

Doctoral thesis

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Chris Margaret Aanonsen

# Assessing and Understanding Mental Health and Quality of Life in Deaf and Hard-of- Hearing Children and Adolescents

**NTNU**  
Norwegian University of Science and Technology  
Thesis for the Degree of  
Philosophiae Doctor  
Faculty of Medicine and Health Sciences  
Department of Mental Health



Norwegian University of  
Science and Technology



Chris Margaret Aanondsen

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Trondheim, June 2022

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# Sammendrag

## Kartlegging og forståelse av psykisk helse og livskvalitet hos døve og hørselshemmede barn og unge

Psykiske vansker forekommer hyppigere blant døve og hørselshemmede – (D)HH – barn og unge enn barn og unge med typisk hørsel (TH). Kartlegging av tegnspråklige DHH barn og unges psykiske helse med skriftspråklige spørreskjema kan bidra til underrapportering av symptomer på psykiske vansker. Kulturelle, språklige og kliniske faktorer kan også bidra til feildiagnostikk ved utredning av (D)HH barn og unge. For å unngå dette er det behov for kartleggingsverktøy på tegnspråk. Hvordan livskvaliteten til (D)HH barn og unge er sammenlignet med TH barn og unge er fremdeles et diskusjonstema. Gode kommunikasjonsferdigheter på både tale- og tegnspråk har vist seg å være en beskyttende faktor for psykiske vansker hos (D)HH barn og unge. Teknologisk utvikling (bl.a. cochlea implantat), anerkjennelse av norsk tegnspråk som fullverdig språk, universell hørselsscreening, og tidlig intervensjon er faktorer som har en gunstig påvirkning på språkutvikling, og sannsynligvis også på psykisk helse og livskvalitet.

Målet med denne studien var å forbedre kartleggingen av psykiske vansker og livskvalitet hos (D)HH barn og unge ved å oversette reliable og valide spørreskjemaer til norsk tegnspråk (NSL) og validere disse. Videre ønsket jeg å få en bedre forståelse av psykisk helse, livskvalitet og kommunikasjon, og hvordan disse henger sammen hos både tegnspråklige DHH og talespråklige hørselshemmede (HH) barn og unge. “Strengths and Difficulties Questionnaire” (SDQ) og “Inventory of Life Quality in Children and Adolescents” (ILC) ble oversatt til NSL. 107 (D)HH barn og unge, derav 60 DHH og 47 HH, og deres foreldre fylte ut selv- og foreldrerapporten av SDQ og ILC. Tegnspråklige DHH barn og unge svarte på både den skrift- og tegnspråklige versjonen, mens talespråklige HH barn og unge kun svarte på den skriftspråklige. Foreldrene svarte i tillegg på spørsmål om barnas tale- og tegnspråklige ferdigheter, kommunikasjon, hørselstap og skole. Data ble samlet inn mellom 2016 og 2018.

SDQ-NSL og ILC-NSL oppnådde akseptabel reliabilitet og validitet. Videre var de psykometriske egenskapene sammenlignbare med de psykometriske egenskapene til den opprinnelige valideringen. Svakt samsvar mellom den tegn- og skriftspråklige ILC for barn bør imidlertid følges opp nærmere. Dobbelt så mange DHH og HH barn og unge rapporterte om psykiske vansker i det kliniske området sammenlignet med TH barn og unge. SDQ-NSL så ut til å differensiere bedre mellom psykiske vansker i normal-, grense- og klinisk område for tegnspråklige DHH barn og unge enn SDQ-NOR. På selvrappertert livskvalitet fant vi ingen forskjell mellom (D)HH barn og unge og TH barn og unge. Videre, fant vi sammenheng mellom barnas foreldrerapporterte kommunikasjonsferdigheter og foreldrerapportert psykisk helse og livskvalitet. Det var imidlertid ingen sammenheng mellom grad av hørselstap og psykisk helse eller livskvalitet.

Oppsummert er SDQ-NSL og ILC-NSL reliable og valide spørreskjema for å kartlegge hhv. psykiske vansker og livskvalitet hos (D)HH barn og unge. Den forhøyede forekomsten av psykiske vansker understreker behovet for tidlig oppdagelse av hørselstap, tidlig intervensjon, og jevnlig kartlegging av sosioemosjonell, kognitiv og språklig utvikling i tillegg til kartlegging av psykisk helse og livskvalitet. Risikoen for feildiagnostikk og den forhøyede forekomsten av psykiske vansker tydeliggjør behovet for et spesialisert utrednings og behandlingstilbud for (D)HH barn og unge. For å forbedre utredning av komorbide språkvansker og til videre forskning er det behov for å utvikle verktøy som kartlegger pragmatiske språkferdigheter og sosial kommunikasjon hos tegnspråklige (D)HH barn og unge.

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## **Abstract**

### **Assessing and Understanding Mental Health and Quality of Life in Deaf and Hard-of-Hearing Children and Adolescents**

Mental health problems are more prevalent in deaf and hard-of-hearing - (D)HH - children and adolescents. Using written measures to assess mental health problems in (D)HH children and adolescents has been found to underestimate symptoms and prevalence. Misdiagnosis is also more common among (D)HH children and adolescents due to an overlap of cultural, linguistic and clinical factors. Therefore, validated measures in sign language are needed. Controversies still exist regarding Quality of Life (QoL) in (D)HH children and adolescents compared to typically hearing (TH) children and adolescents. Good communication skills in spoken and sign language are associated with better mental health in (D)HH children and adolescents. Technological advances, recognition of sign languages as natural languages, universal neonatal hearing screening and early intervention programs have been introduced, affecting language outcomes. These changes are also likely to have impacted mental health and QoL outcomes.

