ($\chi 2$), and fit indices were based on chi-square: the incremental fit index of Tucker and Lewis (TLI), the comparative fit index (CFI) and the root mean square error of approximation

(RMSEA). A good model fit is typically reflected by high TLI and CFI (optimally above 0.95) and low RMSEA (optimally below .05) (Hooper et al., 2008).

- Examine latent variable regression - a type of structural equation modelling (SEM) analysis.

4. Summary of the articles

4.1 Summary of article 1

Aim: This paper aimed to study the applicability of the Everyday Feeling Questionnaire (EFQ) as a screening tool for parental mental health in a neuropaediatric sample. Another aim was to evaluate the psychometric properties including the structure of the EFQ, and to examine which child variables and background variables that were associated with parental mental health.

Methods: The participants included children and parents (*N* = 299) referred for neurodevelopmental/neurological assessment at neuropaediatric outpatient clinics who were assessed for concurrent mental health problems. One of their parents completed the EFQ. Background variables were mapped. Confirmatory factor analysis (CFA) for the EFQ was conducted. The internal consistency was calculated, and external validity was evaluated.

Results: It was confirmed that the EFQ has good reliability in terms of Cronbach's alpha, and correlates with well-known mental health evaluators supporting the construct validity. CFA revealed that the EFQ might be used as a unidimensional scale screening general mental health/illness, while taking into account additional sub-dimensions – stress symptoms and psychological well-being - gives a much better fit to the data. Parental mental health was more strongly associated with child functional impairment than child emotional/conduct difficulties; it was not associated with child neurodevelopmental disorders. Lower child adaptive functioning was associated with reduced parental mental health. Contextual variables such as SES and living without a partner were significantly related to parental mental health, although to a smaller degree.

Conclusions: The EFQ is a suitable screening tool for parental mental health in a neuropaediatric population. The EFQ might be used to screen parental mental health, yet we should be aware of its bi-factorial structure. The results partly confirmed earlier research that behaviour and emotional problems in a child, as well as the disadvantaged socioeconomic situation and living without a partner, are related to poorer parental mental health. Nevertheless, the impact of a child's difficulties in terms of reduced level of adaptive functioning and distress, appeared to

be a more important predictor of parental mental health than the child's intellectual function or behavioural/emotional difficulties.

4.2 Summary of article 2

Aim: This study aimed to examine the validity and usefulness of the impact supplement of the SDQ in measuring functional impairment in children diagnosed with ADHD or ASD.

Methods: Participants were children and adolescents (*N* = 337) referred to neuropaediatric outpatient clinics for neurodevelopmental assessment. Functional impairment was evaluated using three instruments: SDQ impact, VABS-II and CGAS. Mental health symptoms and intellectual function were also assessed. Convergent and concurrent validity of the SDQ impact were investigated. Correlations were calculated, and hierarchical multiple logistic regression analyses were performed, using ADHD and ASD diagnoses as dependent variables. In addition, the sensitivity and specificity of SDQ impact in classifying ADHD and ASD diagnoses were checked by receiver-operating characteristic curve analysis.

Results: The convergent validity of the SDQ impact was shown by its significant correlations with VABS-II composite score and CGAS total score. The concurrent validity of the SDQ impact was demonstrated by its significant relationship with ADHD and ASD diagnoses in logistic regression analyses. Using established cut-offs, the sensitivity of the SDQ impact to reveal functional impairment in children with ADHD and ASD diagnoses was demonstrated in this neuropaediatric sample, but at the cost of low specificity.

Conclusion: The SDQ impact is an easy-to-use tool. The overall study results support the construct validity and criterion-related validity of the test score, suggesting it may be used to screen general functional impairment in the neuropaediatric population.

4.3 Summary of article 3

Aim: The aim of this study was to examine determinants of parental satisfaction and the perceived benefit of e child neurodevelopmental assessment in neuropaediatric clinics.

Methods: The study was conducted among caregivers of children and adolescents aged 4-18 years (*N* = 330) referred for neurodevelopmental assessment in two neuropaediatric clinics in the specialised health service in Northern Norway. The GS-PEQ for child psychiatric outpatient patients was distributed to caregivers immediately following the assessment. Two of its items were used as outcome measurements of caregiver satisfaction with and perceived benefit of the assessment.

Results: Caregiver satisfaction with the assessment was correlated with a child's better general level of function, higher socioeconomic status, Norwegian as mother tongue, referral by a specialist, and the respondent being female. The higher perceived benefit of the assessment was correlated with higher SES, Norwegian as mother tongue and child's lower age. Regression analysis revealed that caregivers' perception that the assessment was suited to their child's situation and that there was good cooperation with other public services (e.g., primary care and social/educational services) seemed more important for caregiver satisfaction with neuropaediatric clinics' services than any background variable. A younger age of the child, caregivers' perception that the assessment was suited to their child and receiving sufficient information about the child's diagnosis/afflictions, were essential to the perceived benefit of the assessment.

Conclusions: Caregiver satisfaction with child neurodevelopmental assessment in neuropaediatric clinics partly depends on variables unrelated to the assessment experience *per se*. An assessment suited to the child, good cooperation with other public services such as primary health care and social/educational services, and sufficient information about the child's diagnosis are essential for an overall positive caregiver evaluation of neurodevelopmental assessments.

5. Discussion

This thesis focuses on assessment in the neuropaediatric clinics from the caregiver standpoint. The general objective was to study the validity and usefulness of screening instruments filled out by the caregivers, and the caregivers' satisfaction with the assessment. Three papers studied the objective from different perspectives. The following discussion begins with summarising the discussion from the papers, including limitations and clinical/research implications, followed by general and methodological considerations.

5.1 Discussion of the main findings

5.1.1 Screening of parental mental health

The usefulness of the EFQ as a screening instrument for parental mental health in a neuropaediatric clinical population was examined in Article 1. The additional aim was to check the relationship between parental mental health and some variables related to their children.

Overall, the results showed that the EFQ, with its good reliability and plurality of the screened symptoms associated with psychological well-being and distress, can be an indicator of whether a parent has some mental health problems. It can be concluded that the EFQ is as useful for the parents in the neuropaediatric population as for other adult populations. The issue may be whether screening parental mental health is necessary or meaningful in this child population.

Many studies pointed out that parents of children with developmental disorders suffer from more parental and parenting stress and worse mental health than parents of the normal child population (Eisenhower et al., 2005; Singer, 2006; Totsika et al., 2011a). The study results presented in article 1 indicate that parents in the studied neuropaediatric sample do not experience significantly reduced mental health compared to the general population. The EFQ score in this population was almost identical to the EFQ results in the general population (Wesselhoeft et al., 2019), and much lower than in the clinical adult population (Mann et al., 2013). Similarly to Hastings (2016), one can conclude that focusing on poorer mental health in the parents could be misleading, as most of the parents of children with

neurodevelopmental disabilities do not have emotional problems. As the results do not show reduced mental health at the group level, we can ask ourselves if the screening is necessary. It probably would be a misuse of health service resources if it took much time. However, the EFQ is not time-consuming if included in the DAWBA, and may provide the parents with a feeling of being seen and heard. Even though the mean EFQ score of the parental population did not indicate reduced mental health, it would be of high importance to identify those parents who have mental health difficulties as part of preventive mental health work. Furthermore, parental mental problems should be treated as a risk factor for developing child difficulties (Manning & Gregoire, 2006) instead of assuming *ad hoc* what is indirectly indicated in some studies (e.g., Olsson & Hwang, 2001), namely that parental mental health problems are somehow a result of experiencing difficulties with a child.

In this study, no significant relationship between parental mental health and a child's neurodevelopmental disorder or intellectual level was found (contradictory to e.g., Dekker & Koot, 2003b; Eisenhower et al., 2005; Hastings et al., 2006; Olsson & Hwang, 2001; Singer, 2006; Totsika et al., 2011a). However, parental mental health was associated with the child's behavioural and emotional problems (similar results from Baker et al., 2005; Emerson, 2003b; Giovagnoli et al., 2015, Raina et al., 2005; Tonge & Einfeld, 2003). These results can be explained by methodological issues such as high comorbidity within the diagnostic groups, and relatively small single-diagnostic groups in my study related to the clinical reality, where clinical diagnoses concern the clearest cases, and many more patients have symptoms that are regarded as problematic by parents.

The results showed that parental mental health was more strongly associated with a child's functional impairment than the child's clinical caseness. It seems that functional impairment can be more useful in studies on parental mental health, as this impact might be applied to all disorders (Stringaris & Goodman, 2013), and it brings important information about those who experience distress because of the symptoms but who do not meet criteria for a psychiatric disorder (Angold et al., 1999b). Therefore, parentally evaluated functional impairment can be a good expression of parental experience of the child's symptoms independently of which "diagnosis" they concern.

Of course, the statistical analyses show the relations between parental mental health variables and child symptoms. However, the possibility that these relations

result at least in part from a response bias cannot be excluded. Child symptoms variables used in the study were emanations of the difficulties perceived by parents and reported together with the measure of parental mental health during the same online session. In any case, these relations should be seen as complex and reciprocal.

The results also indicated that poorer parental mental health was related to being a single parent and lower socioeconomic status (existence of economic stressors), pointing out that factors related to parents are probably of higher importance to their well-being than child-centric variables (Falk et al., 2014). It is known from other studies that emotional and behavioural difficulties in children were related to lower socioeconomic status (Heiervang et al., 2007; Wichstrøm et al., 2012), and Emerson (2003b) reported that the association between child emotional and behavioural difficulties and maternal distress was significant only for families living in poverty. These known relations can indirectly imply that both parental mental health and child mental health can be affected by third variables, such as socioeconomic situation or family life problems. The extent to which the child's symptoms impair parents' life can depend on the other family-related factors (Rapee et al., 2012). Parents' subjective perceptions and evaluation of life events can be great predictors of parental well-being (King et al., 1999), and their coping strategies are of high importance for their well-being or experienced stress (Hsiao, 2018).

It is worth mentioning that in neuropaediatric clinics, it would be much more reasonable to measure parenting stress directly related to bringing up children with functional impairment (as in Almogbel et al., 2017; Craig et al., 2016; Esbensen, 2010; Hayes & Watson, 2013), and not general parental stress/mental health/depression that, as mentioned above, can be influenced by third variables.

5.1.2 Importance of functional impairment assessment

The validity and usefulness of the impact supplement of the SDQ in measuring functional impairment in children and adolescents diagnosed with ADHD or ASD in neuropediatric clinics were addressed in Article 2.

The results of this study supported the partial validity and usefulness of the SDQ impact supplement. The results indicated that screening with parentally reported functional impairment as measured by SDQ impact could be useful to

determine whether there is a problem. A test is not useful unless it leads to significantly better decisions than those taken randomly (Murphy & Davidshoffer, 2004). My results indicated that the SDQ impact supplement significantly, although slightly, improved the possibility of making correct clinical decisions. Using established cut-offs (Goodman, 1999), the sensitivity of the SDQ impact supplement to detect functional impairment in children with ADHD and ASD was demonstrated in this study. However, good sensitivity came at the cost of low specificity (a large proportion of false positives). Thus, the SDQ impact supplement is unsuitable for capturing functional impairment specific to these diagnoses, but it is valid for capturing general functional impairment in a neuropaediatric population.

It is important to note that the neuropaediatric sample in this study comprised of children and adolescents referred for neuropsychological/neurological assessment. The sample consisted of children with complex difficulties (Gillberg et al., 2014), and children with ADHD and ASD had many coexisting diagnoses that might have resulted in functional impairment. Apparently, the differences in SDQ impact scores between participants with ADHD or ASD and other functionally impaired children in this study were clearly less pronounced than those expected between these diagnostic groups and a control group in a general population (Russell et al., 2013). Such a restricted clinical sample can cause biased results (see Angold et al., 1999a). We cannot conclude which particular symptoms of ADHD, ASD, or coexisting psychopathology (e.g., Bakken et al., 2010; Mitchison & Njardvik, 2019; Simonoff et al., 2008) might lead to a specific functional impairment (Vazquez et al., 2018), as the relationships between these factors are complicated and reciprocal (Dykens, 2000; Thapar & Rutter, 2015), and often underpinned by shared biological vulnerability (Barnett et al., 2006).

The operational criteria for psychiatric or neurodevelopmental disorders stipulate that symptoms must result in substantial distress for the child or significant impairment in the child's ability to fulfil normal role expectations in everyday life (APA, 2013, WHO, 2019). Defining disorders solely in terms of symptoms results in implausibly high caseness rates, with most of the supposed cases not being significantly socially impaired by their symptoms, not appearing to be in need of treatment, and not corresponding to what clinicians would typically recognise as cases (Bird et al., 1990). Without an impairment, it is difficult to imply a disorder. However, the steadily increasing prominence of the neurodiversity paradigm and

social model of disability run contrary to the idea that characteristics of, for example, autism must be essentially impairing (Jellett & Muggleton, 2022). Some atypical symptoms may instead highlight the diversity amongst people (Cooper, 2013).

Cognitive capacity/reserve influences the expression of symptoms, and it results in more or less significant functional impairment because of impaired adaptive behaviour. The cognitive reserve model has been proposed to explain the relationship between learning disabilities and mental disorders (Barnett et al., 2006). The construct of "cognitive reserve" has also been used to explain the disjunction between the severity of neurological disease or damage and clinical outcomes (Stern, 2009). Cognitive reserve is a protective factor and a proxy measure (e.g., education, occupational attainment or IQ) of the brain's available reserve capacity to cope with brain damage and can explain differences in functional impairment in persons with similar symptoms.

In the unidimensional (global) measures, unlike the multidimensional measures (domain-specific), a single score is interpreted as the individual's overall level of impairment, and these are more helpful for research purposes than in clinical practice (Lewandowski et al., 2006). As Spitzer and Wakefield (1999) noted, the functional impairment criterion often plays little role in clinical practice (Zimmerman et al., 2004). Furthermore, in a clinical study such as my study, it is evident that most of the participants basically meet the impairment criteria.

From a clinical point of view, screening with SDQ impact may not be beneficial because the study participants in a naturalistic clinical study were somehow already "screened" for reduced adaptive functions through being referred to the specialist health care. Children referred to neuropaediatric clinics, entities on a specialised health service level, are considered in need of help because of disturbing symptoms and/or impairment at home, school or social life by their GP or a specialist. Before the referral, this initial screening could help to ensure that clinicians in specialised health care see only these children who are likely to be experiencing symptoms that cause impairment. The SDQ impact supplement could be used outside the specialist health care context by GPs or other helpers in primary health care to screen for functional impairment, indicating whether there is a need for a more comprehensive assessment.

How parents perceive impairments caused by the symptoms or, in other words, the influence that a child’s functional impairment has on its parents, is an

essential factor for parents seeking medical/psychological help for their children and a common reason for referral (Angold et al., 1998; Burns et al., 1995; Ezpeleta et al., 2002). When assessing functional impairment, it is crucial to remember that clinically-significant impairment can be based either on relative discrepancies between presumed potential and actual performance or absolute abnormality relative to the general population. Lewandowski et al. (2006) believe that impairment decisions should be made in comparison to the general population (the average person standard), not within-person comparisons (relative to their IQ), and not cohort comparisons (for example, a specific school class).

Considering these different approaches, it can be entirely possible that functional impairment as evaluated by parents may be exaggerated or underestimated. What does it really mean when somebody has significant problems in some life function areas? Determining the nature and range of distress or functional impairment, denoted together as a harm (Cooper, 2013; Wakefield & First, 2013) is more a philosophical problem. In fact, functional impairment should be related to a good life, not necessarily the best one. There is comprehensive agreement about the components of a good enough life or lack of functional impairment, which include the following: freedom from distress/persistent unpleasant experiences, being able to engage in those activities that are essential for self-maintenance, such as washing and cooking, having some friends, and being able to engage in some kind of meaningful activity (which may be a job or a hobby), (Cooper, 2013). However, estimating a life as good or impaired depends on the individual's own and others' expectations about fulfilling life roles or functions. Moreover, the difference between functional impairment (there is something not working concerning life functions) and disability (reduced participation due to impairment, activity limitation and participation restriction; WHO, 2001) is not always understood.

One might question whether it is acceptable to use a short form to evaluate a phenomenon as complex as functional impairment (Winters et al., 2005). However, Bird et al (1996) supported using global measures of impairment for both epidemiological and clinical purposes. Obviously, the best way to determine functional impairment specific to some symptoms is screening all the important functioning areas. Yet, such advanced measurement methods need to incorporate diagnosis-specific impairment indicators to avoid the potential for cognitive biases,

such as the halo effect in ratings for specific impairments (Bird et al., 2000). At the same time, we should be aware that functional impairment can be caused by both symptoms and a non-adapted environment (WHO, 2001).

Considering the issues described above the SDQ impact supplement has a clear advantage; it is culturally and contextually neutral (see: Haack & Gerdes, 2011). Parents are generally asked about the child's problems in everyday life without highlighting specific situations. Then the parent evaluates the child's functional impairment from a cultural or contextual perspective appropriate for a child brought up in this specific environment.

5.1.3 Experiences of the neuropsychological/neurological assessment

The third article aimed to examine which parental experiences with the neuropaediatric clinics were crucial for satisfaction with and perceived benefit of the service, and which background variables were associated with these outcome variables.

The clearest result of this study was that most parents were highly satisfied with the assessment. In other words, the results were seriously positively skewed, a known tendency in standardised surveys (Carr-Hill, 1992). It is assumed that satisfaction surveys embody patients' evaluations of services, but as most surveys report high satisfaction levels, it is problematic to interpret satisfaction as the outcome of an active evaluation (Williams et al., 1998). In that situation, only less satisfied parents with less positive experiences constituted the base for further analyses and conclusions. Relatively many caregivers evaluated experiences with involvement in the assessment, cooperation with other services, and getting sufficient information about a child's diagnosis/afflictions as either more negative or not relevant for them compared to other experience areas. User experiences can be an essential component of health services evaluation and may be used for quality improvement of service delivery. Accordingly, there are some improvement areas when caregivers' experience is both neutral or negative. Thus, there is room for improvement in the neuropaediatric clinics in the area of cooperation with other public services, caregivers' involvement in decisions regarding child's treatment and giving sufficient information about child's diagnosis or afflictions. However, the results

also showed that only around 13% of parents were not fully satisfied, and often only to a small degree. In comparison, Arnadottir and Egilson (2012) proposed that the boundary for inadequate service areas should be based on items that at least 33% of respondents marked as less positive.

From regression analyses, two main types of experiences with the assessment were crucial for explaining the overall satisfaction, i.e. assessment suited to the child's situation and cooperation with other public services, highlighting that these are highly important for experiencing satisfaction with health care. The situation seemed different for the perceived benefit of the assessment. Parental experiences explained this outcome to a smaller degree. Crucial experiences for the perceived benefit of the assessment were assessment suited to the child's situation, and getting sufficient information about the child's diagnosis/affliction after the assessment. In fact, all evaluated experiences were correlated with satisfaction and benefit and each other to such a degree that some experiences were not significant due to high inter-correlations between predictors in the regression analyses. One can assume that the relations typically between experiences, satisfaction and benefit were related to the third factor - possibly the way of answering, especially in a situation where questions about experiences and satisfaction were combined in a single survey.