To improve assessment and interventions for (D)HH children and adolescents, this thesis aimed to translate reliable and valid questionnaires for mental health and QoL into Norwegian Sign Language (NSL) and validate these. The second aim of the study was to gain a better understanding of signing DHH and hard-of-hearing (HH) children and adolescents' mental health, QoL and communication as well as associations between these aspects. To do so, the Strengths and Difficulties Questionnaire (SDQ) and the Inventory of Life Quality in Children and Adolescents (ILC) were translated into NSL. Then, 107 (D)HH children and adolescents, 60 DHH and 47 HH, and their parents completed the self- and parent-reports of the SDQ and ILC. DHH children and adolescents completed both the written and NSL versions in randomised order, while the HH children and adolescents completed the written versions only. Parents also provided information about their children's spoken and sign language skills, communicative competence, hearing loss (HL), and school. Data were collected between 2016 and 2018.

The SDQ-NSL and the ILC-NSL showed acceptable reliability and construct validity. Their psychometric properties were also found to be similar to the original validations. The lack of associations between the two language versions of the child ILC, however, requires

further attention. The prevalence of self-reported mental health problems in the clinical range was about twice as high for DHH and HH children as their TH peers. The SDQ-NSL seemed to differentiate better between mental health problems in the normal, borderline and clinical range for DHH children and adolescents than the SDQ-NOR. Self-reported QoL of (D)HH children and adolescents, on the other hand, was found to be similar to that of TH children and adolescents. Associations between communicative competence and parent-reported mental health and QoL were significant, whereas severity of hearing loss (HL) was not associated with either QoL or mental health.

In conclusion, the SDQ-NSL and ILC-NSL are reliable and valid measures to assess mental health and QoL in signing DHH children and adolescents. The elevated prevalence of mental health problems in (D)HH children and adolescents emphasises the importance of early detection of HL, early intervention and regular monitoring of socio-emotional, cognitive and language development, mental health and QoL. The risk of misdiagnosis combined with the elevated prevalence also confirms the need for robust and accessible specialised CAMHS for (D)HH children and adolescents. Furthermore, validated measures for assessment of pragmatic skills and social communication in NSL are needed to improve assessment of co-morbid language disorders and future research.



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## List of papers

- I. Aanonsen, C. M., Jozefiak, T., Heiling, K., Rimehaug, T. (2019). Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language. *Journal of Deaf Studies and Deaf Education*, 25 (1), 91-104. doi: 10.1093/deafed/enz026
  
- II. Aanonsen, C. M., Jozefiak, T., Heiling, K., Lydersen, S., Rimehaug, T. (2021). Psychometric properties of the Inventory of Life Quality in Children and Adolescents in Norwegian Sign Language. *BMC Psychology*, 9 (1), 89. doi: 10.1186/s40359-021-00590-x
  
- III. Aanonsen, C. M., Jozefiak, T., Heiling, K., Lydersen, S., Rimehaug, T. (2022). *Deaf and hard-of-hearing children and adolescents' mental health, Quality of Life and communication*. Manuscript submitted for publication.



## Acronyms

AVE	Average variance extracted
CAMHS	Child and Adolescent Mental Health Services
CAP	Categories of Auditory Performance
CCC-2	Children's Communication Checklist - Second Edition
CFA	Confirmatory Factor Analysis
CI	Cochlear Implant
CMV	Cytomegalovirus
DHH	Deaf and hard-of hearing (signing)
(D)HH	Deaf and hard-of-hearing (both DHH and HH)
DG rho	Dillon-Goldstein's rho
FCEI	Family centred early intervention
GCC	General Communication Composite of the CCC-2
HH	Hard-of-hearing
HL	Hearing loss
ICC	Intraclass correlations
ILC	The Inventory of Life Quality in Children and Adolescents
ILC-NOR	ILC in written Norwegian (original ILC)
ILC-NSL	ILC in Norwegian sign language
MAR	Missing at random
NSL	Norwegian Sign Language
PCHL	Permanent childhood hearing loss
PLS-SEM	Partial Least Squares Structural Equation Modelling

SDQ	Strength and Difficulties Questionnaire
SDQ-NOR	SDQ in written Norwegian (original)
SDQ-NSL	SDQ in Norwegian Sign Language
SIR	Speech Intelligibility Rating
SNHL	Sensorineural hearing loss
SPS	Sign Language Production Scale
SUS	Sign Language Understanding Scale
UNHS	Universal neonatal hearing screening
QOL	Quality of Life



## Clarification

Deaf and hard-of-hearing children and adolescents are often divided into two categories. Those with relatively milder hearing loss (HL), who benefit from hearing aids and prefer spoken language (hard-of-hearing - HH); and those with severe to profound HL, who often prefer sign language to communicate (deaf and hard-of-hearing - DHH). Children using Cochlear Implants (CI) are found in both categories. The term “Deaf” with capitalisation is traditionally used to refer to people who identify with deaf culture, share common values, beliefs and experiences where sign language is central (Grønlie, 2005; Meadow-Orlans & Erting, 2000). In this thesis, the term “deaf and hard-of-hearing” without capitalisation is used for signing DHH children as we do not know enough of the participants’ cultural self-identification. “Hard-of-hearing“ is used to refer to the children and adolescents with a spoken language preference such as in paper III. The term (D)HH is used throughout the thesis when referring to both groups. When citing other studies in this thesis (D)HH is used to describe participants with spoken and/or sign language, with HL ranging from moderate to profound.

The term “language” is used to refer to all natural languages in this thesis, i.e., both spoken and sign languages independent of modality and country unless otherwise specified. When describing our own studies, the term “communication” is used to describe language skills and communicative competence. When referring to other studies the respective authors’ terms are used for vocabulary, pragmatic skills, social communication, etc.



# 1 Introduction

*“If I say yes to another person’s language, I have said yes to that person.  
If I say no to another person’s language, I have said no to that person,  
Because language is a part of who we are.”*  
(Terje Basilier, cited in Klim et al., 1991, p.6)

## Topic of the thesis

This thesis contributed to translating measures for mental health problems and Quality of Life (QoL) into Norwegian Sign Language (NSL) for deaf and hard-of-hearing – (D)HH children and adolescents. The psychometric properties of these mental health and QoL measures were examined for both the written Norwegian and NSL versions. Finally, the same measures were used to gain a better understanding of (D)HH children and adolescents’ mental health, QoL and communication, as well as the associations between these concepts.

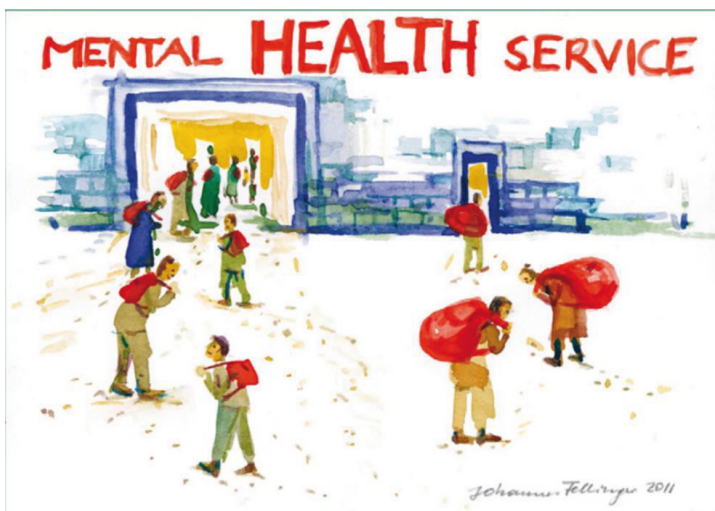
### 1.1 Rationale of the thesis

Mental health problems have been found to be more frequent in (D)HH children and adolescents than in typically hearing (TH) children (Fellinger et al., 2012; Overgaard et al., 2021; Stevenson et al., 2015; Theunissen, Rieffe, Kouwenberg, et al., 2014). Although there are several studies on the topic, there are few, compared to those on TH children’s mental health, and therefore also few systematic reviews, reviews, or meta-analyses except for those by Fellinger et al. (2012); Stevenson et al. (2015); Theunissen, Rieffe, Netten, et al. (2014). The use of written measures to assess mental health problems in signing DHH children has been found to lead to underestimating symptoms (Cornes & Brown, 2012; Cornes et al., 2006). Due to the complexity and overlap of cultural, linguistic and clinical factors, late or misdiagnosis of (D)HH people is common (Fellinger et al., 2012; Glickman, 2007; Hall et al., 2017; Heiling & Eidevall, 2011). (D)HH children are referred to Child and Adolescent Mental Health Services (CAMHS) with more severe symptoms and 1;4 years later at first referral than their TH peers (van Gent et al., 2012).

Good communication skills in both spoken and sign language have been shown to have a positive effect on (D)HH children’s mental health (Dammeyer, 2010; Stevenson et al., 2017; Theunissen, Rieffe, Kouwenberg, et al., 2014; Theunissen, Rieffe, Netten, et al., 2014). Even though sign languages were acknowledged as natural languages in the 1960s (Stokoe, 1960), they are only recently being recognized as official languages; Norwegian Sign

Language (NSL) as late as 2021 (Språklova, 2021). Several changes have occurred in the field of mental health and deafness during the last 20 years, among them technological advances such as cochlear implants (CI) and the introduction of universal neonatal hearing screening (UNHS; Roberts et al. (2015)). These have contributed to better spoken language outcomes in (D)HH children (Holzinger et al., 2021; Niparko et al., 2010). Early intervention (Stevenson et al., 2011), especially parents' involvement in it has been shown to have a positive effect on language development in (D)HH children (Holzinger et al., 2021). The extent of parental support provided in the Nordic countries has been proposed as a protective factor for (D)HH children's mental health in the same countries (Mejstad et al., 2009).

Despite the mentioned advances, validated measures for assessing mental health and Quality of Life (QoL) in signing (D)HH children were not available in Norway prior to this study. There was also a lack of research on signing DHH children's mental health and QoL in Norway at the time of data collection (Aanondsen et al., 2018). Translating and validating mental health and QoL measures into NSL provided an opportunity to try to improve assessment, increase the likelihood of early detection of mental health problems, and timely referral to CAMHS. Insight into prevalence of mental health problems and QoL in (D)HH children and adolescents in Norway is especially interesting because of the unique and extensive intervention program. Parents of DHH children and adolescents are offered 40 weeks (i.e., 2-4 weeks per year) of NSL classes over 16 years while their children attend the regional deaf school with all expenses covered (Statped, 2016).



*Fig. 1 "Burden of mental health problems in deaf people. The burden of mental health problems is symbolized by rucksacks, which everyone carries and from which they seek relief. The rucksacks of deaf people are bigger, but the entrance to services is smaller, because accessibility is poor." Fellinger et al. (2012)*

## 1.2 Theoretical framework

The integration of the biopsychosocial and transactional model forms the basis of developmental psychopathology, which provides a developmental, lifespan framework to understand the direct and indirect pathways that can lead to psychopathological outcomes (Cicchetti & Rogosch, 2002; Engel, 1977). Engel (1977) first proposed the biopsychosocial model as an extension to the biomedical one, including psychological and social factors alongside biological factors to understand mental health outcomes. An example related to this thesis would be a child with a severe HL due to congenital cytomegalovirus (CMV). Due to the aetiology of HL, the child is likely to suffer from neurodevelopmental deficits in addition to HL (biological factors) (Stach, 1998). This, in turn, can interact with the child's temperament (psychological factor) and parent's resources (social factor) and affect the child's mental health. Masten and Cicchetti (2010) call these cumulative consequences developmental cascades.

Attachment theory provides an understanding of how the interactions between child and parenting environment lead to the formation of relational behavioural patterns (attachment styles) that influence the child's socioemotional development (Ainsworth & Bowlby, 1991; Bowlby, 1969). The bidirectionality of these interactions affects the child's development, the parent's childrearing practices and the quality of their relationship (Sameroff, 2009; Sroufe et al., 1999). Variations in attachment style are not regarded as pathological in themselves or as direct causal pathways to psychopathological outcomes; more as increasing or decreasing the likelihood of such outcomes depending on numerous other experiences. Early experiences and parent-child attachment variations play a dynamic role in the developmental process influenced by affective and neurophysiological regulation (Schorre & Schorre, 2008; Sroufe, 2013). In addition to the dynamic dyadic interactions between parent and child, wider ecological systems ranging from family, school, and neighbourhood to society and culture also exert a significant influence (Bronfenbrenner, 1979).