It also was found that some background variables, such as the child's age and global psychosocial functioning, family's mother tongue and socioeconomic status, were weakly correlated to the parental evaluation of the assessment. The conclusion is that the background variables should be considered when interpreting user satisfaction surveys. The possible explanations of these relations were explained in the discussion in my third article. From the regression analyses, it was observed that specific experiences with the assessment explained overall satisfaction with the assessment in the highest grade, beyond almost all the background variables, probably because these background variables were more or less correlated to all these questions about experiences and satisfaction. Generally, existing small relations between demographics and service evaluations can have two explanations: different groups may have different response tendencies, or different groups may be treated differently in the process of care (Carr-Hill, 1992). It was then concluded that specific experiences with service delivery were related to the outcome, such as global satisfaction and benefit, to a much greater extent than background variables

(compare Bleich et al., 2009), confirming the Norwegian study by Danielsen et al. (2010).

An important issue that should be discussed is the usefulness of the GS-PEQ in the neuropaediatric outpatient clinic population, and it is evident that this survey is not the best choice. When creating the GS-PEQ, one criterion for exclusion was that the prevalence of “not applicable” responses should not exceed 20%; otherwise the question/item should be excluded from the questionnaire for a specific clinical group (Sjetne et al., 2011). In my study, as many as one-fifth of the respondents evaluated questions about involvement and cooperation as irrelevant for the situation of their child; thus, these questions should be reformulated or excluded from the questionnaire for neuropaediatric clinics. Moreover, the development of questionnaires for new groups should incorporate their specific experiences, which focus group interviews may provide (Iversen et al., 2012), and that was not done for the studied population.

Many answers about "irrelevant questions" indicate that the respondents did not recognise these areas as a responsibility of the clinics, especially if a child was referred only for a one-time assessment by specialists, and this assessment was well-defined. In this situation, other questions could be better fitted to the survey. Alternatively, there is a possibility that the questionnaire was delivered to the parents too close to the assessment time, and some questions were not relevant because it was impossible to evaluate the consequences of the treatment, such as the subsequent cooperation. The term "treatment" used in the questionnaire might also be problematic and could cause questions to be misunderstood (including the question about involvement). This is because it was not strictly "treatment" these parents came for, but "assessment", including diagnosis. Some children came for re-assessment and check-ups, and for them, the survey questions were not so relevant.

5.2 General limitations and methodological considerations

5.2.1 General limitations

Overall, the study has significant strengths, such as a natural clinical context and real clinical diagnoses. However, the study also has some limitations.

No control or comparison group was included in the study. The studied group itself had some complex difficulties. Children with neurodevelopmental disorders are often dealing with a diverse constellation of symptoms and levels of impairment, which are not necessarily separable diseases (Gillberg et al., 2014), or with a considerable variation in executive functions in the same diagnostic group (for example heterogeneity of ADHD and ASD; Dajani et al., 2016).

The diagnostic groups were small, and many of the children had coexisting neurodevelopmental or neurological disorders. Moreover, several patients had coexisting mental health problems (Halvorsen et al., 2019b). This creates some limitations on statistical calculations as explained in article 2 (discussed in 5.1.2). Even though the sensitivity and specificity of the SDQ impact were determined in my second study, they should be determined again in new groups or contexts, as tests may perform differently in different groups of subjects and for different severities of diseases (van Stralen et al., 2009). It is important to remember that the results are not ultimate or permanent, as measures of diagnostic accuracy are very sensitive to the design of study and can easily over- or underestimate the subject of the test in studies that do not meet strict methodological standards, and thus limit the applicability of the results of the study (Eusebi, 2013).

In my studies, a clinical sample with children referred for neuropaediatric assessment was employed; this presupposes that their parents probably regarded them as impaired, so the results are limited to comparable clinical populations. Both statistical and conceptual challenges arise in criterion-related validation when conducted on a preselected sample, making the generalisation of the results to decision-making in the broader population challenging (Guion & Cranny, 1982). Furthermore, the observed associations may be smaller, as the variation in a selected population is restricted (i.e., participants are too similar to each other and too different from other samples) (Murphy & Davidshoffer, 2004). However, the

possibility that the statistically significant relations in this clinical population can be even stronger in the general population cannot be ruled out.

The cross-sectional design limits the possibility of drawing conclusions about causality between the variables; we cannot exclude the possibility of a reciprocal association between the “predictive” variables such as, for example, child mental health (article 1) or parental experiences with the assessment (article 3) and "outcome" variables such as parental mental health (article 1) or satisfaction with the assessment (article 3).

There are some limitations related to the data collection. For example, there was a lack of complete information on who filled each of the questionnaires; thus analysing data in relation to the parent gender was not always possible. In addition, there is no information about whether the EFQ/SDQ was filled in by the same parent who filled in the GS-PEQ. The EFQ and the rest of the questionnaires related to the assessment were completed before evaluating experiences with the assessment. Therefore, it is possible that it was not filled in by the same caregiver.

There are also some other limitations related to the study design. The methods used do not thoroughly support the perspectives in the articles. For example, questions about parental demographics for study 3 could be more child-focused (e.g. instead of a question about being married, a question about a child living with both parents). To check relations between child difficulties and parental well-being, parenting stress related strictly to bringing up a child with some impairment would be a much more reasonable choice than general parental mental health (well-being and distress). The study design did not directly concern the parents and SES, even though there are some indicators of both issues.

Limitations of the study also include the surveys used. The most problematic choice was the GS-PEQ, which was not validated in the neuropaediatric population and could not be validated in my study because of a lack of necessary validation steps such as focused group work. For example, GS-PEQ was not piloted with health professionals for content validity, i.e. if it covered the important aspects of patient experience and care coordination in neuropaediatric outpatients. It was not piloted with outpatient patients/their parents to ensure face validity and acceptability, for example clarification, wording, whether the questionnaire was acceptable, with logical response categories and if the questions covered their children's clinical path. Regarding the EFQ, it was not possible to look closely at convergent and divergent

validity because there were no other parental mental health/well-being measures in this study, and no separate measures to be used for examination of divergent validity.

Another possible limitation concerns short forms that probably do not consider the complexity of the measured phenomena. Using generic surveys, maximising variation of the questions from diverse user dimensions for different patient groups, can be questionable when we again use the questionnaire with specific patient groups.

Most of the limitations in this study are related to the organisational and planning matters around "the umbrella project". My study, not being an exception in comparison to many others, was based on a ready dataset, and no additional data collection was possible because of the privacy policy restrictions.

A problem related to the “ready dataset” can be so-called "cherry-picking": searching through data to find the results that offer the strongest possible support for a particular research question (see Murphy & Aguinis, 2019), mainly related to the choice of variables for regression analyses in my studies. Every chosen variable for a regression analysis can change the final result. Therefore, the interpretation of the results from studies presented in the first and third articles must be taken with caution. In the result of regression analyses, correlations between variables are included in the calculations, which can cause some methodological bias depending on which dependent variables we choose. For example, in the study on parental mental health, the conclusion was that functional impairment was most strongly related to parental mental health, while both SES and living with a partner were related to parental mental health as well, but contributed to the explanation of parental mental health to a minor degree. In fact, parental mental health is causally probably more related to SES and living with a partner. However, parents evaluated both functional impairment and their own mental health, and we cannot exclude the possibility that the strongest relationship between child's functional impairment and parental mental health is related to the responding bias.

All the conclusions in my studies emphasise the importance of found statistically significant relations, while relatively small correlations express these relations.

5.2.2 Biases

Because parents were the only respondents for most of the surveys in my study, there is possibility for source information bias. That is especially important to take into account as covariation is estimated based on variables that were all assessed by parents.

The phenomenon of response bias was first described by Cronbach (1946, 1950) as a response set. It can be defined as the existence of stable and consistent individual differences in the way of responding to self-report items/surveys. The most known response sets are acquiescence (yea-saying), socially desirable responding and extreme responding (Austin et al., 1998). Sitzia and Wood (1997) mentioned some of the biased ways of answering to user evaluations, such as social desirability bias, cognitive consistency theory, Williams' theory (dissatisfaction is only expressed when an extreme negative event occurs), or gratitude. Such psychosocial determinants are important for how patients evaluate health care services and could influence responses to the satisfaction survey and cause an implausibly high ceiling effect in the study presented in the third article.

Some authors studied the depression-distortion hypothesis, i.e. the distorting influence of maternal depression on the ratings of child functioning. Richters (1992) proposed two models concerning the influence of maternal depression on informant reliability. The distortion model refers to overreporting of child behaviour problems by depressed mothers, and the accuracy model refers to accurately reported child behaviours by depressed mothers. Garstein et al. (2009) examined the depression–distortion hypothesis and revealed a modest effect of maternal depression, leading to the inflation of reported son-externalising and daughter-internalising problems. Study results from Müller et al. (2011) suggested that ratings of child behaviour by mothers may be biased by maternal psychopathology; the conclusion is based on only low to moderate agreement between different informants. Later studies confirmed a psychopathology-related bias in mothers' ratings that overestimate a child's psychopathology (Müller & Furniss, 2013; Müller et al., 2014). It is possible that children of depressed mothers have more internalising problems, and depressed mothers overstate and overgeneralise their offspring's behaviour problems (Chilcoat & Breslau, 1997). In addition, caregiver depression, anxiety and stress are related to

higher disagreement with other informants such as children or teachers (Briggs-Gowan et al., 1996; Youngstrom et al., 2000).

Results from my first article can confirm the distortion model. Parental distress/reduced mental health was significantly related to child behavioural problems, but not to child behavioural diagnosis given by clinicians, contradictory to emotional diagnosis which remained related to parental mental health (see tables in article 1).

Another source for biased responding can be defensive responding, which describes personal or social goal-directed behaviour used to control the perceptions and evaluations others have of oneself (Leary and Kowalski 1990). Some parental characteristics, their motives and goals can affect responses about children. Results of the study on defensive responding on a widely used measure of child psychopathology, while controlling for maternal psychopathology, child race, age, and gender, indicated that mothers who were engaged in defensive responding reported reduced internalising and externalising symptoms in children (Castagna et al., 2017). There is a great deal of evidence that a wide range of parental characteristics are related to their way of responding. For example, mothers with a history of alcohol dependence, and mothers who rate their marital satisfaction differently from their spouses, may be more sensitive to their child's true anxiety than the child itself, or the father, or from a different perspective: they may overrate their child's anxiety as a function of their own personal or marital difficulties (Foley et al., 2005).

The relationship between the informant (e.g. a parent) and the child is complex and influenced by the interplay of the individual characteristics of both child and parent, and can confuse child behaviour research and clinical evaluations. The quality and usefulness of parental reports on child behaviour depend on the informant's beliefs about specific behaviours related to child characteristics, such as the child's age, and the informant's mental state during reporting (Smith, 2007). Ordway (2011), in an integrative review, concluded in particular that multiple informants and identification of maternal depression should be incorporated in research on child behaviour. As shown, evaluations made by parents with decreased well-being can be biased, and that is probably the best reason for checking for parental distress together with screening a child's symptoms. The conclusion is that the reliability and validity of maternal reporting on child behaviour in the presence of

self-reported maternal depressive symptoms should be carefully reviewed for potential psychosocial influences on outcomes (Mulvaney et al., 2007).

5.3 Clinical implications and future directions

5.3.1 Clinical implications

The failure to understand the distinction between statistical and clinical significance is a common error in the reporting and interpretation of clinical research. Statistically significant results mean there is a probability that the results are not the effect of chance. In contrast, clinically significant results mean the impact of the outcome on a patient's management and care. Applying clinical data requires clinical judgement, not just calculations of quantitative data. The statistically significant result on a large sample does not need to be of a high clinical significance and small effects can be of high clinical importance (Thomas et al., 2015).

As clinicians have overall positive attitudes toward using standardised assessment methods (Danielson et al., 2019; Jensen-Doss & Hawley, 2010), including screening instruments in clinical practice beyond standard assessment questionnaires and interviews could be time-saving in some less complicated cases.

This study shows the usefulness of some screening tools for clinical decision-making/evaluation, and may show some implications about the use of these tools in preventive work outside the clinic. For example, early knowledge about parental mental health problems might help initiate early intervention strategies that can prevent parental stress and reduce the risk of potential incidence of depression and anxiety in parents. According to Popov et al. (2021) who explored the value of parent mental health screening in children´s rehabilitation services, simply identifying parents who struggle is only the first step in possible screening programmes which should initiate an adequate follow up with identified parents.

Knowledge about reduced parental mental health can be used both to give more extended support to the families, and as a potential help in the interpretation of reported child difficulties by these parents. Screening of functional impairment using a single question could be used to immediately determine the child's functioning level, as this level does not differ from well-established instruments such as VABS-II, as proved in article 2.

Screening of parental mental health, functional impairment and evaluation of the assessment can be a useful way to start a discussion about the environment around a child, and parental expectations and hopes concerning the assessment. Screening instruments are easy to use and can be very convenient, as they provide useful information without taking up much of parents' time and also saving clinicians' time. Screening for mental health problems allows for reaching more people and maximising the appropriate identification of mental health problems (Lavigne et al., 2016). The use of standardised screening tools for developmental delays or developmental disorders is of critical importance for early identification, evaluation, and intervention (Chlebowski et al., 2013; Hatakenaka et al., 2017; Nygren et al., 2012; Radecki et al., 2011), and my study given in the second article supports using SDQ impact supplement in such early identification.

5.3.2 Future research

Given the limitations of my study, I have deliberated over future research using the same studied subjects, but with a more acceptable methodology than used in my studies.

Future research could measure parenting stress directly related to bringing up impaired children, rather than parental mental health/well-being. It would also be interesting to obtain further knowledge about sick leave parents are given, registered usage of medical/psychological consultations, and parents' diagnoses to obtain more objective knowledge about their health status (see: Brekke & Nadim, 2017; Wendelborg & Tøssebro, 2016).

Models of understanding distress/ well-being in parents in the context of bringing up a child with functional impairment need to consider a range of contextual and psychological factors, including poverty (income), family functioning, coping strategies, optimism etc. that were not assessed within the present study.

Regarding the second article about functional impairment, using a control group would be the best way to validate the further use of SDQ impact supplement outside the specialised health care.

Future research could apply a longitudinal design to the association between parental distress/well-being and other factors. For example, it would be interesting to know how getting a diagnosis or medical help for children improves the life quality of

the parents and family in terms of well-being, parental distress, direction and the dynamic of the relationship. In addition, one could consider the evaluation of the assessment and its relation to the earlier and further usage of health care services.

The user evaluation survey should be better adjusted to a clinical group. There is a worldwide recognised tool Measure Processes of Care (Bjerre et al., 2004; Cunningham & Rosenbaum, 2013; King et al., 2004) for this type of population, and it should be used on neuropaediatric population in future research in Norway as well. In addition, a mixed-method approach – both quantitative and qualitative is a better choice for studying parental evaluation of the child's assessment. A mixed-method approach allows researchers to move beyond the ceiling effect of quantitative patient satisfaction measures and achieve a more meaningful explanation of user satisfaction (Andrew et al., 2011).

5.4 Conclusion

The short surveys used in my study are time-saving, more motivating to be filled in, create less burden, are easier to interpret, and allow comparisons between different populations and health care units. There are also some disadvantages to using them as they can be superficial and not capture specific experiences or states. The screening tools tested in specialised health care can be considered as a suitable choice for use in primary health care settings when considering factors such as their accuracy, time of application, ease of scoring, and utilisation charges, even if they were not tested in that context.

Screening parental mental health problems can be used to give extended support to families with more distressed parents, and it may help interpret reported child difficulties. Screening for a child's functional impairment by SDQ impact supplement can capture general functional impairment in a neuropediatric population and possibly in the general population, eliciting further investigation. The conclusion is that this tool is easy to use and can be particularly convenient, as it provides useful information about functional impairment as seen by parents without taking up much of parents' time and also saving clinicians' time. Overall, as assessed by parents, the child's functional impairment is a good indicator of clinical significance and the child's symptoms and burden experienced by parents, as it is also related to parental distress.

The conclusion about parental experiences with the assessment was that an assessment that was adapted to the child's needs, good cooperation with other public services such as primary care and social/educational services, and giving sufficient information about the child's diagnosis are experiences that are essential to an overall positive evaluation of child neurodevelopmental assessment. In addition, clinicians should be particularly vigilant in including caregivers in decision-making and in discussing the possibilities for cooperation with other services. This is because parents undoubtedly have an indispensable role in assessing a child's problems, and their opinions can be used to improve health service delivery.

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Paper I

Received: 2 October 2019 | Revised: 4 June 2020 | Accepted: 30 October 2020

DOI: 10.1111/jar.12834

ORIGINAL ARTICLE

JARID Journal of Applied Research in Intellectual Disabilities bild WILEY

Parental mental health screening in a neuropaediatric sample: Psychometric properties of the Everyday Feeling Questionnaire and variables associated with parental mental health

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Funding information
Helse Nord RHF, Grant/Award Number: PFP1178-14.

Abstract

Background: Many previous studies have highlighted distress in parents of children with neurodevelopmental disorders. Further knowledge about the relationship between parental mental health and children's characteristics could help neuropaediatric services improve treatment. The current study examined the applicability of the Everyday Feeling Questionnaire (EFQ) as a screening tool for parental mental health in a neuropaediatric sample.

Methods: Children and adolescents (N = 299) referred to neurodevelopmental/neurological assessment at neuropaediatric outpatient clinics in Northern Norway were assessed for concurrent mental health problems; one of their parents completed the EFQ.

Results: The EFQ items loaded highly on a general mental health factor. Parental mental health was more strongly associated with child functional impairment than child emotional/conduct difficulties; it was not associated with child neurodevelopmental disorders.

Conclusions: The EFQ is a suitable screening tool for parental mental health in a neuropaediatric population. Child functional impairment seems an important predictor of parental mental health.

KEYWORDS
behavioural problems, emotional difficulties, functional impairment, neurodevelopmental disorders, parental mental health, screening tool

1 | INTRODUCTION

Parental mental health problems negatively affect the social, cognitive, emotional and behavioural development of children (Goodman & Gotlib, 1999; National Research Council and Institute of Medicine, 2009; Manning & Gregoire, 2009; Totsika et al., 2013). Knowledge about parental mental health is especially important among parents of children with intellectual and developmental disabilities, as minimising parental stress and maximising parental well-being could lead to more positive outcomes for these children (Cachia et al., 2016; Neece, 2014; Wickramaratne et al., 2011).

There is an association between reduced parental mental health and child neurodevelopmental disorders (e.g. attention-deficit/hyperactivity disorder, ADHD, autism spectrum disorder, ASD, and intellectual disability, ID; Eisenhower et al., 2005; Singer, 2006; Totsika et al., 2011). However, parental mental health problems seem to be more strongly associated with behavioural problems in these children than with neurodevelopmental disorders *per se* (Baker

et al., 2005; Emerson, 2003a; Giovagnoli et al., 2015; Harrison & Sofronoff, 2002; Raina et al., 2005; Tonge & Einfeld, 2003; Totsika et al., 2011). Fewer reports have linked parental mental health and child emotional problems in populations with neurodevelopmental disorders (Emerson, 2003a; Giovagnoli et al., 2015). Some authors have suggested a relationship between parental mental health and specific child difficulty outcomes, emphasising the role of parent-reported psychological and social impacts (Emerson, 2003a) or general caregiving demands (e.g. Raina et al., 2005).