Developmental psychopathology provides a framework that comprises the complexities involved in understanding the development of psychopathology. This is achieved by including risk and protective factors, age-dependent periods with increased vulnerability, the interplay between child and environment, and between different domains of

development, as well as the resilience of nature-nurture (Rutter & Sroufe, 2000). Therefore, developmental psychopathology can provide a framework for understanding the mental health of (D)HH children and adolescents, including the complexities of the field. It can incorporate biological and risk factors such as aetiology of HL, sensitive periods for language development, protective factors such as resilience, communication skills and cognitive ability, mode of communication, child characteristics such as cognitive ability and temperament, difficulties in communication between child and parent, as well as the influence of the macrosystem (Bronfenbrenner, 1979) such as access to Deaf culture and society's attitude towards DHH people and sign language. The following sections will provide more information about HL (aetiology, severity, age at detection and early intervention), as well as deaf education and sign language from a historical perspective. Relevant rights and empowerment will also be addressed. Developmental outcomes such as mental health, QoL and communication in (D)HH children and methodological considerations will be covered.

### **1.3 Aspects of hearing loss and deafness**

About 34 million children and adolescents are affected by HL >35dB, most of them living in South and East Asia and Sub-Saharan Africa (World Health Organization, 2018a). One recent systematic review on HL detected by universal neonatal hearing screening (UNHS) found a prevalence of permanent childhood hearing loss (PCHL) in 1 per 1000 infants and 5.9 per 1000 for those admitted to the neonatal intensive care unit (Butcher et al., 2019). Another recent systematic review and meta-analysis, on the other hand, found an overall prevalence of 2.21 per 1000 across countries, varying from 1.2 in Ireland to 6 per 1000 in Nigeria (Bussé et al., 2020). The same authors also reported a trend of higher prevalence in countries with lower income. Fortnum et al. (2001) found the prevalence of PCHL to increase with age up to 1.65 to 2.05 by the age of nine.

(D)HH children and adolescents are a highly heterogeneous group (e.g., Fellinger et al. (2012); Heiling and Eidevall (2011)). HL, independent of degree, has been shown to represent a risk factor for language development (Fellinger et al., 2012; Holzinger et al., 2020; Lederberg et al., 2013). Aetiology, severity and age at onset of HL or linguistic and

cultural identity are often used as identifying characteristics (Israelite et al., 2002; Meadow-Orlans & Erting, 2000).

### 1.3.1 Classification of hearing loss

There are numerous causes of HL, and these have been shown to play an essential role in understanding the heterogeneity in the (D)HH population. Acquired infections such as meningitis that can result in HL are associated with an increased risk of other neurodevelopmental disorders (Stach, 1998; Taylor et al., 2000). The most common classifications of HL are presented in this section.

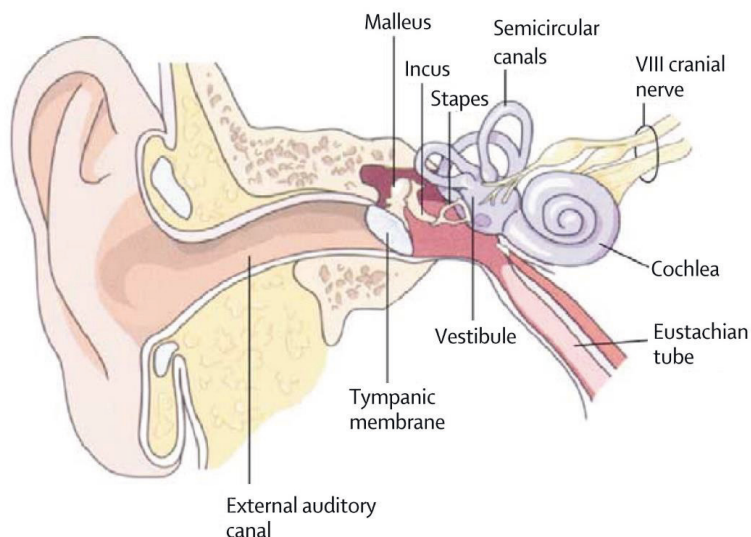


Fig. 2 Cross-section of the outer, middle and inner ear (Smith et al., 2005)

*Conductive/mechanical hearing loss* is caused by structural defects or changes in the outer and middle ear. These can be due to congenital anomalies, infections or acquired acoustic trauma. Otitis media is a common middle ear disorder in children < 6 years (Stach, 1998). *Sensorineural hearing loss (SNHL)* is a result of structural defects or changes in the inner ear (cochlea) and auditory nerve. These can be either congenital or acquired through

acoustic trauma, infections, ototoxic drugs or others (Stach, 1998). HL can also be caused by a combination of conductive and sensorineural HL, i.e., mixed HL (Stach, 1998).

HL is also classified by the time of onset as either congenital or acquired and aetiology, as hereditary (genetic) or environmental (non-genetic) and as stable or progressive (Smith et al., 2005; Stach, 1998). Until recently, studies on aetiology have been conducted with adults. Due to advances in genetic and imaging technology and the introduction of UNHS, information about the aetiology of HL in infants and young children is now increasingly available (Liddle et al., 2021). Non-genetic factors such as congenital rubella syndrome or CMV infection, toxoplasmosis, or prematurity account for about 50% of congenital SNHL in infants. Congenital CMV infections result in late-onset hearing loss in about 50% of the infected children who *pass* UNHS (Nagel et al., 2020) and are among the most common prenatal causes of HL (Holzinger et al., 2021; Liddle et al., 2021). A further 50% of SNHLs are accounted for by genetic factors. About 15% of these are syndromic (e.g. Usher's, CHARGE or Waardenburg's) and 35% non-syndromic hereditary autosomal recessive, autosomal dominant or X-linked contributions (Liddle et al.; Stach, 1998). Syndromic HL is often associated with additional disorders such as visual, neurological, endocrinologic, or other disorders (Neumann et al., 2020). Bacterial meningitis is one of the most common causes of acquired SNHL in children, about 6% of all SNHLs (Fortnum & Davis, 1993), and is associated with neuropsychological sequelae (Anderson et al., 2004; Anderson et al., 1997). HL can also be a result of dysfunction of the central auditory nervous system, such as in auditory processing disorder (Rouillon et al., 2021) or auditory neuropathy spectrum disorder (Lin et al., 2020; Pham, 2017). Despite advances in genetic and imaging technology, that have improved assessment of aetiology of HL in children, aetiology of HL is still classified as unknown in 20% to 40% of all cases (Boudewyns et al., 2020; Liddle et al.; van Beeck Calkoen et al., 2019).

Neumann et al. (2022) recently reported that only 33% of the countries screened at least 85% of their infants (UNHS), while 38% offered none or minimal hearing screening. In countries with high screening coverage by UNHS age at detection is now six months or younger (Neumann et al., 2022; Smith et al., 2005). In the low- and middle-income countries with the lowest screening coverage, PCHL is especially common due to lack of immunisation programs and poor pre-, peri- and postnatal care (World Health Organization, 2018b) as well



as the number of consanguineous marriages (World Health Organization, 2016). In high-income countries, on the other hand, causes such as bacterial meningitis and congenital rubella syndrome have been almost eliminated because of immunisation programs (Smith et al., 2005).

### 1.3.2 Severity of hearing loss

Hearing loss is measured in decibels (dB) with pure tone audiometry at the following frequencies: 500, 1000, 2000 and 4000 Hz.

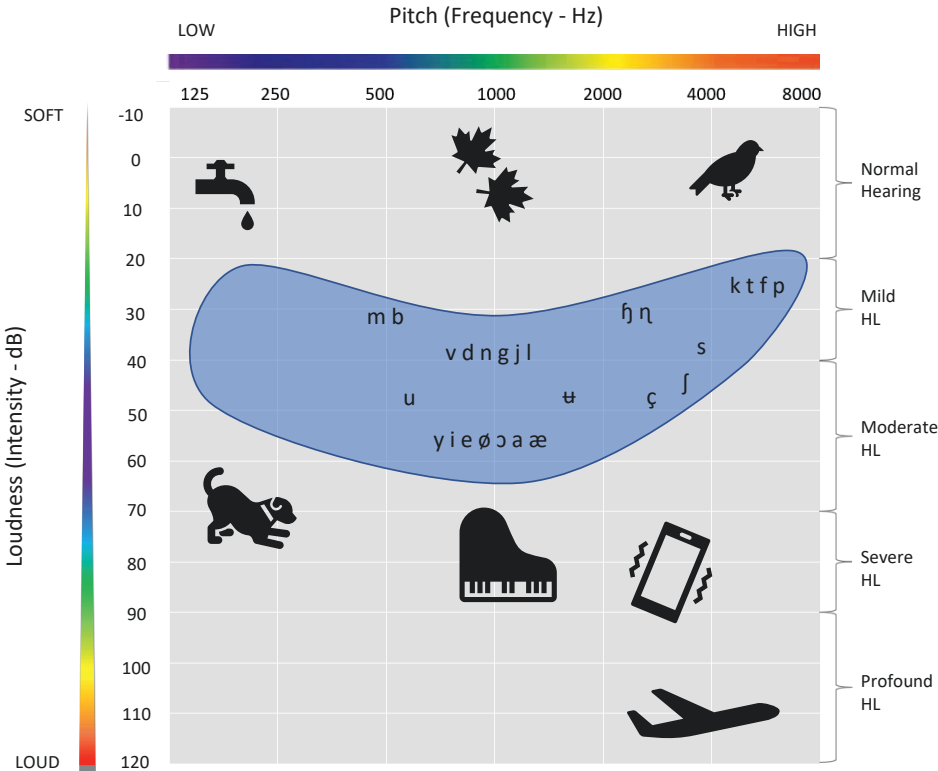


Fig. 3 Audiogram depicting grades of HL, range of conversational speech including speech sounds and intensity of other familiar sounds

As can be seen in Figure 3, HL between 20 to 40 dB is graded as mild, between 41 to 70 dB as moderate, between 71 and 90 dB as severe and as profound for 91 dB or larger (Smith et al., 2005; Stach, 1998). Caluraud et al. (2015) report that 13% of all children with PCHL are affected by mild HL, 50% by moderate HL, 17% severe HL and 20% profound HL. It is important to note that degrees of HL are a functional classification and do not necessarily coincide with a person's personal language preference or cultural and social identity (Grønlie, 2005; Israelite et al., 2002). Severity of HL is not associated with either the level of QoL or the number of mental health symptoms in (D)HH children (Dammeyer, 2010; Fellinger et al., 2008). HL is, however, also associated with fund of knowledge deficits as HL restricts the number of opportunities to benefit from passive learning in settings such as dinner table conversations or public transport (McKee et al., 2015).

**1.4 Early Intervention** The implementation of UNHS has been emphasised to counteract the negative effects of PCHL on language, cognitive, social and educational development (World Health Organization, 2016, 2021). UNHS can help reduce the age at detection, enable rehabilitation with hearing aids or CIs and initiate early intervention during sensitive periods for auditory pathways (Neumann et al., 2022) and language acquisition (Holzinger et al., 2021). UNHS was introduced in Norway in 2008 (Haukedal et al., 2020). Guidelines recommend screening all infants before one month of age, followed by diagnostic assessment before three months of age for those who do not pass the screening, and initiating early intervention before six months (Subbiah et al., 2018).

Cochlear implantation is a rehabilitation option for most (D)HH children with severe or profound HL. As can be seen in Figure 4, a CI has both internal and external components. The receiver is implanted in the mastoid bone while the electrodes are inserted into the cochlea. Sound is converted to coded signals and passed on through the transmitter to the electrodes in the cochlea and on to the auditory nerve (Kral & O'Donoghue, 2010; Roberts et al., 2015; Smith et al., 2005).