Mental health problems are usually associated with significant distress and a reduced level of adaptive functioning in important daily activities (American Psychiatric Association, 2013). Measuring the impact of child mental health symptoms in terms of distress (worry and upset caused by the symptoms) and functional impairment (reduced level of adaptive functioning in everyday activities) allows for greater accuracy in distinguishing between clinical and community subjects than does the use of symptom scores alone (Goodman, 1999; Stringaris & Goodman, 2013). However, few studies have focused on the direct relationship between child functional impairment and parental mental health. Miller et al. (2016) showed that child functional characteristics were more strongly associated with parental health and well-being than child diagnosis. In another study (Almogbel et al., 2017), parents of children with neurodevelopmental disabilities classified as functionally impaired had a 5.5-fold higher risk of clinically significant scores of parenting stress. A higher social impact of the difficulties in children with ID significantly increased the odds for maternal psychiatric morbidity in another study (Emerson, 2003a). This relationship is also visible in the general population, including the psychological impact of child difficulties on psychiatric morbidity in mothers (Emerson, 2003a).

Socioeconomic status (SES) and the presence of adult support in the household have also been found to be related to parental mental health. In a study by Olsson and Hwang (2001), single mothers of children with disabilities more often suffered from severe depression than mothers living with a partner. Many studies have pointed out the moderating effect of SES on the relationship between parental mental health and child difficulties (Emerson, 2003a; Emerson et al., 2006; Hatton & Emerson, 2009; Olsson & Hwang, 2008).

The current study focuses on parental mental health in relation to child characteristics and examines the usefulness of the Everyday Feeling Questionnaire (EFQ; Uher & Goodman, 2010) as a screening tool for parental mental health in a neuropaediatric sample in Norway. Few studies have examined the applicability of the EFQ (Bøe et al., 2014; Mann et al., 2013; Uher & Goodman, 2010; Wesselhoeft et al., 2018), and to the best of our knowledge, it has never been tested among parents in a neuropaediatric sample.

This study aimed to examine if the EFQ is a unidimensional instrument, as assumed by Uher and Goodman (2010), and whether it is reliable and useful for parental mental health screening in a neuropaediatric population. Another aim was to investigate associations between the EFQ and child diagnoses, symptom scores and functional impairment, controlling for demographic variables in a neuropaediatric clinical sample. Based on earlier studies, we hypothesised that both neurodevelopmental disorder diagnoses (ADHD, ASD or ID) and emotional and behavioural difficulties in the child would be related to parental mental health problems. We expected that the impact of child difficulties in terms of distress and functional impairment, as evaluated by parents, would be significantly associated with parental mental health. In addition, we expected that lower SES and living without a partner would be associated with decreased parental mental health.

2 | METHODS

2.1 | Participants

Patients aged 4–18 years were recruited from the neuropaediatric outpatient clinics at the University Hospital of North Norway between October 2012 and July 2016 (n = 251) and the Finnmark Hospital Trust between January 2014 and July 2016 (n = 48) (see Halvorsen et al., 2019 for more information). The neuropaediatric outpatient clinics are specialised health care service units in the counties of Troms and Finnmark in Northern Norway and serve a population of 266,000 inhabitants. These facilities provide services to children and adolescents with neurodevelopmental/neurological disorders or early acquired disabilities, developmental delays, ID and developmental disabilities. Assessment teams are interdisciplinary, including specialists such as paediatricians, neuropsychologists, special education therapists and physiotherapists. The present analysis is based on a sample of 299 children and adolescents referred to neurodevelopmental/neurological assessment and who had one parent who completed the EFQ (N = 299).

2.2 | Measures

2.2.1 | Parental mental health

Parental mental health was assessed with the self-administered version of the EFQ (Uher & Goodman, 2010), which is a part of the Development and Well-Being Assessment (DAWBA; Goodman et al., 2000), and consists of 10 items that measure symptoms related to depression and anxiety (e.g. "tired or lacking in energy" and "worried or tense"), as well as items on psychological well-being, such as optimism, self-esteem and coping (e.g. "positive about yourself" and "able to cope with what life brings"). There are five response options reflecting the frequency with which the respondent experienced these symptoms in the last 4 weeks (from "none of the time" to "all of the time"). The scoring of positively worded items regarding psychological well-being was reversed, and all the items were summarised into a total score. Higher scores represent higher levels of distress and lower levels well-being. The EFQ has been validated in both epidemiological (Uher & Goodman, 2010) and clinical populations (Mann et al., 2013). Factor analyses demonstrated that distress and well-being existed

on a single continuum (Mann et al., 2013; Uher & Goodman, 2010). The EFQ has good internal consistency, with Cronbach's α = .89 reported in a non-clinical population (Uher & Goodman, 2010), and Cronbach's α = .90 (test) and .97 (retest) reported in a clinical population (Mann et al., 2013).

2.2.2 | Child neurodevelopmental diagnoses

Participants' neurodevelopmental/ neurological diagnoses were provided at the interdisciplinary assessment at the neuropaediatric clinics and recorded in electronic medical records. International Classification of Diseases, Revision 10 criteria were applied to code the diagnoses (World Health Organization, 1993, 2010). The presence of an ID was operationalised as a score below 70 on both a standardised Wechsler Intelligence Test and Vineland-II (Halvorsen et al., 2019).

2.2.3 | Child mental health diagnoses

The DAWBA (Goodman et al., 2000) was used to determine diagnoses of mental health disorders based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders, Version IV (DSM-IV; American Psychiatric Association, 2000) (www.dawba.info). The present study used a web-based DAWBA, which included a detailed psychiatric interview for parents (N = 299), a youth interview (n = 103) and a short questionnaire for teachers (n = 220). The DAWBA contains modules for diagnoses related to common emotional disorders like anxiety and depression, conduct/oppositional disorders, and other, less common, disorders, as well as modules for background information (more about the child's health, the Family Stress Scale, the EFQ) and the child's strengths. The DAWBA discriminates both between population-based and clinical samples and between different diagnoses (Goodman et al., 2000). The DAWBA generates realistic estimates of the prevalence of mental illness and has shown high predictive validity when used in public health services in Norway (Brøndbo et al., 2013; Heiervang et al., 2007). Good to excellent agreement between diagnoses from clinical practise and diagnoses based exclusively on the DAWBA has been reported, with Kappa values between 0.57 and 0.76 for different diagnoses (Foreman & Ford, 2008; Foreman et al., 2009). Inter-rater reliability was reported in British and Norwegian studies, with Kappa values of 0.69–0.91 for any disorder, 0.57–0.93 for internalising disorders and 0.82–1.00 for externalising disorders (Brøndbo et al., 2012; Ford et al., 2003; Heiervang et al., 2007). After completion of the DAWBA interview, two expert raters (BM and PHB), both senior clinical specialists in neuropsychology with long experience in the field and trained in DAWBA ratings (Brøndbo et al., 2012), generated diagnostic ratings based on the answers provided by the parents, teachers and youths (Halvorsen et al., 2019). Inter-rater agreement rates for diagnoses in this study are not available. However, our expert raters achieved agreement rates of κ = 0.70 for emotional diagnosis and κ = 0.82 for conduct diagnosis in another study (Brøndbo et al., 2012).

2.2.4 | Child mental health symptoms

The parent version of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1999) was also part of the web-based DAWBA. The SDQ consists of 25 items measuring symptoms in four problem domains (emotional difficulties, hyperactivity-inattention, conduct problems and peer problems) and one area of strength (prosocial behaviour). There are three response alternatives: "not true," "somewhat true" and "certainly true." The SDQ includes an Impact Supplement of eight questions focusing on child functional impairment in everyday activities. The first question asks whether the parent believes that the child has difficulties. If the parent answers "yes" to this question, the remaining questions assess chronicity; overall child distress; social impairment related to family, friends, classroom learning and leisure activities; and burden for others. Answers of "not at all" and "only a little" are scored as 0; the answer "quite a lot" is scored as 1; and "a great deal" is scored as 2 points. Items assessing impairment and distress were combined to give a total impact score, ranging from 0 to 10. A total impact score of 0 is considered normal, 1 is defined as borderline and 2 as abnormal. Burden for others is not included in the total impact score. The SDQ has satisfying to good psychometric properties, and it has been used in clinical and non-clinical child and adolescent populations (Emerson, 2005; Goodman, 2001; Smedje et al., 1999; Stringaris & Goodman, 2013). In the present study, the included scales had the following Cronbach's alphas: .75 for emotional difficulties, .68 for conduct problems, .85 for total difficulties score and .79 for total impact score. The alpha value for conduct problems fell below the conventional acceptable range. An alpha value of .68 with five items in the scale corresponds to an average correlation between the items of approximately .30. However, given that the conduct problem items describe very different conduct behaviours, it is not surprising that the average correlation was of moderate size.

2.2.5 | Sociodemographic and socioeconomic factors

Children's age and gender were taken from electronic medical records. Information on parental age, partnership status (married, cohabiting or without partner), education level and occupational status were taken from the background section of the DAWBA (The Family Stress Scale; Goodman et al., 2000) or additional questions from an adapted version of The Parent Experience Questionnaire for Outpatient Child and Adolescent Mental Health Services (Garratt et al., 2011). These data were used to describe the sociodemographic status of participants. A single scale from The Family Stress Scale (i.e. socioeconomic/housing score) was employed to assess parents' subjective experience of their

socioeconomic situation in the last 12 months. The variable included questions about individually assessed stressors related to unemployment, financial difficulties, home inadequate for needs and neighbours/neighbourhood. The parents rated the items on a 3-point scale (from 0 (no, or does not apply) to 2 (a lot)). A dummy variable was created, where scores equal to two or higher were categorised as lower SES (score = 0).

2.3 | Ethical considerations

Informed consent was obtained from the parents of all participants included in the study. The data protection officer at the University Hospital of North Norway and the Finnmark Hospital Trust approved the use of de-identified data for research purposes.

2.4 | Statistical analyses

We explored the internal structure of the EFQ through confirmatory factor analysis (MPlus v. 7.4, Muthén & Muthén, 1998–2012) of the polychoric correlation matrix for the 10 EFQ items. Goodness-of-fit was compared for two models (similarly to Mann et al., 2013; Uher & Goodman, 2010): a single common factor model (general mental health), and a model with a common factor (general mental health) with residualised first-order method factors expressing positive and negative experiences. Goodness-of-fit for the factor models was assessed using the chi-square test (χ^2), and fit indices were based on chi-square: the incremental fit index of Tucker and Lewis (TLI), the comparative fit index (CFI) and the root mean square error of approximation (RMSEA). A good model fit is typically reflected by high TLI and CFI (optimally above 0.95) and low RMSEA (optimally below 0.05) (Hooper et al., 2008).

Latent variable regression, a type of structural equation modelling (SEM) analysis, was used to examine the relationship between parental mental health and background variables; child neurodevelopmental disorders; either DAWBA child mental health diagnoses (emotional disorders and conduct/oppositional disorders, model 1) or SDQ child mental health symptom scores (emotional difficulties and conduct problems, model 2); and the SDQ total impact score (indicating functional impairment).

The remaining statistical analyses were carried out using SPSS version 25 for Windows (IBM Corp., 2017). Descriptive statistics were computed to present child, parent and family characteristics. Cronbach's alpha was calculated to assess the internal consistency of the scales used in the study (EFPA, 2013).

As we have chosen to use only participants who underwent the DAWBA assessment, and specifically those whose parents completed the EFQ, our missing data are limited to 0.3% for DAWBA child mental health diagnoses and 9.6% for parental relationship. Parents not reporting difficulties in the SDQ Impact Supplement did not complete the impact questions (10.4% of the participants), and their children were coded as zero on the functional impairment variable.

3 | RESULTS

3.1 | Participant characteristics

Mean age of participants was 10.01 years (standard deviation, *SD* = 3.68) and 63.5% were males. The mean Full Scale Intelligence Quotient for the participants (*N* = 266) was 77.13 (*SD* = 16.91, range 40–140). The mean level of adaptive ability (Vineland-II total score) for the participants (*N* = 285) was 67.42 (*SD* = 14.78), including communication score (*M* = 64.66, *SD* = 13.35), daily living skills (*M* = 74.76, *SD* = 14.07) and socialisation (*M* = 73.08, *SD* = 15.42). The most frequent neurodevelopmental/neurological disorders among participants were specific developmental disorders (34.1%), ID (18.1%, none with severe ID), diseases of the nervous system such as epilepsy and cerebral palsy (15.1%), ASD (13.7%), ADHD (13.7%), and congenital malformations and chromosomal abnormalities (11.7%). Diagnoses of neurodevelopmental/neurological disorder were not mutually exclusive, so a participant could have more than one diagnosis, and 26.3% of children with a neurodevelopmental/neurological disorder had at least two separate diagnoses. A total of 44 (14.7%) participants were not diagnosed with any neurodevelopmental/neurological disorder. DAWBA emotional disorders were present in 14.7% of participants (anxiety disorders *n* = 37; major depression *n* = 14) and DAWBA behavioural disorders were present in 14.7% of participants (oppositional defiant disorder *n* = 38; conduct disorder *n* = 6), although some of these cases overlapped.

3.2 | Parental characteristics

Most EFQ respondents (91.6%) were parents of the participants; 7.7% were foster parents; and the remaining 0.7% were social workers. Parents' mean age was 41.3 years (range 24–59; *SD* = 7.1) and most parents were either married (47%) or cohabiting with a partner (33.3%) (Table 1). The mean EFQ score for the parents of this neuropaediatric population was 11.59 (range 0–29; *SD* = 5.05). The inter-item correlations varied between .19 and .62. The Cronbach's α for the total scale in a single common factor model was .87.

3.3 | Bivariate relationships between participant and parental characteristics

Parental mental health was significantly correlated with child emotional difficulties and child conduct problems, and with child functional impairment. A higher number of symptoms in children was associated with elevated parental mental health problems.

TABLE 1 Parental sociodemographic and socioeconomic characteristics

	N	%
Partnership status (*n* = 270)		
Married	127	47.0
Cohabitating	90	33.3
Without partner	53	19.6
Parental separation in the last year (*n* = 299)		
Yes	26	8.7
Education level – 1. parent (*n* = 268)		
Primary school	22	8.2
Secondary school	115	42.9
Higher education (short)	83	31.0
Higher education (long)	48	17.9
Education level – 2. parent (*n* = 238)		
Primary school	38	16.2
Secondary school	117	50.0
Higher education (short)	51	21.8
Higher education (long)	28	12.0
Occupational status (*n* = 244)		
Both parents working (at least one full-time)	192	78.7
One parent working full-time, second not working	31	12.7
No parent working full-time	21	8.6

Presence of parental mental health problems was weakly correlated with a child emotional diagnosis, lower SES and not cohabitating with a partner; it was not correlated with a child conduct diagnosis (Table 2).

3.4 | Confirmatory factor analysis results

A single common factor model (unidimensional mental health factor) provided a not acceptable fit to the EFQ data (χ^2 = 165.70, df = 35, p < .001, TLI = 0.95, CFI = 0.96, RMSEA = 0.11). All items loaded significantly on the single factor, with standardised loadings ranging from 0.58 to 0.86. A model with one first-order common factor and two residualised first-order method factors expressing positive and negative experiences gave an acceptable model fit (χ^2 = 70.24, df = 25, p < .001, TLI = 0.98, CFI = 0.99, RMSEA = 0.08).

3.5 | Results of latent variable regression models with DAWBA diagnoses

The results of the first latent variable regression model (model 1 in Table 3, Figure 1) indicated that SDQ child functional impairment was significantly associated with parental mental health (b = 0.43, p < .001). In addition, child emotional disorder (b = 0.60, p = .01), SES (b = −0.59, p < .05) and partnership status (b = −0.55, p < .01)

TABLE 2 Bivariate relationships between parental mental health (EFQ score) and parent demographic characteristics and child variables

	M (*SD*) / *n* (%)	1	2	3	4	5	6	7	8	9	10
1 Parental mental health (EFQ)	11.59 (5.05)										
2 SDQ child emotional difficulties	3.40 (2.62)	.26***									
3 SDQ child conduct problems	2.13 (2.02)	.24***	.25***								
4 SDQ child functional impairment	3.52 (2.87)	.30***	.49***	.37***							
5 DAWBA child emotional diagnosis	48 (14.5)	.16**	.56***	.12*	.35***						
6 DAWBA child conduct/ oppositional diagnosis	47 (14.2)	.09	.14*	.51***	.22***	.08					
7 Child ADHD status	50 (13.7)	−.01	−.01	.23***	.26***	.04	.17**				
8 Child ASD status	56 (15.3)	.06	.04	.03	.19***	−.02	.10	−.06			
9 Child ID status	77 (21.1)	.04	.04	.13*	.11*	.00	.05	−.03	−.02		
10 SES	271 (89.7)	−.16**	−.07	−.11	−.08	−.05	.01	.04	−.08	.05	
11 Partnership	267 (80.9)	−.14*	−.06	−.12*	−.01	−.06	−.06	.04	.02	−.06	.11

Note: Parental mental health: higher scores mean higher distress; Diagnoses and status: 0 – absent, 1 – present; SES: 0 – lower SES, 1 – higher SES; Partnership: 0 – without partner, 1 – married or cohabiting; *n* (%) for variable value = 1.

*p < .05.(2-tailed).

**p < .01.

***p < .001.

TABLE 3 Estimates and standard errors from latent variable regression, model 1 and 2.

	Model 1		Model 2	
Variable	***b***	***SE***	***b***	***SE***
SES	−0.59*	0.26	−0.62*	0.26
Partnership status	−0.55**	0.20	−0.56**	0.20
Child ADHD status	−0.03	0.23	0.03	0.23
Child ASD status	0.23	0.24	0.25	0.24
Child ID status	0.15	0.19	0.15	0.20
DAWBA child emotional disorder	0.60*	0.23		
DAWBA child conduct/ oppositional disorder	0.15	0.22		
SDQ child emotional difficulties			0.21	0.13
SDQ child conduct problems			0.00	0.11
SDQ child functional impairment	0.43***	0.08	0.35**	0.13

Note: Fit indices to model 1: χ^2 (372) = 674.57***; RMSEA = 0.055; CFI = 0.94; Fit indices to model 2: χ^2 (174) = 420.50***; RMSEA = 0.072; CFI = 0.94. Parental mental health: higher scores indicate more mental health problems; SES: 0 = lower, 1 = higher; Partnership status: 0 = living without a partner, 1 = married or cohabiting.

Abbreviations: ADHD, attention deficit/hyperactivity disorder; ASD, autism spectrum disorder; *b*, unstandardised coefficient; ID, intellectual disability; *SE*, standard error.

*p < .05.

**p < .01.

***p < .001.

were significantly associated with parental mental health. The proportion of the total variance explained in parental mental health was R^2 = .276.

3.6 | Results of latent variable regression model with SDQ symptoms

In the second latent variable regression model (model 2 in Table 3, Figure 2), only demographics SES (b = −0.62, p < .05) and partnership status (b = −0.56, p < .01), as well as SDQ child functional impairment (b = 0.35, p < .01) were significantly related to the latent variable parental mental health. The proportion of the total variance explained in parental mental health was R^2 = .254.

4 | DISCUSSION

Reliable and valid information about parental well-being plays a vital role in the assessment of and interventions for children with neurodevelopmental disorders, as these children often have concurrent mental health problems, such as emotional and behavioural challenges (e.g. Dekker et al., 2002; Emerson, 2003b). One way in which child behavioural problems can be reduced is through improvements in parental well-being (e.g. Totsika et al., 2013; Wickramaratne et al., 2011). Therefore, the overall aim of the present study was to examine the psychometric properties of a short measure of mental health (i.e. the EFQ) among parents in a neuropaediatric sample.