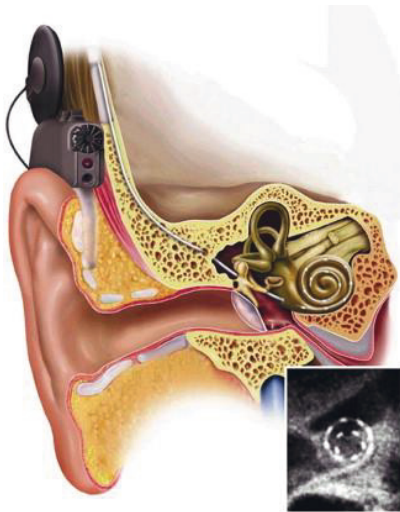


Fig. 4 Cochlear implant with key components (Smith et al., 2005)

Even though CIs have significantly improved (D)HH children's acquisition of expressive and receptive spoken language, (D)HH children with CIs are delayed in their spoken language development (Lund, 2016; Yoshinaga-Itano et al., 2018).

About 90% to 95% of all (D)HH children are born to TH parents with no prior knowledge of sign language, deaf culture or HL (Grønlie, 2005; Meadow-Orlans & Erting, 2000). Family-centred early intervention (FCEI) has been proposed as the preferential approach to ensure positive outcomes (Holzinger et al., 2021; Moeller et al., 2013; World Health Organization, 2016). After confirmation of HL, parents need to make informed decisions about rehabilitation and mode of communication to ensure the best linguistic and overall outcome for their child in a field with opposing opinions (DesGeorges, 2016; du Feu & Chovaz, 2014; Wright, Hargate, et al., 2021). Several authors recommend access to sign language as the visual modality is more accessible to (D)HH children, which can help ensure good cognitive, social and emotional development (du Feu & Chovaz, 2014; Holzinger et al., 2021; Lund, 2016).

Empowerment of parents is based on cooperation between professionals and parents, adapted to the individual family's needs. Providing the necessary knowledge for parents to make informed choices and emotional support are key elements (Holzinger et al., 2021;

Moeller et al., 2013; Wright, Hargate, et al., 2021). Other essential elements are supporting communication and language acquisition and facilitating responsive parent-child interactions (Moeller et al., 2013). Parents' use of higher-level facilitative language techniques, such as expansions of child utterances or the use of open-ended questions, is strongly connected to the child's expressive language development and better phonological awareness and reading abilities (DesJardin et al., 2009; DesJardin & Eisenberg, 2007; Holzinger et al., 2020). Parental engagement in early intervention is also strongly associated with the child's language development (Moeller, 2000). Parents' social-economic (SES) status, on the other hand, was found to only have a slight influence on the child's language development (Holzinger et al., 2020). Cruz et al. (2013) concluded that parents with lower income and education are equally competent in using higher-level facilitative language techniques. In addition, FCEI has been documented to empower parents by re-establishing emotional availability and increasing responsiveness (Moeller et al., 2013).

Although there is a consensus on the importance of FCEI, there are few randomised controlled trials and few other high-quality studies on the effectiveness of early intervention programs (Wright, Hargate, et al., 2021). Wright, Hargate, et al. (2021) also found that most studies included in their scoping review were based on intervention targeting the (D)HH child's language development or the parents' well-being. There were no studies on interventions that provided parental support to understand or improve the socio-emotional development of (D)HH children.

A recent systematic review studied the impact of father-child play interactions on child development in TH children (Robinson et al., 2021). The authors reported positive associations between fathers' enthusiasm, sensitivity and playfulness and the child's emotional regulation and pro-social behaviour with peers, emphasising the importance of fathers for child development. Moreover, several associations have been found between paternal participation in the childcare of TH children and improved cognitive and language development (Lewis & Lamb, 2003), as well as more positive peer relationships (Frosch et al., 2001) and fewer behavioural problems in TH children (Sarkadi et al., 2008). There are few studies on fathers of (D)HH children and adolescents. In one of these few, Ingber and Most (2012) found a positive association between parental involvement and the self-efficacy of fathers. In Hintermair and Sarimski's (2018) study, about 15% of all fathers reported

difficulties coping with their child's HL and adapting plans for the child's future. In the same study, 75% of the fathers reported not being included when appointments for early intervention were scheduled, and 40% of them did not feel acknowledged in early intervention settings. Several authors (Hintermair & Sarimski, 2018; Pedersen & Olthoff, 2019) have highlighted the lack of literature on fathers' involvement in early intervention, and interaction with their (D)HH children and encourage service providers to consider alternative ways of increasing father participation. One important point is ensuring frequent participation of fathers at early intervention appointments and conducting a thorough analysis of factors hindering fathers involvement, both psychological and societal ones so that programmes can compensate for these. (Hintermair & Sarimski, 2018)

## **1.5 Deaf education and access to sign language**

Debates on providing education for (D)HH children in sign language or spoken language started in 1750 (du Feu & Chovaz, 2014; Grønlie, 2005; Stokoe, 1960). The first deaf school in Norway was founded in Trondheim in 1825 by Andreas Christian Møller (Grønlie, 2005), who was deaf himself. At that time, sign language was still used for teaching. However, after an international congress in Milano in 1880, the use of sign language was banned from deaf schools all over Europe.

The acknowledgement of sign languages as natural languages in 1960 helped reinstate sign language in deaf education and increased understanding of sign language users as a cultural and linguistic minority (Haualand et al., 2021; Stokoe, 1960). Further support was provided by Petitto et al. (2001), who found TH bilingual babies with access to Quebec sign language and spoken French to reach linguistic milestones for (visual) babbling and first words/signs at the same time as their monolingual peers. This research also helped illustrate that the human infants' brain is primed for language acquisition independent of modality (du Feu & Chovaz, 2014).

The student-led protest "Deaf President Now" at Gallaudet University in 1988 resulted in the first appointment of a deaf president at the university. It increased awareness among the TH population and helped widen the perspective of deafness as a medical

disability to include a civil rights movement (Andrews et al., 2004). It is also a clear example of deaf empowerment.