First, in relation to the structure of the EFQ, our findings corroborated those from the original validation study of Uher and Goodman (2010), which confirmed a one-factor model with an orthogonal method factor viewing distress/well-being as a unified construct. The original validation study on the EFQ was a population-based study conducted among caregivers in the UK. In contrast, the current study was conducted in a clinical neuropaediatric outpatient sample and included a mix of children and adolescents with neurodevelopmental (e.g. specific learning disorder, ADHD, ASD, ID) and neurological disorders (e.g. cerebral palsy and epilepsy). However, despite these sample differences, we observed fit indices for the original one-factor model that were comparable to those reported by Uher & Goodman, 2010. When testing different factor models in the current study, the confirmatory factor analyses revealed that the EFQ might be used as a unidimensional scale, while keeping in mind the existence of additional orthogonal method factors (i.e. negatively formulated distress symptoms and symptoms of psychological well-being) that may explain residuals after including the general factor. The EFQ appears to measure a single construct of mental health, but response patterns differed between negatively worded and positively worded reverse-scored items (Mook et al., 1991). Uher and Goodman (2010) concluded that the residual common variance between items scored in the same direction is unrelated to the underlying theoretical concept, and therefore, the inclusion of a method factor has more statistical than practical significance. Despite this conclusion, we should keep in mind that the EFQ appeared to partly measure indicators of psychological well-being related to personal potential, such as optimism, meaning or self-esteem (Huppert & So, 2011; Tov, 2018); it also partly measured distress indicators like worries, tiredness or feeling stressed. Psychological well-being and distress are not exactly at opposite ends of the continuum, but it has been reported that well-being and depression are highly negatively associated (e.g. Krieger et al., 2014). Taken together, even though the EFQ includes items that represent diverse psychological symptoms, the original one-factor model was fairly robust, and the internal consistency of the original scale (total score α = .87) was high. Accordingly, the most appropriate and convenient way to use the EFQ in a clinical neuropaediatric sample would be to use the sum score of all items (Uher & Goodman, 2010). Future research among different clinical populations is needed to test the generalisability of the original one-factor model. In practise, the EFQ can be used as a screening tool; however, it cannot be used alone to assess depression or anxiety, as it is not a diagnostic measure (Mann et al., 2013; Uher & Goodman, 2010).

It is worth mentioning that, in our study, the EFQ score correlated with child mental health symptoms and SES, both of which have also been associated with parental mental health measured by

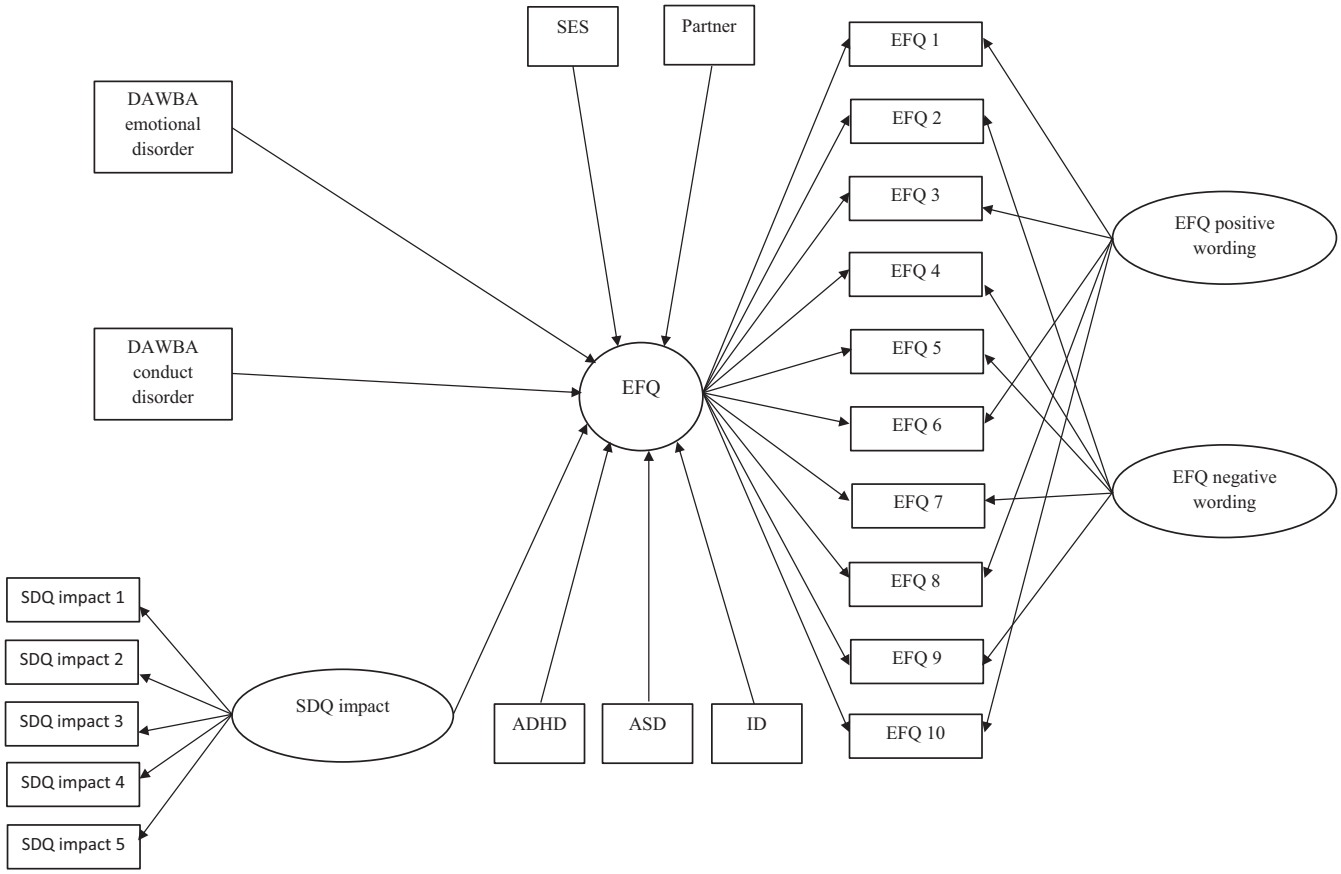

FIGURE 1 Latent variable regression, model 1

other well-established scales (Emerson, 2003a; Olsson & Hwang, 2008). In addition, we found a relationship between worse mental health and being a single parent, which is consistent with previous works (Brown & Moran, 1997; Cairney et al., 1999). All these relationships indicate the good criterion-related validity of the EFQ.

Contrary to our hypotheses based on the literature (e.g. Eisenhower et al., 2005; Olsson & Hwang, 2001), we did not find any significant relationship between parental mental health (EFQ) and child neurodevelopmental disorder (ADHD, ASD or ID) status. One explanation for this may be a difficulty in detecting differences in parental mental health across child diagnostic groups, as single diagnostic groups in our analysis were relatively small.

Both child behavioural and emotional difficulties were correlated with more parental mental health problems, as expected (e.g. Emerson, 2003a; Giovagnoli et al., 2015). More specifically, severity of SDQ symptoms (i.e. dimensional approach) correlated more strongly with elevated levels of parental mental health problems than DAWBA child mental health diagnoses (i.e. categorical approach). However, although these initial bivariate links were found, regression analyses revealed that both SDQ emotional and behavioural symptoms and DAWBA conduct diagnoses were not uniquely associated with parental mental health after controlling for all the other variables. One possible explanation is that the group of children with a DAWBA conduct diagnosis was too small. Another explanation is that the EFQ measures emotional symptoms, and parental mental health related to anxiety and depression is more related to child emotional problems than to child behavioural problems. Moreover, in the second model, SDQ emotional and behavioural symptoms were substantially correlated with each other (and SDQ impact), and this may have affected their lack of significance in explaining the EFQ variance.

Furthermore, as expected, severity of child functional impairment in everyday activities, lower parental SES and single partnership status was correlated with worse parental mental health. In the regression analyses, these relations remained significant and were uniquely associated with parental mental health problems both in the model with SDQ symptoms and the one with DAWBA diagnoses. The fact that child functional impairment was associated with parental mental health problems after controlling for parental demographics and child mental health diagnoses and symptoms, points to the importance of this variable. This finding corresponds with the results of Emerson (2003a) and of Miller et al. (2016), and it is consistent with the studies on increased accuracy in predicting clinical caseness by functional impairment in addition to symptoms (Goodman, 1999; Stringaris & Goodman, 2013). Measuring the impact of child functional impairment can be applied to all disorders (Stringaris & Goodman, 2013) and brings important information about those who do not meet the criteria for a psychiatric disorder, but nevertheless suffer from symptoms (Angold et al., 1999). Therefore, parental evaluations of functional

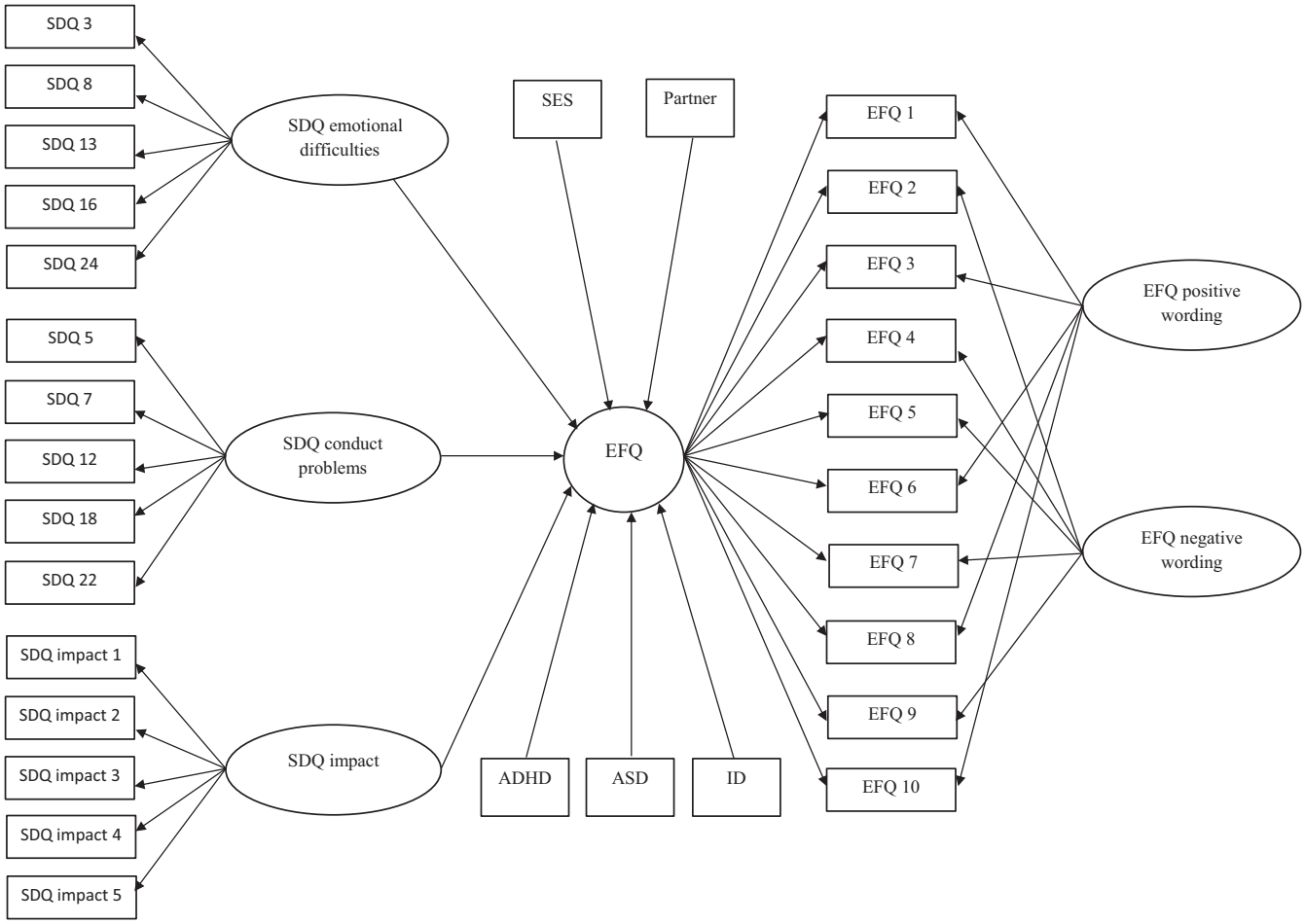

FIGURE 2 Latent variable regression, model 2

impairment can be a good expression of parental experience of the child's symptoms. One possible explanation for the observed association is that perceived child functional impairment contributed to mental health problems in parents. Alternatively, parents with mental health problems might be more inclined to perceive their child's difficulties as problematic. A third possibility is that the relationship between the impact of child difficulties and parental mental health is reciprocal. These results should be interpreted with consideration for the concept of "goodness-of-fit": parents vary in the extent to which their lives are impaired by their child's symptoms, depending on different factors, such as parental resilience or marital functioning (Rapee et al., 2012).

In agreement with previous reports, and beyond the importance of child mental health problems, our study once more proved the importance of environmental factors, like the relationship between lower SES and worse parental mental health (Emerson, 2003a; Emerson et al., 2006; Hatton & Emerson, 2009; Olsson & Hwang, 2008). In addition, our findings indicated that married/cohabiting parents had increased well-being when compared to single parents, similar to existing results about mothers (Emerson, 2003a; Olsson & Hwang, 2001). Single parents could have experienced divorce or a break-up that might have negatively influenced their mental health. We can assume that a single parent has much more responsibility, especially when a child has health problems, whereas parents in a relationship can offer each other more support, stability and security. For example, Kersh et al. (2006) concluded that greater marital quality predicts fewer depressive symptoms.

We were not able to assess psychiatric morbidity in parents, nor do we have data on their psychiatric history; therefore we cannot exclude the possibility that some of them suffered from serious psychiatric problems before they became parents. However, even though we focused on reduced mental health, the mean parental EFQ score in our neuropaediatric sample was similar to that observed in the general parent population (M = 11.59, SD = 5.05 compared to M = 11.63, SD = 5.44; Wesselhoeft et al., 2018), and was much lower than that reported in a clinical adult population with depression (M = 24.9, SD = 6.9; Mann et al., 2013). Hastings (2016) concluded that focusing on poorer mental health in parents could be misleading, as the majority of parents of children with neurodevelopmental disorders do not have emotional problems or other mental health problems. In our diagnostically heterogeneous patient population, parental mental health was associated with some child characteristics, and they were emanations of child difficulties, like functional impairment or behavioural problems (similarly to Wesselhoeft et al., 2018), rather than of the neurodevelopmental disorders themselves. Although the mean EFQ score of the parental population did not

indicate mental health problems in the whole sample, it remains of high importance to identify and reach those parents who do have indications of mental health difficulties.

The present study has significant strengths, such as a natural clinical context together with real clinical diagnoses and a good response rate. Nevertheless, the study has some limitations. The cross-sectional design limits our ability to draw conclusions about causality between the variables; we cannot exclude the possibility of bidirectional associations between the predictive factors and parental mental health. Parental mental health is at the centre of our study; however, it is known that family relationships are both reciprocal and transactional (Goodman & Gotlib, 1999; Neece et al., 2012), and depression in parents can affect children's mental health and development (Institute of Medicine, 2009; Manning & Gregoire, 2009; Totsika et al., 2013). As mentioned earlier, due to the relatively small size of single diagnostic groups, relationships between parental mental health and child diagnosis may not have been detected. Furthermore, due to variation in prevalence and a large number of potential diagnoses within the sample, relationships between parental mental health and child diagnosis may not have been detected despite our relatively large sample size. In addition, we ought to be aware of possible source information bias, as parents assessed both child symptoms, child functional impairment and their own mental health.

5 | CONCLUSIONS

The results of the present study indicate that the EFQ is useful as a short measure of mental health among parents of children with neurodevelopmental and neurological disorders. The original factor structure was confirmed, as were meaningful relationships between parental sociodemographic, socioeconomic and child variables. Overall, the EFQ, with its good reliability and plurality of the screened symptoms associated with both psychological well-being and distress, can be an indicator of potential mental health problems in parents. Knowledge about parental mental health problems can be used to give extended support to families with more distressed parents, and it may help in the interpretation of reported child difficulties, especially child functional impairment, by these parents.

ACKNOWLEDGEMENTS

This study was supported by the Northern Norway Regional Health Authority (PFP1178-14). The study was also supported in part by the Norwegian Directorate of Health and the Regional Centre for Child and Youth Mental Health and Child Welfare North at UiT The Arctic University of Norway, Tromsø, Norway. The authors would like to thank the participants who contributed to the dataset.

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How to cite this article: Kjærandsen KS, Handegård BH, Brøndbo PH, Halvorsen MB. Parental mental health screening in a neuropaediatric sample: Psychometric properties of the Everyday Feeling Questionnaire and variables associated with parental mental health. *J Appl Res Intellect Disabil*. 2021;34:648–658. https://doi.org/10.1111/jar.12834

Paper II

JOURNAL OF MENTAL HEALTH RESEARCH IN INTELLECTUAL DISABILITIES
2023, VOL. 16, NO. 1, 1–22
https://doi.org/10.1080/19315864.2022.2148788

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Impact Supplement of the Strengths and Difficulties Questionnaire in the Assessment of Functional Impairment in Children with ADHD or ASD in a Mixed Neuropediatric Sample: A Partial Validation Study

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Abstract

Background: In addition to symptoms of neurodevelopmental disorders, functional impairment is crucial to the determination of clinical significance. The aim of this study was to examine partial validity and usefulness of the Strengths and Difficulties Questionnaire's (SDQ) impact supplement (SDQ impact) in measuring functional impairment in children and adolescents diagnosed with attention deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) in neuropediatric clinics.

Methods: Participants were children and adolescents (N = 337) referred to neuropediatric outpatient clinics for neurodevelopmental assessment. Functional impairment was evaluated using three instruments: the SDQ impact, the Vineland Adaptive Behavior Scale (VABS-II), and the Children's Global Assessment Scale (CGAS). Mental health symptoms and intellectual function were also assessed. We investigated convergent and concurrent validity of the SDQ impact.

Results: The convergent validity of the SDQ impact was shown by its significant correlations with the VABS-II composite score and the CGAS total score. The concurrent validity of the SDQ impact was demonstrated by its significant relationship with ADHD and ASD diagnoses in logistic regression analyses. Using established cutoffs, the sensitivity of the SDQ impact to reveal functional impairment in children with ADHD and ASD diagnoses was demonstrated in this neuropediatric sample, but at the cost of low specificity.

Conclusion: The SDQ impact is an easy-to-use tool, and the overall study results indicate that it is partially valid, suggesting it may be used for the screening of general functional impairment in the neuropediatric population.

KEYWORDS
Attention deficit and hyperactivity disorder; autism spectrum disorder; functional impairment; parental evaluation; screening tool; validity

Introduction

One of the purposes of a diagnostic assessment of a child referred to a neuropediatric clinic is to obtain an accurate picture of the child's developmental functioning and the severity of behavioral difficulties and functional

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impairment across various domains, such as friendships, other close relationships, school, recreation, and health (Hunsley & Mash, 2020). In this article, we focus on the assessment of functional impairment in children with neurodevelopmental disorders, and specifically children with attention deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD).

Neurodevelopmental disorders are behavioral and cognitive syndromes with onset in the developmental period; they are characterized by developmental deficits that vary from specific limitations to global impairments of social skills or intelligence (American Psychiatric Association[APA], 2013; World Health Organization[WHO], 2018). Similarly to mental health disorders, the diagnosis of most neurodevelopmental disorders requires that certain criteria should be fulfilled, including the presence of both specific symptoms and functional impairment or significant distress (APA, 2013).

Functional impairment has been discussed, and partly doubted, as a criterion for diagnosing mental health disorders, with authors pointing out a lack of operationalization and inconsistency in the importance of functional impairment across diagnoses (Ustun & Kennedy, 2009; Wakefield, 2009). Even so, functional impairment is broadly used and is a necessary criterion for clinical significance in the diagnosis of neurodevelopmental disorders, both in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) diagnostic systems (APA, 2013; WHO, 2018). Distress refers to subjective emotional discomfort and is a core component of some mental disorders like depression and anxiety. In neurodevelopmental disorders, distress may also be a consequence of the disorder itself (Rapee et al., 2012). In relation to distress, functional impairment has more noticeable and objective aspects of deficits in various domains of functioning across different aspects of life (Rapee et al., 2012; Winters et al., 2005). Unlike criteria related to symptoms, the DSM has little to say about what exactly constitutes impairment (Lewandowski et al., 2006; Ustun & Kennedy, 2009). Nevertheless, functional impairment in daily activities is of high importance in reducing high caseness rates to a clinical significance level (Bird et al., 1990; Narrow et al., 2009; Regier et al., 1998).

To be impaired means to be unable to handle the routine demands of life (Goldstein & Naglieri, 2016). The threshold for functional impairment is based on a conviction of which activities are central to functioning for a particular person according to her age and developmental level. There are a variety of concepts and terminologies related to functioning: functional impairment, adaptive functioning, psychosocial functioning, social competence, social adaptation, disability, or interference (Colburn et al., 2018; Winters et al., 2005). Even though there is no strict definition of impairment in the DSM, popular measurement methods (Zander & Bölte, 2015), like the composite score of the Vineland Adaptive Behavior Scales II (VABS-II; Sparrow et al., 2011), can be used to operationalize impairment criteria. The

VABS-II is typically used in neuropediatric clinics to assess adaptive functioning and impairment in the domains of socialization, communication, and daily living skills in children with neurodevelopmental disorders (e.g., Ashwood et al., 2015). Another method to assess impairment is via omnibus global impairment measures, such as the Children's Global Assessment Scale (CGAS; Bird et al., 1997; Rapee et al., 2012; Shaffer et al., 1983).

The extended version of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1999) includes an impact supplement with questions on distress and social impairment in four domains: home life, friendships, classroom learning, and leisure activities. These domains are the main areas of consideration when rating psychosocial disability due to mental disorder, intellectual disability, or other developmental disorders using the WHO's multiaxial classification of child and adolescent mental disorders (WHO, 1996). The VABS-II interview version consists of a lengthy interview with caregivers scored by the clinician, and the unidimensional measure of global functioning in the CGAS represents a clinician's evaluation, based on a wide variety of information gathered about the child. The VABS-II is time-consuming, but routinely used in the evaluation of impaired adaptive functioning in ASD and other neurodevelopmental disorders. The use of the CGAS requires good training, and much time is needed to collect the necessary information. In contrast, the SDQ impact supplement is a questionnaire that is filled out by caregivers; thus, it represents a more efficient use of clinicians' time, and it is directly adapted to the DSM clinical significance criteria for functional impairment and distress. In addition, the SDQ impact score has been found to be a significant predictor of child mental disorders (Lai et al., 2014; Stringaris & Goodman, 2013). Therefore, it would be interesting to determine if routine assessment of functional impairment in children with suspected neurodevelopmental disorder could be done with the SDQ impact supplement with results that are similar to those of established, time-consuming scales or clinical judgment (VABS-II and CGAS).

Accordingly, the aim of this study was to examine indicators of validity and usefulness of the SDQ impact supplement (SDQ impact) in measuring functional impairment in children and adolescents diagnosed with ADHD) or ASD in neuropediatric clinics. Validity is not a property of a test, but a function of what the achieved scores mean, often in some context and sample (Murphy & Davidshofer, 2013). We used a convergent validity strategy (Campbell & Fiske, 1959), a type of a measurement validity (Murphy & Davidshofer, 2013), to show the meaning and implications of the SDQ impact score by comparing its properties with the results of the VABS-II and CGAS. In addition, we used a concurrent validity strategy, a type of criterion-related validity, to examine if a test could be used to make correct decisions (Hayden & Brown, 1999; Murphy & Davidshofer, 2013; Søreide, 2009). We evaluated the accuracy of a diagnostic decision by comparing estimated functional impairment

measured by the SDQ impact score and an ADHD or ASD diagnosis based on an evaluation of both symptoms and functional impairment.

Methods

Participants and Study Setting

Participants were 337 children and adolescents aged 4–18 years (mean [*M*] = 10.03, standard deviation [*SD*] = 3.77; 35% females) referred to developmental/neurological assessment at the neuropediatric outpatient clinics of the University Hospital of North Norway (UNN) (n = 286) and the Finnmark Hospital Trust (n = 51) by a general practitioner (n = 231) or a medical specialist in specialist health services (n = 106). In order to be included in the study, patients had to be referred between October 2012 and July 2016 at the UNN, or between January 2014 and July 2016 at the Finnmark Hospital Trust. The exclusion criteria included age below 4 years, due to a lack of suitability of one or more of the instruments for that age group, and lack of fluency in the Norwegian language. In total 518 children and adolescents were eligible for the study, however around 30% of them were excluded from the study due to time constraints, lack of parental motivation, or insufficient knowledge of the Norwegian language.

The aforementioned neuropediatric outpatient clinics are health service units in the counties of Troms and Finnmark in Northern Norway that serve a population of 266,000 residents. These facilities provide services to children and adolescents with neurodevelopmental disorders or early-acquired disabilities, developmental delays, or intellectual and developmental disabilities. Assessment teams are interdisciplinary, including specialists such as pediatricians, neuropsychologists, special education therapists, and physiotherapists.

The children underwent clinical treatment as usual; the ordinary interdisciplinary developmental/neurological assessment typically takes place over two consecutive days. Participants' neurological/neurodevelopmental diagnoses were provided at the interdisciplinary assessment at the neuropediatric clinics and recorded in electronic medical records. ICD-10 criteria were applied to code the diagnoses (WHO, 1993, 2010). The presence of an intellectual disability (ID) was operationalized as a score below 70 on both a standardized Wechsler Intelligence Test and the VABS-II (for more details see, Halvorsen et al., 2019).

The most frequent neurodevelopmental disorders in the sample were, in decreasing order, specific developmental disorders (33.5%), ID (20.5%), diseases of the nervous system such as epilepsy and cerebral palsy (15.1%), ASD (14.2%), ADHD (13.6%), and congenital malformations, deformations, and chromosomal abnormalities (10.4%). The diagnoses were not mutually

Table 1. Co-existing diagnoses of participants with ADHD and ASD.

ADHD		ASD	
Co-existing diagnoses	*n*	Co-existing diagnoses	*n*
Intellectual disability	8	Intellectual disability	8
ASD	4	ADHD	4
Specific learning disorder	17	Specific learning disorder	2
Neurological disorders	10	Neurological disorders	9
None	0	None	28

ADHD – attention deficit/hyperactivity disorder; ASD – autism spectrum disorder; FSIQ – Full Scale Intelligence Quotient; SDQ – Strengths and Difficulties Questionnaire; VABS-II – Vineland Adaptive Behavior Scales II; CGAS – Children's Global Assessment Scale. **In ADHD –** Neurological disorders: Acquired periventricular cysts of newborn, five cases of congenital malformation syndromes and chromosomal abnormalities, delayed development, focal traumatic brain injury, two cases of diseases of the nervous system (epilepsy and cerebral palsy). **In ASD –** Neurological disorders: three cases of congenital malformation syndromes and chromosomal abnormalities, six cases of diseases of the nervous system (epilepsy, cerebral palsy and hydrocephalus).

exclusive, so a given participant could have more than one diagnosis. Among the participants, 46 were diagnosed with ADHD and 48 with ASD. Most participants with ADHD were diagnosed with "disturbance of activity and attention" (ICD-10 code F90.0; $n = 30$), and some cases of "hyperkinetic conduct disorder" (F90.1, $n = 3$), "other hyperkinetic disorders" (F90.8; $n = 3$), "hyperkinetic disorder, unspecified" (F90.9, $n = 1$), and "attention deficit disorder without hyperactivity" (F98.8; $n = 4$). Participants with ASD were diagnosed with "childhood autism" (ICD-10 code F84.0, $n = 15$), "atypical autism" (F84.1, $n = 14$), "Asperger syndrome" (F84.5, $n = 17$), and "pervasive developmental disorder, unspecified" (F84.9, $n = 2$). Most children with ADHD or ASD had additional, co-existing diagnoses (Table 1).

Measures

Mental Health Symptoms

The parent version of the SDQ, a brief behavioral screening questionnaire (Goodman, 1997), is part of the Development and Well-Being Assessment (DAWBA; Goodman, Ford et al., 2000) and was used to assess mental health symptoms. The SDQ consists of 25 items that measure symptoms in four problem domains (emotional symptoms, conduct problems, hyperactivity-inattention, and peer problems) and one area of strength (prosocial behavior). The scores in these problem domains are then summed to generate a total difficulties score. There are three response alternatives: "not true" – scored as 0, "somewhat true" – scored as 1, and "certainly true" – scored as 2. The SDQ has satisfying to good psychometric properties, and has been used in clinical and non-clinical child and adolescent populations (Emerson, 2005; Goodman, 2001; Smedje et al., 1999; Stringaris & Goodman, 2013). In the present study, the included domain scores had the following Cronbach's alphas: .76 for

emotional symptoms, .70 for conduct problems, .78 for hyperactivity-inattention, .72 for peer problems, and .78 for prosocial behavior.

Intellectual Function

Children were individually assessed with a standardized Wechsler intelligence test appropriate for their age (WPPSI, WISC; Wechsler, 2007, 2008a, 2008b, 2009, 2012). A small number of children were assessed with Raven's Colored Progressive matrices (Raven, 2004) because of insufficiently completed subtests on the Wechsler test to estimate the FSIQ score, which defined intellectual function. FSIQ scores were missing for 30 children, who were administered a test for younger children.

Functional Impairment

The extended version of the SDQ part of the DAWBA, (Goodman, 1999) includes the SDQ impact supplement, which focuses on the functional impairment of the child in everyday activities. The first question asks whether the parent believes that the child has difficulties in any of the following areas: emotions, concentration, behavior, or getting along others. If the parent answers "yes" to this question, the remaining questions assess chronicity, overall child distress, social impairment, and burden to others. Functional impairment is calculated from the evaluation of overall child distress, and impairment related to family, friends, classroom learning, and leisure activities. There are three response alternatives: "not at all" and "only a little" – scored as 0, "quite a lot" – scored as 1, and "a great deal" – scored as 2. The scores are then combined to give an impact score, ranging from 0 to 10. If the parent answered "no" to the first question on whether the child has difficulties, the SDQ impact score is coded as zero. An SDQ impact score of 0 is considered normal, 1 is defined as borderline, and 2 as abnormal. The SDQ impact score has high concurrent and predictive validity (Stringaris & Goodman, 2013), and demonstrates acceptable to good internal consistency (Aitken et al., 2017; Stringaris & Goodman, 2013).

Adaptive Function

The VABS-II (Sparrow et al., 2011) was used to measure a child's adaptive abilities. It consists of a semi-structured interview with a parent and includes four domains with related subdomains: communication (receptive, expressive, and written), daily living skills (personal, domestic, and community), socialization (interpersonal relationships, play and leisure time, and coping skills) and motor skills (gross and fine). In the present study, we used an Adaptive Behavior Composite score (hereafter referred to as the VABS-II composite score), which was condensed from scores in the subdomains of communication, daily living skills, and socialization. A VABS-II composite standard score of 130 and above was defined as a high adaptive level, a standard score of 115–

129 as moderately high, 86–114 as adequate, 71–85 as moderately low, and 70 and below as a low adaptive level.

General Functioning

The CGAS (Shaffer et al., 1983) is a clinician-rated tool that is used to assess the global psychosocial functioning of the child, taking into account all available information. The score on this scale reflects the lowest overall level of psychosocial functioning (at home, at school, and with peers) of the child or adolescent during the preceding month. The scale is separated into 10-point intervals that are headed with a description of the level of functioning followed by examples of matching behavior and life situations adequate for children and adolescents. The scores range from 1, which represents the most impaired level, to 100, which represents the best level of functioning. In a large Norwegian study of clinicians in outpatient child and adolescent mental health services (Hanssen-Bauer et al., 2007), the interrater reliability of the routine use of the CGAS was found to be moderate (intraclass correlation coefficient = .61).

cutoffs for Functional Impairment

Mild functional impairment was defined as a SDQ impact score of 1 (borderline or quite a lot distress/impairment in just one domain), which conceptually corresponds to a CGAS score of 61 to 70 (Goodman, 1999). An SDQ impact score of 2 or more corresponds conceptually to a CGAS score of 60 or less and is defined as indicating definite functional impairment (Goodman, 1999). The VABS-II composite score served as a proxy for a third functional impairment measure, in addition to the SDQ impact score and the CGAS score. The following cutoffs were applied for the VABS-II composite score (Zander & Bölte, 2015): 1 SD below the mean (85 points) corresponded to mild functional impairment, and 2 SD below the mean (70 points) corresponded to definite functional impairment.

Statistical Analysis

The statistical analyses were carried out using SPSS version 26 for Windows (IBM Corp, 2019). We used Cronbach's alpha (European Federation of Psychologists' Association[EFPA], 2013) to calculate the internal consistency of the scales used in the study. Bivariate associations were examined using the Pearson correlation coefficient.

The convergent validity of the SDQ impact supplement was evaluated by the association between the SDQ impact score, and the VABS-II composite score and CGAS total score, respectively. In order to demonstrate convergent validity, it is generally recommended that the correlation between

the measure in question (SDQ impact score) and the criterion measure meet or exceed 0.30 (Campbell & Fiske, 1959). A concurrent validity strategy is used to determine if a test can be validly used in decision-making (for example, to determine a diagnosis). The recommended procedure is to correlate the score of the test with a measurable outcome (Murphy & Davidshofer, 2013). The concurrent validity of the SDQ impact supplement was demonstrated by a significant relationship between the SDQ impact score and the ADHD and ASD diagnosis status, both using Pearson's correlation coefficients, and by the results of hierarchical logistic regressions controlled for possible covariates of functional impairment.

Three separate hierarchical multiple logistic regression analyses were performed, using ASD and ADHD diagnoses as dependent variables. In the first step, we included control variables: gender, age, and intellectual function expressed as FSIQ; the next step included mental health symptoms. The last step consisted of one of the indicators of functional impairment or adaptive ability: SDQ impact score (indicating functional impairment and distress = clinical significance), VABS-II composite score indicating adaptive ability, or CGAS score indicating global psychosocial functioning. The overall model was tested using a chi-square statistic.

Descriptive statistics were used to determine the different levels of functional impairment measured in children diagnosed with ADHD and ASD. Percentages of children with ADHD and ASD that belonged to groups with mild/borderline and definite impairment were calculated.

Receiver-operating characteristic curve analysis (ROC-analysis; Ogilvie & Creelman, 1968) was used to assess how well the SDQ impact score captured diagnoses. The overall diagnostic accuracy of the SDQ impact supplement was measured by the area under the curve (AUC), and sensitivity, specificity, and diagnostic likelihood ratio [DLR = sensitivity/(1-specificity); a ratio of true positives to false positives] were also calculated for each of the possible SDQ impact scores (Deeks & Altman, 2004; Hayden & Brown, 1999; Søreide, 2009). AUC can range from 0 (prediction worse than random decision-making) through 0.5 (no predictive ability; random decision-making) to 1 (perfect discrimination/accuracy), (Søreide, 2009).

Ethical Considerations

Written informed consent was obtained from the parents of all participants and children above 12 years included in the study. The data protection officer at the UNN and the Finnmark Hospital Trust has approved the use of de-identified data for research purposes.

Results

The majority of the parents (N = 337) that completed the SDQ impact supplement reported that they believed their child had difficulties in one or more of the following areas: emotions, concentration, behavior, or getting along with others. Only 10.7% reported that they did not believe their child had any problem in these areas, while 26.0% perceived minor problems and 63.3% experienced definite or severe problems. Parents who believed their child had difficulties reported that these difficulties interfered with the child's everyday life in different areas. The majority 95.7% (N = 303) of the parents answered that their child's problems had lasted for over a year. The SDQ impact scores ranged from 0 to 10 (M = 3.48, SD = 2.90), and the VABS-II composite scores ranged from 20 to 112 (M = 67.10, SD = 15.15). Likewise, the range of the CGAS total scores was between 11 and 100 (M = 55.58, SD = 13.85).

SDQ Impact Supplement and Convergent Validity

The SDQ impact score correlated significantly with the VABS-II composite score (r = – .36, p < .001); the correlation with the CGAS score was weaker, yet still significant (r = – .29, p < .001). However, the strongest association was between the VABS-II composite score and the CGAS score (r = .55, p < .001; Table 2).

SDQ Impact Supplement and Concurrent Validity

The SDQ impact score correlated significantly with both ADHD diagnosis (r = .28, p < .001) and ASD diagnosis (r = .21, p < .001; Table 2). Similarly, the VABS-II composite score correlated significantly with ADHD diagnosis (r = – .17, p < .01) and ASD diagnosis (r = – .23, p < .001). Comparably, the CGAS total score was significantly associated only with ASD diagnosis (r = – .29, p < .001). Logistic regression analyses (Tables 3 and 4) confirmed the relationship between the SDQ impact score and ADHD and ASD diagnoses, when symptom and control variables were taken into account.

Functional Impairment, Assessed by Different Measures, and Clinical Diagnoses

Thirty-six participants (10.7%) had missing data on FSIQ score. As logistic regression analyses included only those participants with measurements recorded for all three instruments (i.e., SDQ impact score, VABS-II composite score, and CGAS total score), 61 participants without these measurements were excluded.

Table 2. Bivariate relationships between ADHD and ASD diagnosis, and predictor variables.

	M (*SD*)/*n* (%)	1	2	3	4	5	6	7	8	9	10	11	12	13
1 ADHD	40 (13.2%)	–												
2 ASD	48 (15.8%)	−.06	–											
3 Gender	106 (35%)	−.16**	−.03	–										
4 Age	10.04 (3.77)	.03	−.05	.09	–									
5 FSIQ	76.93 (16.63)	−.03	−.27***	−.11	−.05	–								
6 SDQ emotional symptoms	3.31 (2.62)	−.02	.06	.20***	.14*	−.08	–							
7 SDQ conduct problems	2.12 (2.01)	.24***	.04	−.07	−.05	−.02	.25***	–						
8 SDQ hyperactivity-inattention	5.26 (2.56)	.36***	.09	−.07	−.17**	−.10	.28***	.51***	–					
9 SDQ peer problems	3.86 (2.51)	.10	.29***	−.02	−.19**	.03	.36***	.39***	.35***	–				
10 SDQ prosocial score	7.06 (2.32)	−.09	−.19***	.09	−.02	−.11	−.17**	−.52***	−.31***	−.39***	–			
11 SDQ impact score	3.48 (2.90)	.28***	.21***	.03	.08	−.04	.50***	.36***	.46***	.54***	−.34***	–		
12 VABS-II composite score	67.10 (15.15)	−.17**	−.23***	.07	.14*	.31***	−.17**	−.31***	−.36***	−.32***	−.37***	−.36***	–	
13 CGAS total score	55.58 (13.85)	−.08	−.29***	.09	−.06	.24***	−.14*	−.22***	−.19**	−.32***	.27***	−.29***	.55***	–

ADHD – attention deficit/hyperactivity disorder; ASD – autism spectrum disorder; *M* – mean; *SD* – standard deviation; FSIQ – Full Scale Intelligence Quotient; SDQ – Strengths and Difficulties Questionnaire; VABS-II – Vineland Adaptive Behavior Scales II; CGAS – Children's Global Assessment Scale. ADHD/ASD diagnosis: 0 – absent, 1 – present; gender: 0 – male, 1 – female; *n* (%) for variable value = 1; *p <.05. **p <.01, ***p < .001 (two-tailed test).