In Norway, a curriculum for and in NSL was implemented in 1993 to provide (D)HH children with bilingual education. In 1996 an extensive 40-week NSL programme extending over 16 years for TH parents of (D)HH children followed (Mosand & Malmquist, 1996; Statped, 2016). In the same year, the right to receive education in NSL became part of the Education Act. TH teachers, however, are not required to have more than one to two semesters of NSL studies to teach in deaf schools (Haualand & Holmström, 2019). The number of deaf schools has declined rapidly over the past decades because of mainstreaming, CIs and focus on an auditory-verbal approach (Haualand et al., 2021). Consequently, most (D)HH children today attend their local schools as the only (D)HH child in their class or school. In addition, they participate in a part-time program at a deaf school for two to four weeks per year (Haualand & Holmström, 2019; Haualand et al., 2021). As a result, the number of NSL arenas for (D)HH children is dwindling, which affects NSL acquisition and fluency (Lyxell, 2019) and is likely to affect deaf identity, which is achieved through contact with deaf peers (Meadow-Orlans & Erting, 2000). Although the NSL curriculum and education act ensured the right to an education in NSL in the 1990s, NSL was not recognised as an official language in Norway until 2021 (Språklova, 2021).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 to ensure that people with disabilities enjoy the same rights as others. Among these rights are equal access to health services, education in sign language, and equal participation in cultural and leisure activities (United Nations Convention on the Rights of Persons with Disabilities, 2006). Norway signed the CRPD in 2007, ratified it in 2013, but has still not incorporated it into Norwegian law. Moreover, Norway has not signed the optional protocol which grants individuals the right to submit a complaint to the CRPD committee when the rights stated in the CRPD are violated (United Nations Convention on the Rights of Persons with Disabilities, 2006). The recently elected government has stated on their platform that they intend to incorporate the CRPD into Norwegian law (Arbeiderpartiet & Senterpartiet, 2021). The ratification of the optional protocol, however, is not mentioned.

## **1.6 Developmental outcomes**

### **1.6.1 Mental Health in (D)HH children and adolescents**

#### *Historical background*

Terje Basilier was the first Norwegian psychiatrist to study mental health in (D)HH children and adults (Basilier, 1964, 1973). He described the consequences of language deprivation on developmental outcomes and mental health and framed these as a mental health disorder specific to (D)HH people; he classified it as “surdophrenia” (Basilier, 1973). Later studies, however, have confirmed that (D)HH people suffer from the same common mental health disorders as TH, i.e., that the “symptoms” described by Basilier (1973) were consequences of language deprivation and not deafness itself (Fellinger et al., 2012; Grønlie, 2005). To offer adequate assessment and treatment to the (D)HH population, he stressed the need for communication in sign language between therapist and patient (Basilier, 1964, 1973). Although mental problems in (D)HH children and adolescents have been studied by clinicians and researchers, literature on this topic is scarcer than for the TH population.

#### *Current status*

Mental health problems in (D)HH children and adolescents have been studied in community and clinical samples and have been found to be twice to four times as frequent as in TH children depending on other protective and risk factors (Dammeyer, 2010; Fellinger et al., 2012; Overgaard et al., 2021; Stevenson et al., 2015; Theunissen, Rieffe, Netten, et al., 2014). Whereas severity of HL has shown no association with mental health problems (Dammeyer, 2010; Fellinger, Holzinger, Sattel, et al., 2009; Hintermair, 2007; Theunissen, Rieffe, Netten, et al., 2014), aetiology of HL has (Brown et al., 2000; Hindley et al., 1994; Theunissen, Rieffe, Netten, et al., 2014; van Gent et al., 2012), especially when Central Nervous System disorders are involved (Theunissen, Rieffe, Netten, et al., 2014). Between 25% to 40% of (D)HH children and adolescents have been reported to have additional disabilities (Das, 1996; Gallaudet Research Institute, 2013; Heiling, 1995; Mejstad et al., 2009; van Gent et al., 2007), which in turn are associated with a greater likelihood of mental health problems (Dammeyer, 2010; Hintermair, 2007; Stevenson et al., 2011; Theunissen, Rieffe, Netten, et al., 2014). Cognitive ability has been found to be associated with mental health problems, acting respectively as a protective or risk factor (Theunissen, Rieffe, Netten,

et al., 2014; van Eldik, 2005; van Eldik et al., 2004; van Gent et al., 2007). Level of communication, independent of modality, follows the same pattern, acting as either protective or risk factor (Dammeyer, 2010; Hindley, 1997; Hintermair, 2013; Theunissen, Rieffe, Netten, et al., 2014; van Eldik et al., 2004; Vostanis et al., 1997). Some authors reported a higher prevalence of mental health problems in (D)HH children and adolescents attending deaf schools (Theunissen, Rieffe, Kouwenberg, et al., 2014; Theunissen, Rieffe, Netten, et al., 2014; van Eldik, 2005; van Gent et al., 2007), whereas others found no significant differences (Fellinger, Holzinger, Sattel, et al., 2009; Mejstad et al., 2009; Titus et al., 2008). The authors (Theunissen, Rieffe, Kouwenberg, et al., 2014; Theunissen, Rieffe, Netten, et al., 2014; van Eldik, 2005), however, point out that (D)HH children with more mental health problems and additional disabilities are more likely to be referred to deaf schools. Therefore, it is difficult to conclude the directionality of this matter.

Most of the results cited so far are based on multi-informant questionnaires such as the Strengths and Difficulties Questionnaire (SDQ). Most of these, in turn, have been completed by parents and teachers. In studies based on self-reports, (D)HH children and adolescents did not rate themselves as having significantly more mental health symptoms (Anmyr et al., 2012; Huber & Kipman, 2011; Overgaard et al., 2021; Stevenson et al., 2015) than their TH peers. Few studies on the mental health of (D)HH children are based on diagnostic interviews (Oerbeck et al., 2021). Hindley et al. (1994) found a point-prevalence of 50.3% for psychiatric disorder in (D)HH adolescents based on the combination of both borderline and clinical scores. A more recent Austrian study based on a structured diagnostic interview (Kinder DIPS) reported a point prevalence of 32.6% and lifetime prevalence of 45.3% for any psychiatric disorder (Fellinger, Holzinger, Sattel, et al., 2009). Compared to a TH German sample, the lifetime and point prevalences for any psychiatric disorder were 2.5 and 10 times as high, respectively. The lifetime prevalence for depression in (D)HH children was especially high at 26.3%. Van Gent et al. (2007) found a prevalence of 49% based on expert dossier ratings and 49% based on a semi-structured diagnostic interview in (D)HH adolescents. Fellinger, Holzinger, Sattel, et al. (2009) found the ability to make oneself understood in the family to be strongly associated with the lifetime prevalence of any psychiatric disorder.