Table 3. Summary of three models with hierarchical logistic regression analyses predicting an ADHD diagnosis (N = 274).

	Model 1[a]			Model 2[b]			Model 3[c]		
Predictor	*B*	*S.E.*	*OR*	*B*	*S.E.*	*OR*	*B*	*S.E.*	*OR*
Step 1									
Gender	−2.25*	0.60	0.29	−1.11*	0.56	0.33	−1.03	0.56	0.36
Age	0.17*	0.07	1.18	0.15*	0.07	1.16	0.13*	0.06	1.14
FSIQ	0.01	0.01	1.01	0.02	0.01	1.02	0.01	0.01	1.01
Step 2									
SDQ emotional symptoms	−0.32**	0.11	0.72	−0.16	0.09	0.85	−0.14	0.09	0.87
SDQ conduct problems	0.20	0.13	1.23	0.12	0.12	1.13	0.13	0.12	1.14
SDQ hyperactivity-inattention	0.46***	0.12	1.59	0.49***	0.11	1.63	0.51***	0.11	1.67
SDQ peer problems	−0.21	0.12	0.81	−0.10	0.11	0.91	−0.07	0.11	0.93
SDQ prosocial behavior	0.14	0.11	1.15	0.13	0.11	1.14	0.07	0.11	1.08
Step 3									
SDQ impact score	0.46***	0.11	1.58						
VABS-II composite score				−0.05*	0.02	0.95			
CGAS total score							−0.02	0.02	0.98

ADHD – attention deficit/hyperactivity disorder; *B* – estimated change in log odds for a one-unit change in the independent variable; *S.E.* – standard error; *OR* – odds ratio; FSIQ – Full Scale Intelligence Quotient; SDQ – Strengths and Difficulties Questionnaire; VABS-II – Vineland Adaptive Behavior Scales II; CGAS – Children's Global Assessment Scale. * $p < .05$, ** $p < .01$, *** $p < .001$.

[a]Overall model: χ^2 (9) = 65.31***. Cox & Snell R^2 = .21, Nagelkerke R^2 = .40. $\Delta\chi^2_{1step}$ = 8.58*; $\Delta\chi^2_{2step}$ = 37.93***; $\Delta\chi^2_{3step}$ = 18.79***.

[b]Overall model: χ^2 (9) = 50.88***. Cox & Snell R^2 = .17, Nagelkerke R^2 = .32. $\Delta\chi^2_{1step}$ = 8.58*; $\Delta\chi^2_{2step}$ = 37.93***; $\Delta\chi^2_{3step}$ = 4.36*.

[c]Overall model: χ^2 (9) = 47.78***. Cox & Snell R^2 = .16, Nagelkerke R^2 = .30. $\Delta\chi^2_{1step}$ = 8.58*; $\Delta\chi^2_{2step}$ = 37.93***; $\Delta\chi^2_{3step}$ = 1.27.

Table 4. Summary of three models with hierarchical logistic regression analyses predicting an ASD diagnosis (N = 274).

	Model 1[a]			Model 2[b]			Model 3[c]		
Predictor	*B*	*S.E.*	*OR*	*B*	*S.E.*	*OR*	*B*	*S.E.*	*OR*
Step 1									
Gender	0.10	0.46	1.11	0.22	0.47	1.25	0.35	0.50	1.41
Age	−0.15*	0.06	0.86	−0.11	0.06	0.90	−0.18**	0.06	0.83
FSIQ	0.06***	0.01	1.06	0.08***	0.02	1.08	0.07***	0.01	1.07
Step 2									
SDQ emotional symptoms	−0.09	0.09	0.92	0.01	0.08	1.01	−0.03	0.09	0.97
SDQ conduct problems	−0.20	0.12	0.82	−0.23	0.13	0.80	−0.26*	0.12	0.77
SDQ hyperactivity-inattention	0.01	0.09	1.01	0.01	0.10	1.01	0.11	0.10	1.11
SDQ peer problems	0.41***	0.11	1.50	0.43***	0.11	1.54	0.39***	0.11	1.48
SDQ prosocial behavior	−0.06	0.10	0.94	0.02	0.11	1.02	−0.04	0.11	0.96
Step 3									
SDQ impact score	0.25**	0.10	1.28						
VABS-II composite score				−0.09***	0.02	0.91			
CGAS total score							−0.10***	0.02	0.91

ASD – autism spectrum disorder; *B* – estimated change in log odds for a one-unit change in the independent variable; *S.E.* – standard error; *OR* – odds ratio; FSIQ – Full Scale Intelligence Quotient; SDQ – Strengths and Difficulties Questionnaire; VABS-II – Vineland Adaptive Behavior Scales II; CGAS – Children's Global Assessment Scale. * $p < .05$, ** $p < .01$, *** $p < .001$.

[a]Overall model: χ^2 (9) = 61.72***. Cox & Snell R^2 = .20, Nagelkerke R^2 = .35. $\Delta\chi^2_{1step}$ = 21.06***; $\Delta\chi^2_{2step}$ = 33.48***; $\Delta\chi^2_{3step}$ = 7.17**.

[b]Overall model: χ^2 (9) = 73.72***. Cox & Snell R^2 = .24, Nagelkerke R^2 = .41. $\Delta\chi^2_{1step}$ = 21.06***; $\Delta\chi^2_{2step}$ = 33.48***; $\Delta\chi^2_{3step}$ = 19.17***.

[c]Overall model: χ^2 (9) = 78.09***. Cox & Snell R^2 = .25, Nagelkerke R^2 = .44. $\Delta\chi^2_{1step}$ = 21.06***; $\Delta\chi^2_{2step}$ = 33.48***; $\Delta\chi^2_{3step}$ = 23.53***.

Table 5. Percentage of children with ADHD (n = 40) and ASD (n = 48) at different impairment levels as measured by VABS-II composite score, CGAS total score and SDQ impact score.

	At least mild impairment (%)		Definite impairment (%)	
	ADHD	ASD	ADHD	ASD
SDQ impact score	98	92	96	83
VABS-II composite score	100	98	83	83
CGAS total score	98	96	78	78

ADHD – attention deficit/hyperactivity disorder; ASD – autism spectrum disorder; SDQ – Strengths and Difficulties Questionnaire; VABS-II – Vineland Adaptive Behavior Scales II; CGAS – Children's Global Assessment Scale. Cutoffs for mild/borderline and severe/definite impairment: SDQ impact score cutoffs: 1 and 2; VABS-II cutoffs 85 and 70; CGAS cutoffs 70 and 60.

The overall regression models for an ADHD diagnosis were significant (Table 3, footnote). The first two steps in all three models were significantly associated with an ADHD diagnosis. There were differences between the models in the third step (Table 3). The effect of the SDQ impact score in predicting an ADHD diagnosis was significant ($\Delta\chi^2_{3step} = 18.79^{***}$, $p < .001$), as was the effect of the VABS-II composite score ($\Delta\chi^2_{3step} = 4.36^{*}$, $p < .05$). The CGAS total score did not significantly improve the model ($\Delta\chi^2_{3step} = 1.27$, $p = .26$).

In relation to the association between functional impairment and an ASD diagnosis, results of overall regression analyses were also significant (Table 4, footnote). All three steps were significantly associated with an ASD diagnosis (Table 4). Prediction of an ASD diagnosis was significantly improved by the SDQ impact score ($\Delta\chi^2_{3step} = 7.17^{***}$, $p < .01$), VABS-II composite score ($\Delta\chi^2_{3step} = 19.17^{*}$, $p < .001$), and CGAS total score ($\Delta\chi^2_{3step} = 23.53$, $p < .001$).

We looked at the number of children with ADHD and ASD diagnoses that met the criteria of at least mild/borderline and severe/definite functional impairment as measured by the three chosen instruments (Table 5). Applying the selected cutoffs for at least mild/borderline functional impairment, 98 to 100% of children with an ADHD diagnosis ($N = 40$), and 92% (SDQ impact score) to 98% (VABS-II composite score) of children with an ASD diagnosis ($N = 48$), fulfilled the criterion. When applying cutoffs for severe/definite functional impairment, 78% (CGAS score) and 83% (VABS-II composite score and SDQ impact score) of children diagnosed with ADHD and ASD, and 83% children diagnosed with ASD and 95% children diagnosed with ADHD (SDQ impact score) fulfilled the criterion.

Sensitivity and Specificity of the SDQ Impact Score

The extent to which the SDQ impact score distinguished ADHD and ASD diagnoses was examined by computing sensitivity and specificity (i.e., false positives; Table 6). For the comparisons in ADHD diagnoses, a SDQ impact score of 8 (score range 0–10) gave the highest DLR of 2.81. For ASD diagnoses, a SDQ impact score of 10 gave the highest DLR (Table 6). However, all DLRs

Table 6. Sensitivity and false positives (1 – specificity) when applying SDQ impact score to determine ADHD and ASD diagnoses.

	ADHD			ASD		
SDQ impact score	Sensitivity	False positives	DLR	Sensitivity	False positives	DLR
1	97.8%	75.6%	1.29	91.7%	76.5%	1.20
2	95.7%	64.9%	1.47	83.3%	66.8%	1.25
3	89.1%	55.0%	1.62	72.9%	57.4%	1.27
4	69.6%	42.6%	1.63	64.6%	43.3%	1.49
5	58.7%	32.3%	1.82	50.0%	33.6%	1.49
6	47.8%	19.6%	2.44	45.8%	19.7%	2.32
7	39.1%	14.1%	2.77	31.3%	15.2%	2.36
8	26.1%	9.3%	2.81	22.9%	9.7%	2.36
9	13.0%	5.5%	2.36	16.7%	4.8%	3.48
10	2.2%	3.1%	0.71	8.3%	2.1%	3.95

ADHD – attention deficit/hyperactivity disorder; ASD – autism spectrum disorder; DLR – diagnostic likelihood ratio. Sensitivity is defined as the percentage of children who have the ADHD or ASD diagnosis and who were positively identified as belonging to these groups by their SDQ impact scores. Specificity is defined by the percentage of children without these diagnoses who were identified as not having functional impairment as measured by SDQ impact scores.

have poor discriminative value (Hayden & Brown, 1999; Søreide, 2009). In children with an ADHD diagnosis, the DLR was 1.29 for the cutoff of SDQ impact score equal to 1 (mild/borderline functional impairment), and 1.47 for the SDQ impact score cutoff equal to 2 (severe/definite functional impairment). In children with ASD, the corresponding DLRs were 1.2 and 1.25. The accuracy of the SDQ impact score in indicating ADHD and ASD diagnoses is revealed by the AUC in the ROC-analysis. AUC can be interpreted as the probability that a randomly selected individual with an ADHD or ASD diagnosis has a higher SDQ impact score than a randomly selected individual without this diagnosis in our neuropediatric sample. The AUC for those with an ADHD diagnosis was acceptable (.72), while the AUC for those with an ASD diagnosis was .65, interpretable as poor (Hosmer et al., 2013).

Discussion

The aim of this study was to examine partial validity and usefulness of the SDQ impact supplement in assessing functional impairment in children and adolescents diagnosed with ADHD and ASD in the neuropediatric clinics. Overall, the results of our study supported concurrent and convergent validity and usefulness of the SDQ impact supplement, with the nuances discussed below.

The SDQ impact supplement, which contains five questions regarding difficulties in different domains of social and everyday life functioning (family, friends, classroom learning, and leisure activities) and distress, was internally consistent. The SDQ impact score significantly correlated with other indicators of functional impairment. The correlation between the SDQ impact score and the VABS-II composite score met the minimum value ($r \geq 0.30$) to support convergent validity. The correlation between the SDQ impact score

and the CGAS total score fell just below the minimum value. The VABS-II and CGAS – both standardized clinical instruments – were more related to each other, possibly because both are clinician's evaluations based on the information achieved from a parent, in contrast to the SDQ that is a pure parentally reported measurement tool. In addition, the VABS-II and CGAS measure quite different aspects of functional impairment. The VABS-II is designed to assess problems in adaptive functioning compared to a typically developing population, and similarly to SDQ impact capture social impairment; while the CGAS captures functional impairment beyond adaptive skills, including symptom severity, rather than social and occupational impairment (Ditterline et al., 2016; Lewandowski et al., 2016; Smith et al., 2011; Ustun & Kennedy, 2009; Winters et al., 2005).

Because functional impairment is part of having ADHD or ASD (APA, 2013; WHO, 2018), it was expected that there would be an association between the diagnoses and the functional impairment expressed directly by the SDQ impact score. In the bivariate analyses, ADHD diagnosis correlated weakly with the SDQ impact score and the VABS-II composite score. ASD diagnosis was significantly, yet weakly correlated with all indicators of functional impairment. The reason for the quite low correlations observed may be that ADHD and ASD are neurodevelopmental disorders that are diagnosed based on many criteria, of which impairment is only one. Further, using a dichotomous diagnosis variable leads to reduced information that can attenuate correlations. Secondly, validity coefficients greater than .3 are fairly uncommon in applied settings, and the levels of concurrent validity rarely exceed .6 or .7 (Murphy & Davidshofer, 2013). Regression analyses confirmed the results of these initial bivariate analyses. The conclusion from multiple regression analyses could be that functional impairment expressed by the SDQ impact score increased the probability of an ADHD diagnosis. All indicators of functional impairment/adaptive functioning increased the probability of an ASD diagnosis.

We should be aware that the SDQ impact supplement was created as an extension of the SDQ, which focuses on screening for mental health caseness (Goodman, 1999) and is primarily used to evaluate functional impairment in these patients (Goodman, Renfrew et al., 2000). The stronger relationship observed between the SDQ impact score and ADHD than with ASD may be a direct result of the SDQ's application (e.g., the assessment of hyperactivity-inattention). However, when asking about impaired functions related to disorder symptoms, very general functional impairment areas, such as impairment related to family, friends, classroom learning, and leisure activities, in addition to distress, are listed. These can concern both children with ADHD and ASD, and in a study by Russell et al. (2013), children from both diagnostic groups were assessed with similar ranges of SDQ impact scores. The reason for this may be that these impairment domains are known to concern children

both with ADHD (Erskine et al., 2016; Wehmeier et al., 2010) and ASD (Kasari et al., 2011). The neuropediatric sample in our study consisted of children with complex difficulties (Gillberg et al., 2013), and children with ADHD and ASD had many co-existing diagnoses (see, Table 1) that might have resulted in functional impairment. We cannot conclude which specific symptoms of ADHD, ASD, or co-occurring mental disorder (e.g., Bakken et al., 2010; Mitchison & Njardvik, 2019; Simonoff et al., 2008; Taylor et al., 2011) may lead to a particular functional impairment (Vazquez et al., 2018), as the relationships between these factors are complicated and reciprocal (Dykens, 2000; Thapar & Rutter, 2015), and they often have a common biological vulnerability (Barnett et al., 2006).

The cutoffs we chose to define mild and definite functional impairment when measured by the SDQ impact supplement, VABS-II, and CGAS applied to children with ADHD and ASD diagnoses, and indicated that these instruments evenly captured functional impairment, indirectly confirming the concurrent validity of the SDQ impact supplement. Regardless of the instrument used, almost all children with an ADHD diagnosis were classified as having at least mild functional impairment. This number was a little lower among participants with ASD, but there were still no big differences observed across instruments. When applying the criterion of definite functional impairment, all the instruments classified around 80% of participants with ASD as impaired. The situation was different for ADHD, where the same percentages of participants as in the ASD group were classified as having definite functional impairment when using the VABS-II and CGAS, while almost all the participants with ADHD were so classified by the SDQ impact supplement. It is possible that the SDQ impact supplement is especially sensitive when uncovering functional impairment in participants with ADHD. When ADHD is suspected, a clinician may be especially committed to asking about level of function at home, with friends, at school, and in leisure activities, and actively use this information to assess whether the child has ADHD. It is also possible that parents tend to evaluate these children and adolescents as especially impaired when the assessment method does not demand specific descriptions of everyday situations, but instead just a general evaluation.

The validity coefficient (Bubany, 2007) is only one of many factors that determine the degree to which a test may change the quality of clinical decisions. Taking into account the sensitivity and specificity of a test is also important when considering its accuracy (Murphy & Davidshofer, 2013). The SDQ impact supplement at the assumed cutoffs of the SDQ impact score (i.e., 1 and 2) gave high sensitivity, but the likelihood ratios showed that these cutoffs gave many false positives. Therefore, it would be unreasonable to expect that the SDQ impact supplement could assess whether someone meets the diagnostic criteria of functional impairment. Obviously, the diagnostic accuracy of the SDQ impact supplement refers to the quality of the

information provided by the chosen cutoffs; however, the accuracy should be distinguished from the usefulness of the received information (Søreide, 2009). A test is not useful unless it leads to decisions that are significantly better than those taken randomly (Murphy & Davidshofer, 2013), and our results indicate that the SDQ impact supplement significantly, although slightly, improved the possibility to make clinical decisions. Here it is crucial to remember that our neuropediatric sample included children and adolescents referred for neuropsychological/neurological assessment. That kind of restricted sample can cause biased results (see, Angold et al., 1999). Indeed, the differences in SDQ impact score between participants with ADHD or ASD and other functionally impaired children in our study are certainly less pronounced than those expected between these diagnostic groups and a control group in a general population (Russell et al., 2013).

Taking into account the clinical context and the specific patient population, both significant correlations and significant associations of the SDQ impact score with the VABS-II composite score and the CGAS total score, and significant associations between the SDQ impact score and clinical diagnoses of ADHD and ASD, in addition to ROC-analyses on sensitivity and specificity, altogether indicate that the SDQ impact supplement shows indications of both convergent and concurrent validity in screening functional impairment in the neuropediatric population.

Strengths and Limitations

The strength of the present study included the possibility of comparing the SDQ impact supplement with other established instruments that measure functional impairment. Another strength was the use of a standardized assessment of children's intellectual function. The relationship between functional impairment and diagnoses were controlled for by a relatively broad range of correlates, including symptoms of general psychopathology, gender, age, and intellectual function. We studied a population with real clinical diagnoses and had a chance to see the level of functional impairment in children who had already been diagnosed – and then check to what degree these children were impaired in the eyes of their parents. At the same time, we know the influence that child functional impairment has on parents is an important factor for parents seeking medical/psychological help for their children and a common reason for referral (Angold et al., 1998; Burns et al., 1995; Sasser et al., 2017). Mapping functional impairment by parents of youths or children with decreased ability to communicate these difficulties is especially important, as parents have easier access to children's visible impairment than to their internal distress (Colburn et al., 2018), and, generally, recognizing psychological problems is commonly inferred from impairments caused by the problem (Ezpeleta et al., 2001). An advantage of the SDQ impact supplement is its

cultural and context neutrality (see: Haack & Gerdes, 2011), as the parent is generally asked about the child's problems in everyday life areas without pointing out specific situations.

We should note some limitations in our study as well. First of all, we wonder if it is acceptable to use a short form to evaluate a phenomenon as complex as functional impairment (Winters et al., 2005). However, Bird et al. (1997) supported using global measures of impairment both for epidemiological and clinical purposes. We employed a clinical sample, with children that were referred for neuropediatric assessment; this presupposes that their parents probably saw them as impaired, so the results are limited to comparable clinical populations. There is both a statistical and conceptual problem with criterion-related validation of a test in a preselected sample, which makes it difficult to generalize the results to decision-making in the general population (Guion & Cranny, 1982). The observed associations may be less significant, as the variation in a selected population is restricted (i.e., participants are too similar to each other and too different from other samples), (Murphy & Davidshofer, 2013).

In addition, the cross-sectional design precludes any interpretations regarding the causality of the identified associations. The diagnostic groups were small and many of the children had co-existing neurodevelopmental or neurological disorders. Moreover, several had co-existing mental health problems (Halvorsen et al., 2019). A large proportion of the children in our sample were more or less functionally impaired. The SDQ impact score is not specific to a disorder: functional impairment can exist due to many different symptoms. Ratings of symptoms and impairment are at best moderately correlated, because symptoms are not proxies for impairment (Lewandowski et al., 2006). Obviously, the best way to determine functional impairment specific to some symptoms is to screen all the important areas of functioning. However, such advanced measurement methods should include parameters of impairment that are diagnosis-specific, otherwise there is a risk of a halo effect in ratings for specific impairments (Bird et al., 2000). We should also be aware that functional impairment can be caused by both symptoms and an unadjusted environment (WHO, 2001).

Conclusion

Using established cutoffs (Goodman, 1999), we demonstrated the sensitivity of the SDQ impact supplement to detect functional impairment in children with ADHD and ASD, but this comes at a cost of low specificity (large proportion of false positives). Thus, the SDQ impact supplement is not suitable for capturing functional impairment specific to these diagnoses; however, it is valid in capturing general functional impairment in a neuropediatric population. In addition, the SDQ impact supplement is easy to use, and can be especially

convenient, as it provides useful information about functional impairment as seen by parents without taking up much of parents' time and while saving clinicians' time.

Acknowledgments

This study was supported by the Northern Norway Regional Health Authority (PFP1178-14). The study was also supported in part by the Norwegian Directorate of Health and the Regional Centre for Child and Youth Mental Health and Child Welfare North at UiT The Arctic University of Norway, Tromsø, Norway. The authors would like to thank the participants who contributed to the dataset.

Disclosure Statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Helse Nord RHF [Grant/Award Number: PFP1178-14].

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Paper III

Kjærandsen et al. BMC Health Services Research (2021) 21:139
https://doi.org/10.1186/s12913-021-06153-5

BMC Health Services Research

RESEARCH ARTICLE Open Access

Determinants of caregiver satisfaction with child neurodevelopmental assessment in neuropaediatric clinics

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Abstract

Background: In addition to patient evaluations, caregiver evaluations and experiences are important indicators of the quality of health services. The aim of this study was to examine determinants of caregiver satisfaction with and perceived benefit of child neurodevelopmental assessment in neuropaediatric clinics.

Methods: The study was conducted among caregivers of children and adolescents aged 4–18 years ($N = 330$) referred for neurodevelopmental assessment in two neuropaediatric clinics in the specialised health service in Northern Norway. The Generic Short Patient Experiences Questionnaire (GS-PEQ) for child psychiatric outpatient patients was distributed to caregivers immediately following the assessment, and two of its items were used as measurements of caregiver satisfaction with and perceived benefit of the assessment.

Results: Caregiver satisfaction with the assessment was correlated with a better general level of function in the child, higher socioeconomic status, Norwegian mother tongue, referral from a specialist, and the respondent being a woman. Higher perceived benefit of the assessment was correlated with higher socioeconomic status, Norwegian mother tongue, and younger age of the child. Regression analysis revealed that caregivers' perception that the assessment was suited to their child's situation and that there was good cooperation with other public services (e.g., primary care and social/educational services) seemed more fundamental to caregiver satisfaction with neuropaediatric clinics' services than any background variable. Younger age of the child, in addition to caregivers' perception that the assessment was suited to their child and receiving sufficient information about the child's diagnosis/afflictions, were essential to the perceived benefit of the assessment.

Conclusions: Caregiver satisfaction with child neurodevelopmental assessment in neuropaediatric clinics partly depends on variables not related to the assessment experience per se. An assessment that was suited to the child, good cooperation with other public services such as primary health care and social/educational services, and giving sufficient information about the child's diagnosis are essential to an overall positive caregiver evaluation of neurodevelopmental assessments.

Keywords: Neuropaediatric, Neurodevelopmental assessment, Caregiver satisfaction, Caregiver experiences, Health care services research, Health care surveys

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Background

User experiences with health services can be viewed as reports on the quality of these services [1]. Indeed, patient experiences and satisfaction are associated with important quality aspects of health care, like patient adherence to treatment, patient safety, and clinical effectiveness [2–4]. Information on caregiver experiences with neuropaediatric health services or services for disabled children are increasingly sought [5–8] and are important indicators of the quality of health care delivered to children.

The concepts 'experiences with health care' and 'satisfaction' are positively related [9]. Measuring experiences with health services gives providers the opportunity to improve care, meet patients' expectations, and effectively manage and monitor health care performance [9, 10]. Patient satisfaction is a complex concept that depends on several variables, such as social standards, context, needs, values, previous experiences, future expectations, information, education, health, medical care, treatment, and psychological factors [2, 11–13]. Satisfaction surveys are used to capture patient evaluations of many different services and are implicitly or explicitly based on the understanding of satisfaction as the fulfilment of expectations [14]. Reported high satisfaction does not necessarily indicate a good experience, and reported dissatisfaction may be used as an indicator of some negative experience [14]. A study by Norman and colleagues [15] reported that, even when treatment outcomes were poor, satisfaction with Child and Adolescent Mental Health Services (CAMHS) was still high. Collecting information about specific experiences with concrete aspects of health services is a more valid measure of satisfaction, and easier to interpret than satisfaction ratings [16]. Both user experiences and user satisfaction are increasingly employed as quality indicators in the health care sector [17, 18].

From a user perspective, the main components of the quality of service relate to access to information, respect, support, and good coordination and collaboration [2, 19–24]. Parents with children receiving a first-time diagnosis of developmental disability were more satisfied when a large amount of information was provided, and especially appreciated it when clinicians possessed good communication skills and had an understanding of their situation [25]. Previously reported user satisfaction following neuropsychological evaluation [8] was mostly related to clinicians' concern and competence.

In a study of user satisfaction following paediatric neuropsychological evaluation, Bodin et al. [6] concluded that neither wait time nor referral source were associated with this variable. Holmboe and colleagues [24] found that the perceived wait time for a consultation was associated with parents' experiences with mental health services, but found no association with the wait time recorded in patient journals. Other results indicated that patient satisfaction with child outpatient services may be related to shorter recorded wait times [26, 27].

Some demographic factors have been repeatedly related to user satisfaction and may be treated as proxies of expectations. Earlier studies have indicated that more positive parental evaluation of health services was related to younger children [19, 21–23, 28–30], and shorter parental education [6, 7, 24, 30–32]. No significant differences in evaluations by caregivers' mother tongue [22, 24], and in most studies, no significant differences for the gender of the child was found [6, 21, 22, 29, 33]. The reported role of socioeconomic status [2, 34] and the gender of the respondent [18, 35] in satisfaction with health services have been inconsistent.

Generally, good health status of the respondent is associated with a positive evaluation of health services [2, 18, 32, 36, 37]. Parents with poorer health, a lower quality of life, and those who experience more everyday stress may have more negative views of their child's treatment [38–42]. Therefore, it is important to examine to what extent parents' mental health can influence their evaluation of neuropaediatric services.

Different results have been reported for the relationship between children's diagnoses [6, 19, 21, 23, 24, 29, 43] or the number of child health problems and caregiver evaluations of health services [23, 24, 29, 31, 42]. Thus, it is still unclear whether caregivers are experiencing and assessing child rehabilitation services in the context of the severity of their child's problems. Enhancing knowledge in this area would help clinicians and health services to identify those caregivers who need more information and support, as well as contribute to higher satisfaction with neuropaediatric services. Many earlier studies on user evaluations of health services for disabled children included a limited number of factors that could affect caregiver evaluations; they focused mostly on user experiences with health services and their relationship with demographic variables [6, 19, 21–23, 44].

The aim of the current study was to examine determinants of caregiver satisfaction with and perceived benefit of child neurodevelopmental assessment in neuropediatric clinics in Northern Norway. The outcomes caregiver satisfaction and perceived benefit of assessment were measured by a short-form survey, the Generic Short Patient Experiences Questionnaire (GS-PEQ) [1], to reduce the burden of collecting and analysing data [45]. Given the inconsistent results of other studies, we aimed to investigate the association between background variables (health service characteristics, caregiver characteristics, and child characteristics), as well as specific experiences

with neuropaediatric services, and the outcome variables.

Methods

Participants

The study population consisted of caregivers of children referred by a general practitioner or a medical specialist to the neuropaediatric outpatient clinics at the University Hospital of North Norway or the Finnmark Hospital Trust in Norway for neurodevelopmental or neurological assessment [46–48]. These clinics are specialised health service units in Northern Norway serving children and adolescents with neurodevelopmental disorders, early-acquired disabilities or intellectual and developmental disabilities. The participants were included consecutively in the present study. In order to be included in the study, children had to be aged 4 to 18 years at the time of referral, and referred between October 2012 and July 2016 at the University Hospital of North Norway, or between January 2014 and July 2016 at the Finnmark Hospital Trust. A total of 518 children and adolescents met these criteria, of whom 153 (30%) were excluded due to lack of treatment in the clinics either because of time constraints, lack of caregiver motivation, or insufficient knowledge of the Norwegian language because several of the questionnaires were only available in Norwegian or a restricted number of additional languages [46]. The caregivers of the remaining 365 eligible children (247 referred by general practitioner, 118 referred by medical specialist) were invited to complete the GS-PEQ and participate in the study. Three hundred thirty caregivers agreed (90.4%) and were included in the final study sample.

The most frequent diagnostic groups among children in the sample were specific developmental disorders (41.5%), intellectual disability (21.8%), autism spectrum disorder (15.8%), and diseases/disorders of the central nervous system such as epilepsy and cerebral palsy (14.8%). The diagnoses were not mutually exclusive. A total of 12% children were not diagnosed with any neurological or neurodevelopmental disorder.

Measures

The generic short patient questionnaire

The GS-PEQ [1], created by The Norwegian Knowledge Centre for the Health Services, is a generic, 10-item, questionnaire that collects information on user experiences across a range of specialist health services. The GS-PEQ is based on previous testing of six, group-specific questionnaires, among them parents' evaluation of their experiences with somatic inpatient services [49] and psychiatric outpatient services (i.e., CAMHS patients) [50]. The GS-PEQ includes items regarding specific experiences with clinical services, user involvement, information, organisation, accessibility (wait time), incorrect treatment, and outcome (satisfaction and perceived benefit) [1]. The questionnaire's authors also added three items relevant to CAHMS patients: one regarding clinical services, one regarding information about the assessment, and one regarding cooperation [51]. This version is referred to as the "Generic short version – caregivers about CAMHS" of the GS-PEQ [51], which was used in this study. All 13 items in the applied version of the GS-PEQ are formatted as questions. Twelve of them are answered on a 5-point scale from "not at all" (0) to "to a great extent" [4], or as "not applicable". One question regarding the wait time to get an appointment is answered on a 4-point scale from "no wait time" (0) to "way too long" [3]. Two of the questions about wait time and incorrect treatment did not correlate or correlated weakly with the other scores in the GS-PEQ, and they were used for comparison with administrative data, respectively in the Parent Assessment of Outpatient CAMHS [50, 52] and the Parent Experiences of Paediatric Care [49]. GS-PEQ is freely available without a license.

Background variables

Caregivers' demographic data (age, gender, marital status, mother tongue, education, and employment) were collected from the appendix that was distributed with the GS-PEQ [51]. Children's demographic data (age and gender) were taken from the Development and Well-being Assessment (DAWBA [53];). Information about referral source (general practitioner or medical specialist) and wait time for the assessment was taken from patient records. A single subscale of the Family Stress Scale part of the DAWBA, socioeconomic/housing score [53], was employed to assess subjective experience of socioeconomic status in the previous 12 months. The variable consisted of items about subjectively evaluated stressors connected to financial difficulties, unemployment, problems with neighbours/neighbourhood, and having home inadequate for family's needs. Caregivers rated the items on a 3-point scale from "none, or doesn't apply" (0) to "a lot" [2]. Scores equal to two or higher were assigned lower socioeconomic status (score = 0). We have license to use the DAWBA including the Everyday Feeling Questionnaire through the Youth in Mind: https://youthinmind.com/

Caregivers' mental health

The mental health of the caregivers was assessed with the self-administered version of the Everyday Feeling Questionnaire (EFQ [54]), which is part of the DAWBA [53]. The EFQ contains 10 items estimating symptoms of distress (e.g. "stressed" or "very unhappy"), and psychological well-being (e.g. "positive about the

future" or "calmed and relaxed"). Respondents rated the symptoms on a 4-point scale ranging from "none of the time" (0) to "all of the time" [4]. Lower total scores reflect lower levels of distress and higher levels of well-being. The EFQ has good internal consistency, with a Cronbach's α reported between .87 and .90 [48, 54, 55].

Children's global assessment scale

The CGAS [56] is a clinician-rated tool used to assess the global psychosocial functioning of children, taking into account all available information. The score on this scale reflects the lowest overall level of psychosocial functioning (i.e., at home, at school, and with peers) of the child or adolescent during the preceding month. Total CGAS score ranges from 1 (the most impaired level) to 100 (the best level of functioning), and the score is separated into 10-point intervals, each of which describes a specific level of functioning, followed by examples of matching behaviour and life situations adequate for children and adolescents. In a large Norwegian study of clinicians in outpatient CAMHS [57], the interrater reliability of the routine use of the CGAS was found to be moderate (intraclass correlation coefficient = .61). We have license to use the CGAS through The Norwegian Directorate of eHealth: https://ehelse.no/english

Procedure

Children underwent the interdisciplinary assessment of neurodevelopmental/neurological disorders and an additional assessment of the presence of coexisting behavioural and emotional disorders. The interdisciplinary assessment included specialists such as paediatricians, neuropsychologists, special education therapists, occupational therapists, and physiotherapists [46, 47]. The presence of a neurodevelopmental/neurological was examined by paediatricians using methods such as MRI Caput, EEG or genetic testing if indicated. A clinical psychologist/neuropsychologist assessed developmental level in all children using a standardised intelligence scale and the Vineland Adaptive Behaviour Scale II [58]. The GS-PEQ was distributed to and completed by caregivers immediately following child neurodevelopmental assessments. Informed consent was obtained from all individual participants included in the study. The study was approved by the appropriate ethics committee. The use of de-identified data was approved by the data protection officer at University Hospital of North Norway and Finnmark Hospital Trust.

Statistics

The data were analysed using SPSS Version 25. For categorical variables, dummy variables were used (e.g., gender: 0 – man/boy, 1 – woman/girl). Some dummy variables were created for variables with more categories (e.g., mother tongue: 0 – Norwegian, 1 – others; education: 0 – primary/secondary/high school; 1 – college/university). Sami mother tongue was combined with Norwegian mother tongue, as the three participants declaring Sami mother tongue also reported Norwegian mother tongue.

Missing response on items, ceiling effect, demographic characteristics of the respondents, and specific experiences with neuropaediatric services were assessed using descriptive statistics, based on the total number of participants ($N = 330$). An acceptable ceiling effect is generally defined as a maximum of 50% of respondents choosing the most positive response category [59]. Specific experiences with neuropaediatric services were categorised as positive (the two highest item scores), neutral (moderate item scores), and negative (the two lowest item scores). The question "Do you believe that your child was in any way given the wrong treatment?" was excluded from the analyses due to probable misunderstanding by the participants (high scores for wrong treatment were associated with positive experience and satisfaction, $n = 15$).

The relationships between the outcome variables (satisfaction and perceived benefit of the assessment), service characteristics (clinic site, wait time, referral source), caregiver characteristics (gender, mother tongue, socioeconomic status, education, mental health), and child characteristics (age, gender, psychosocial functioning) were examined using Pearson's correlation coefficients. Hierarchical linear regression analyses were conducted to examine which variables could uniquely explain variation in the outcome variables. The predictive variables included service characteristics, caregiver characteristics, child characteristics, and specific experiences with neuropaediatric services. In correlation and regression analyses, only cases with data both on satisfaction and perceived benefit were used ($N = 265$) to assure that exactly the same participants were used both to predict satisfaction and perceived benefit. These 265 participants had missing values for the following variables: socioeconomic status (16.6%), caregiver gender (8.3%), CGAS score (3.4%), and specific experience with neuropaediatric services (between 0.4 and 13.4%). Missing values were not substituted and were dealt with in linear regression by pairwise deletion. We assessed the significance of change in explained variation (R^2) by applying a conventional R^2 change of 2% as a small effect, a change of 13% as a medium effect, and a change of 26% as a large effect [60]. The statistical methods were set on a 5% significance level.

Results

Caregiver characteristics

Of 365 caregivers invited to answer the GS-PEQ-CAMHS, 330 completed it (90.4%). Respondents were between 24 to 71 years of age (mean, $M = 41.5$; standard deviation, $SD = 7.4$). Children's age ranged between 4 and 18 years ($M = 10.2$, $SD = 3.8$), and 34.2% were females. Detailed caregiver characteristics are included in Table 1. There were no significant differences in service or child or characteristics between caregivers who completed the GS-PEQ and those who did not.

Ceiling effect, missing values, and not applicable responses

Only one question about perceived benefit of the assessment met the criterion of maximum 50% responses in the most positive category. All the other questions achieved a high ceiling effect. Missing values occurred in around 2% of answers, with a range 0.9–7% (Table 2).

Caregivers had the possibility to choose "not applicable" in response to all the questions about specific experiences, as well as for the outcome variables. They judged two questions as especially irrelevant to their situation: "Were you involved in any decisions regarding your child's treatment?" (22.1% answered "not applicable") and "Do you find that the clinic cooperated well with other public services?" (20.9% answered "not applicable"). Most of the questions that contained the word "treatment" had a high percentage of "not applicable" answers. Caregivers that chose "not applicable" to answer the question on information about diagnosis/afflictions were statistically significantly more likely to have a child without any diagnosis of neurodevelopmental/neurological disorder ($\chi^2 = 6.6$, $p = .01$). All the questions concerning communication with the clinician and confidence in his/her professional skills were highly applicable (only around 1% "not applicable"), with exception of confidence in the professional skills of other staff (8% responded "not applicable").

Caregiver evaluation of the assessment

Most caregivers were highly satisfied with their child's assessment (97%) (Table 2), and they answered positively to almost all questions about the relationship with clinicians (i.e., communication and confidence in their professional skills). Caregivers evaluated the assessment as highly beneficial (83.9% positive experiences). Most negative experiences were related to caregivers' involvement in decisions regarding the child's assessment (5.9%), the information they were given about their child's diagnosis or afflictions (3.3%), and the clinic's cooperation with other public services (3.2%).

Table 1 Demographic characteristics of caregivers ($N = 330$)

	N	%
Caregivers		
Mother	232	70.3
Father	69	20.9
Mother and father	10	3.0
Other	19	5.8
Marital status		
Married	163	49.4
Cohabitant	104	31.5
Without partner	63	19.1
Mother tongue		
Norwegian	299	90.6
Other Nordic language	7	2.1
Other European language	16	4.8
Non-European language	8	2.4
Education level of caregiver		
Primary/Secondary School	29	7.9
High School	143	43.6
College/University up to 4 years	104	31.7
University above 4 years	52	15.9
Education level of caregiver's partner		
Primary/Secondary School	42	14.9
High School	143	50.7
College/University up to 4 years	59	20.9
University above 4 years	38	13.5
Employment status of caregiver		
Gainfully employed	245	74.2
On sick leave, disability pension or rehabilitation	43	13.0
Under education	9	2.7
Working at home	11	3.3
Unemployed	4	1.2
Another activity	18	5.5
Employment status of caregiver's partner		
Gainfully employed	212	75.4
On sick leave, disability pension or rehabilitation	40	14.2
Under education	11	3.9
Working at home	4	1.4
Unemployed	2	0.7
Another activity	12	4.3

Determinants of caregiver satisfaction with and perceived benefit of the neurodevelopmental assessment

Caregiver satisfaction with and perceived benefit of the child neurodevelopmental assessment were moderately correlated ($r = .47$, $p < .001$). Satisfaction with the assessment was weakly associated with referral from a

Table 2 Caregivers' specific experiences with neuropaediatric services. Questions from the Generic Short Patient Experiences Questionnaire (GS-PEQ)

Question	Missing (%)	Not applicable (%)	Applicable (*N*)	Ceiling effect (%)	Positive experience (%)	Neutral experience (%)	Negative experience (%)	*M*	*SD*
Did the clinicians talk to you in a way that was easy to understand?	0.9	1.2	318	84.9	99.1	0.6	0.3	3.83	.44
Do you have confidence in the clinicians' professional competence?	1.2	1.2	317	82.3	99.4	0.6	0.0	3.82	.40
Do you have confidence in the other staff's professional skills?	1.5	7.9	294	74.5	98.0	2.0	0.0	3.72	.49
Were you told as much as you considered necessary about how tests or examinations would be carried out?	1.2	0.6	319	68.3	92.2	7.2	0.6	3.60	.67
Did you get sufficient information about your child's diagnosis/afflictions?	4.5	11.8	271	57.6	86.7	10.0	3.3	3.39	.88
Did you perceive the treatment that you child received as suited to his/her situation?	1.8	8.5	291	64.6	94.5	4.8	0.6	3.58	.63
Were you involved in any decisions regarding your child's treatment?	4.2	22.1	238	56.7	86.1	8.0	5.9	3.34	.94
Did you perceive the clinic's work as well organised?	1.8	2.1	312	63.5	92.2	6.9	0.9	3.54	.68
Do you find that the clinic cooperated well with other public services?	3.0	20.9	246	50.4	83.7	13.1	3.2	3.30	.82
Overall, was the help and treatment you received at the clinic satisfactory?	3.3	7.3	290	68.6	97.0	2.7	0.3	3.65	.57
Overall, what benefit have you had from the care at the clinic? *	7.0	8.2	280	38.2	83.9	15.0	1.1	3.20	.77

Note. "Missing" and "not applicable" based on initial $N = 330$; Ceiling effect (acceptable ceiling effect was defined as a maximum of 50% of respondents choosing the most positive response category), and positive (the two highest item scores), neutral (moderate item scores), and negative experiences (the two lowest item scores) based on *N* applicable; A five-point response scale was used for 10 items: 0 – not at all, 1 – to a small extent, 2 – to a moderate extent, 3 – to a large extent, 4 – to a very large extent, 5 – not applicable; * A five-point response scale with different answers was used to this question: 0 – no benefit, 1 – a small benefit, 2 – a moderate benefit, 3 – a large benefit, 4 – a very large benefit, 5 – not applicable

specialist, being a woman, having Norwegian mother tongue, higher socioeconomic status, and having a child with higher psychosocial functioning (Table 3). Perceived benefit of the assessment was weakly related to having Norwegian mother tongue, higher socioeconomic status, and being caregiver to a younger child. Wait time, caregiver's education and mental health, and child's gender did not have any significant association with the outcome variables. Caregiver satisfaction with and perceived benefit of the assessment did not differ significantly between the two clinic sites (University Hospital of North Norway and the Finnmark Hospital Trust).

The overall model predicting caregiver satisfaction with the neurodevelopmental assessment was significant ($F(15,158) = 13.03$, $p < .001$) and accounted for 55.3% of the variance in the satisfaction score (Table 4). Background variables (step 1) and specific experiences with neuropaediatric services (step 2) accounted for 13.7, and 41.6% of the variance in satisfaction, respectively, reflecting an effect of medium magnitude in step 1, and an effect of large magnitude in step 2. Specifically, satisfaction was significantly associated with two kinds of specific experiences with neuropaediatric services: perceived suitable assessment and cooperation with other public services (i.e., primary care and social and educational services).

The overall model predicting the perceived benefit of the assessment was significant as well ($F(15,158) = 4.74$, $p < .001$) and accounted for 31% of the variance in the way caregivers answered to the question about the benefit of the assessment. Background variables (step 1) and specific experiences with neuropaediatric services (step 2) accounted for 8.4, and 22.7% of the variance in benefit, respectively, reflecting an effect of small magnitude in step 1, and an effect of medium magnitude in step 2. Specifically, child's lower age, caregiver's perception of a suitable assessment, and getting sufficient information about the child's diagnosis/afflictions significantly predicted the perceived benefit of the assessment.

Discussion

The overall purpose of this study was to examine determinants of caregiver satisfaction with and perceived benefit of the child neurodevelopmental assessment. We looked at specific experiences with neuropaediatric services as well. In general, most of the caregivers were

Table 3 Bivariate relationships between overall caregiver satisfaction with child neurodevelopmental assessment and background variables

	N	*M* (*SD*)/*n*(%)	1	2	3	4	5	6	7	8	9	10	11	12
1 Satisfaction	265	3.65 (.58)												
2 Benefit	265	3.22 (.75)	.47 ***											
3 Clinic	265	227 (85.7%)	.01	−.09										
4 Referral source	265	79 (29.8%)	−.16 *	−.03	.08									
5 Wait time, days	265	90.29 (53.13)	−.02	−.05	−.08	−.09								
6 Gender of respondent	243	58 (23.9%)	.13 *	.06	.08	.05	−.06							
7 Mother tongue	265	241 (90.9%)	−.17 **	−.13 *	−.09	.06	.12 *	−.15 *						
8 Socioeconomic status	221	21 (9.5%)	.23 ***	.14 *	.09	−.01	.06	.02	−.08					
9 Education	265	139 (52.5%)	.05	.04	.04	−.06	.00	.14 *	.04	.05				
10 Mental health	220	11.79 (5.11)	−.11	−.10	.00	.07	.02	.03	.00	−.22 ***	−.09			
11 Age of child	265	10.22 (3.88)	−.08	−.20 **	.03	−.03	−.04	.03	−.04	.13	−.01	−.03		
12 Gender of child	265	162 (61.1%)	.01	.02	.09	−.14 *	.01	.04	−.14 *	.14 *	−.06	−.04	.11	
13 Child's psychosocial functioning	256	56.40 (13.93)	.14 *	.04	.06	−.04	−.09	−.01	.04	.10	.16 **	−.12	−.02	.12

Note. N including only those who answered both questions about satisfaction and perceived benefit with the assessment. Clinic: 0 – University Hospital of North Norway, 1 – Finnmark Hospital Trust; referral source: 0 – medical specialist, 1 – general practitioner; gender: 0 – male, 1 – female; mother tongue: 0 – Norwegian, 1 – others; socioeconomic status: 0 – lower, 1 – higher; education: 0 – lower, 1 – higher; mental health: a score from the Everyday Feeling Questionnaire, higher scores mean higher distress in a caregiver; child's psychosocial functioning measured by CGAS (Children's Global Assessment Scale); *$p < .05$. **$p < .01$, ***$p < .001$ (two-tailed test)

satisfied with their child's assessment in the two neuropaediatric clinics in Northern Norway; similar results have been reported in similar patient populations [6, 8, 29]. In addition, good cooperation with other public services and the assessment suited to the child's situation seemed more fundamental to caregiver satisfaction with neuropaediatric clinics' services than any background variable.

As user surveys tend to be positively skewed [13, 14], it was important to look at the few respondents who were not fully satisfied. A relatively high number of caregivers evaluated their involvement in the assessment, the cooperation with other services, and the provision of sufficient information about their child's diagnosis/afflictions as either more negative or not relevant for them in relation to other specific experiences. Other studies on services for disabled children pointed out that caregivers gave the most negative evaluations for the amount of information received [19, 21–25] and the coordination of delivered services [21], which is in line with our study.

Most of the background variables were negligible in predicting caregiver satisfaction with and perceived benefit of the assessment, especially after specific experiences with neuropaediatric services were included in the regression analyses. These specific experiences explained more of the high overall satisfaction with the assessment than any other background variable. In our study, these specific experiences played a causal role in caregiver satisfaction; and a generic survey that includes single questions on specific indices of different experiences instead of full scales is a good method to identify predictive variables [61]. User experiences with health services were the most powerful determinants of patient overall satisfaction in other studies as well [9, 18, 34, 36]. In our study, two types of specific experiences with neuropaediatric services were especially crucial in the explanation of overall satisfaction, i.e., if the assessment was suited to the child's situation, and cooperation with other public services, demonstrating that these factors are of high importance. The situation seemed different for the perceived benefit of the assessment. Specific experiences with neuropaediatric services explained this outcome to a smaller degree, and among the background variables, child's age was still essential to the explanation of the variance in this outcome. Specific experiences that were crucial to the perceived benefit of the assessment were whether the assessment was suited to the child's situation, and getting sufficient information about child's diagnosis/affliction after the assessment.

Some background variables were clearly only weakly correlated with caregiver satisfaction and perceived benefit. Caregivers of children referred by general practitioners were less satisfied with the assessment than those of children referred by a medical specialist. This result could be due to the different health problems that may be present in patients referred from a medical specialist, as it is likely that these patients spent more time in specialist health services, and/or had more serious health problems, making the neurodevelopmental assessment an important step in the process of clarifying the child's afflictions. Caregivers with Norwegian mother tongue were more satisfied with and perceived a higher benefit

Table 4 Hierarchical multiple regression analysis results for the prediction of caregiver satisfaction with and benefit of the assessment

Predicting variables	Satisfaction		Benefit	
	ΔR^2	β	ΔR^2	β
Step 1: Background variables	.137***		.084*	
Referral source		−.10		.01
Caregiver's gender		.04		−.02
Mother tongue		−.02		−.03
Socioeconomic status		.10		.05
Child's age		−.05		−.20**
Child's psychosocial functioning		.07		−.04
Step 2: Specific experiences with neuropaediatric services	.416***		.227***	
The clinicians easy to understand		.02		−.04
Confidence in the clinicians' professional competence		.09		−.05
Confidence in the other staff's professional skills		−.02		.08
Informed about how tests or examinations would be carried out		−.07		.01
Got sufficient information about the child's diagnosis/afflictions		.05		.17*
The treatment suited to the child's situation		.48***		.26**
Involvement in any decisions regarding the child's treatment		.03		.00
Perceiving the clinic's work as well organised		.07		.14
The clinic cooperated well with other public services		.21**		.10
Total R^2		.553***		.310***

Note. All β (standardised coefficients) were from the final model with all steps included. Referral source: 0 – specialist, 1 – general practitioner; gender: 0 – male, 1 – female; mother tongue: 0 – Norwegian, 1 – others; socioeconomic status: 0 – lower, 1 – higher; child's psychosocial functioning measured by CGAS (Children's Global Assessment Scale); *$p < .05$. **$p < .01$, ***$p < .001$ (two-tailed test)

of the assessment. This difference could be caused by either communication problems or different expectations of health services related to cultural background. Higher socio-economic status was related to both higher satisfaction with the assessment and more perceived benefit of the assessment. Previous results on the relationship between socioeconomic factors and user satisfaction have been inconsistent [2, 34]. In a review, Willems and colleagues [62] concluded that patients from lower social classes could be disadvantaged due to a misperception of their needs on the part of their doctor, as well as their lower ability to participate in the care process. They pointed out that the communication between doctors and these patients was characterised by less information, fewer directions, and less socio-emotional and partnership building. Both our results and the results from the review indicate that clinicians should be aware of contextual differences in their communication patterns with patients/their caregivers. Finally, in our study, caregivers of younger children had a higher perceived benefit of the assessment, confirming other findings [19, 21–23, 28–30]. Younger children are new in the system, and an assessment can be a milestone in understanding the child and learning more about a condition. Another possible explanation is that older children may have more severe neurodevelopmental problems and a higher incidence of mental health difficulties [63]. Egilson [28] explained such results simply by assuming that parents become more critical of the services as their children grow older. Generally, the existence of small associations between demographics and service evaluations can have two explanations – different groups may have different response tendencies or different groups may be treated differently during the care process [12].

Higher child global psychosocial functioning was associated with higher caregiver satisfaction, and this should be taken into consideration when interpreting user satisfaction surveys. This result could indicate that the caregivers of these children needed less help. A study by Ezpeleta et al. [64] showed that parents of children with high functional impairment both more often admitted needing psychiatric help and more often sought such help. It is also possible that expectations of health care delivery did matter [2, 9, 65]. Ambiguous results about the severity of a child's mental health and service evaluation exist in the literature [6, 19, 21, 23, 24, 29, 31, 43], but our results are in accordance with results that showed an association between higher caregiver satisfaction with services and better functioning [42] or less severe

problems of the child [64]. Our finding of no significant relationship between caregiver's mental health and satisfaction with the assessment disproves earlier findings of an association between the health status of a respondent and service evaluation [2, 18, 32, 36, 37, 40–42].

When the GS-PEQ was created, it was assumed that the number of questions inapplicable to any respondent would not exceed 20% [1]. In our study, as many as one-fifth of the caregivers evaluated questions about involvement and cooperation as inapplicable to their child's situation. This may indicate that the caregivers did not recognise these areas as a responsibility of the clinics. Such an evaluation of the service could be influenced by the temporal characteristics of the assessment. A cooperative feedback meeting, where the results are communicated and clinical implications and further treatment is planned, takes place within 2 weeks of the assessment. Visible cooperation with other public services, like primary care and social/educational services, also starts then, whereas our caregivers completed their evaluation of health care delivery directly after the assessment. If our caregivers had completed the GS-PEQ after the cooperative feedback meeting, it may have led to a different evaluation.

Clinical implications

The evaluation of cooperation with other services as inapplicable by many of our caregivers could mean that they did not get clear information about the possibility for cooperation between neuropaediatric clinics and primary care and social/educational services, among others. At the same time, it is difficult to imagine that an assessment in a neuropaediatric clinic could be conducted in a vacuum, without any interaction with other important services. Thus, caregiver evaluations might indicate that The Coordination Reform, which was enacted in Norwegian health care system in the 2000s, and concerned cooperation and coordination across health care units [66], did not affect neuropaediatric services to the extent necessary.

Norwegian national guidelines for child neuropaediatric clinics emphasise the importance of user involvement as a prerequisite for patient and user safety, and a requirement for sound services [67]. Many caregivers in our study replied that the question on being involved in the assessment was inapplicable to their situation. We concluded that the involvement rates and knowledge of the possibility for involvement are definitely areas that require improvement in the clinics. In addition, we found that the use of the term "treatment" in the questionnaire might be problematic, as it could cause respondents to misunderstand the questions (among them the question about involvement); indeed, the health service delivered was primarily an assessment, not a treatment.

Strengths and limitations

Our study has some significant strengths. There are advantages to our close-to-real-time data collection [68]. We had a very good response rate, and the timing of our data collection prevented memory distortion in the participants. A generic survey has its advantages – it is time-saving, more motivating to complete, creates less burden on participants, is easier to interpret, and allows comparisons between different health care units [69]. Of course, our study has some limitations as well. The GS-PEQ is a survey that was created based on health service-specific surveys; it was meant to cover both adults and children, inpatients and outpatients, and short and long-lasting treatment. However, only two of these surveys refer specifically to children [49, 50], and one of them to outpatients [50]. None of these surveys are specific to child rehabilitation or neuropaediatric clinics. This could create a problem with applicability or suitability of the selected questions, and may have influenced the acceptance or understanding of these surveys by the users. The creators of the GS-PEQ [1] recommended it for the use in large samples to help strategic managers monitor quality of care, and to inform decision-making or service evaluation at the operational management level. In addition, our results were positively skewed, indicating the existence of a ceiling effect. Thus, interpretation of satisfaction can be problematic as the outcome of an active evaluation [14]. Another limitation is that we cannot exclude the possibility that the least satisfied caregivers refused participating in our study, and their lack of participation could influence the results.

Conclusions

The GS-PEQ contains questions related to a wide spectrum of specific experiences that explained significant proportions of the variation in satisfaction and perceived benefit of the assessment in our study. These specific experiences are indices of the perceived quality of health services. Caregiver satisfaction with neurodevelopmental assessment in neuropaediatric clinics in our study depended partly on variables not related to specific experiences with neuropediatric services per se. However, an assessment that was adapted to the child's needs, good cooperation with other public services such as primary care and social/educational services, and giving sufficient information about the child's diagnosis are experiences that are essential to an overall positive evaluation of child neurodevelopmental assessment. In addition, clinicians should be especially vigilant in including caregivers in decision-making and in discussing the possibilities for cooperation with other services.

Abbreviations
CAMHS: the Child and Adolescent Mental Health Services; **CGAS**: Child Global Assessment Scale; **DAWBA**: Development and Well-being Assessment; **EFQ**: the Everyday Feeling Questionnaire; **F**: ratio of the mean regression sum of squares divided by the mean error sum of squares; **GS-PEQ**: the Generic Short Patient Experiences Questionnaire; **M**: Mean; **N**: total sample size; **n**: subsample size; **p**: probability of the data arising by chance; **r**: Pearson's product moment correlation coefficient; **SD**: Standard Deviation; **SDQ**: the Strengths and Difficulties Questionnaire

Acknowledgements
The authors would like to thank the participants who contributed to the dataset.

Authors' contributions
KSK planned and wrote the paper and performed statistical analyses. PHB critically revised the manuscript draft and approved the final version of the manuscript. MH is the project manager; she critically revised the manuscript draft, and approved the final version of the manuscript as well.

Funding
This study was supported by the Northern Norway Regional Health Authority (PFP1178–14). The study was also supported in part by the Norwegian Directorate of Health and the Regional Centre for Child and Youth Mental Health and Child Welfare North at UiT The Arctic University of Norway, Tromsø, Norway.

Availability of data and materials
The datasets analysed during the current study are not publicly available due to ethical restrictions and personal data protection but are available from the authors on reasonable request and with permission of the Data Protection Official in the health trusts.

Ethics approval and consent to participate
The study was approved by the Data Protection Official in the health trusts. The participants were informed about the aims of the study, privacy, and the right to withdraw from the project. Written consent to participate was obtained from caregivers and adolescents. For children under the age of 12 years, only caregivers' consent was collected. The Norwegian Regional Committees for Medical and Health Research Ethics evaluated the project and determined that their approval was not required.

Competing interests
The authors have no competing interests to declare.

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Received: 18 March 2020 Accepted: 3 February 2021
Published online: 12 February 2021

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