At the time of data collection for this study, there were only a few studies available on the mental health of (D)HH Norwegian children and adolescents, apart from the studies by Basilier (1973) and Laugen et al. (2016, 2017a, 2017b) and our pilot study on a small clinical sample (Aanondsen et al., 2018). However, a recent study on a national sample found (D)HH children and adolescents to have significantly more parent-reported mental health problems than TH peers; no significant differences were found for self-reported mental health problems (Overgaard et al., 2021).

A recent impact on (D)HH children and adolescents' mental health is the COVID-19 pandemic. A British study assessed mental health in (D)HH adolescents and young adults during the first lockdown; of the (D)HH adolescents and young adults participating in the study, 59.7% reported a decline in mental health, while 57.5% reported increased loneliness and social isolation (Wright, H., et al., 2021). Possible reasons for greater decline than in their TH peers are proposed; among these, the use of face masks that muffle voices and create a barrier for lip reading and communication in sign language. Participants in the same study also reported increased difficulties in accessing school work and online lessons due to a lack of subtitles and interpreting (Wright, H., et al., 2021).

### **1.6.2 Mental health services for (D)HH children and adolescents**

Assessing (D)HH children and adolescents' mental health is complicated by several factors, such as the overlap of both cultural and linguistic factors (Chovaz, 2017; Cornes et al., 2006; Heiling & Eidevall, 2011; Aanondsen et al., 2018). Assessment and treatment can therefore be challenging for professionals without knowledge of the field. As stated in the United Nations Convention on the Rights of Persons with Disabilities (2006), (D)HH have the right to equal access to health care. To reduce inequality in access to mental health services and ensure their quality, several authors and organisations have advocated specialised mental health services for (D)HH people (Cornes & Brown, 2012; Kuenburg et al., 2016; van Gent et al., 2012; Øhre et al., 2011; Aanondsen et al., 2018). However, such specialised services are limited, even in Europe, as stated in the review by Heiling and Eidevall (2011). Existing services are described as small and vulnerable, except for the UK, where national services were established in 2009 and have expanded since (Wright et al., 2012).

A white paper (St. meld. nr. 25 (1996-97), 1997) on mental health services in Norway, in general, concluded that these were insufficient for the whole population but especially lacking for (D)HH people. In 2001, the Norwegian Board of Health Supervision stated that national and regional specialised mental health services were needed (Statens helsetilsyns utredningsserie, 2001). The first regional and national specialised CAMHS were established in Norway in Trondheim and Oslo in 2007, and others in Bergen and Tromsø have followed since. National Norwegian guidelines for referral of (D)HH children, adolescents and adults were published in 2018 (Øhre & Saltnes, 2018).

An analysis of specialised CAMHS in the Netherlands showed that (D)HH patients were, on average, 1;4 years older at first referral and suffered from more pervasive developmental disorders and mental retardation than TH peers (van Gent et al., 2012). This is in line with referrals to the national and regional CAMHS in Norway. A recent national registry study, however, showed that 18.1% of the (D)HH children in Norway were referred to generic CAMHS compared to 5% of the TH population. They were also referred earlier than their peers (Oerbeck et al., 2021). The results of the study are in line with a higher prevalence of mental health problems. The (D)HH children are, however, not being referred to specialised CAMHS. A possible explanation for this might be that the specialised CAMHS are not visible enough to parents and professionals, and action should be taken to improve this.

### **1.6.3 Quality of Life (QoL)**

#### ***Definitions and general concept***

Numerous definitions of Quality of life (QoL) exist, making comparisons of studies challenging (Hintermair, 2011). The World Health Organisation (WHO) defines QoL as “*an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*” (World Health Organization, 1995, p. 1405). In this study health-related QoL (HRQoL) is defined as the child’s subjective well-being in several life domains, i.e., the child’s physical and mental health, self-esteem and perception of functioning with its family and peers and overall (Jozefiak et al., 2012). Due to the subjective nature of QoL as a concept and low agreement between self- and parent-report, self-reported QoL needs to be considered as the

authentic QoL report. Parent or proxy-report should be used only as supplementary information (Holte et al., 2014).

The Norwegian Institute of Public Health emphasises the importance of high QoL for satisfactory physical and mental health (Folkehelseinstituttet, 2015). The need for a measure to assess treatment outcomes and benefits in patients with chronic diseases sparked interest in QoL (Eiser & Jenney, 2007). Bastiaansen et al. (2005) demonstrated that QoL can be improved in CAMHS patients even when psychiatric symptoms are not reduced. QoL and mental health have been shown to be related but distinct concepts for both TH (Jozefiak et al., 2012) and (D)HH children and adolescents (Overgaard et al., 2021).

### *Quality of life in (D)HH children and adolescents*

Interest in the QoL of (D)HH children and adolescents to evaluate treatment outcomes has increased after the advent of CIs. Prior to this, QoL was also studied in (D)HH children without CI in a more general context. Lin and Niparko (2006) concluded that studies included in their systematic review were primarily based on small sample sizes, and few of these were carried out using generic QoL measures. The only other systematic review (and meta-analysis) on QoL in (D)HH children, to our knowledge, concluded that in the majority of studies, QoL was reported to be significantly lower than that of TH peers (Roland et al., 2016). Methodological concerns regarding this review, including misinterpretation of results of two studies included in the review, have been raised and are described in paper II.

Three recent Norwegian studies found significantly lower QoL in (D)HH children based on both self- and parent-report (Haukedal et al., 2020; Haukedal et al., 2018; Overgaard et al., 2021). In contrast, others have reported no significant differences (Hintermair, 2010; Qi et al., 2020; Reeh et al., 2008; Aanondsen et al., 2018) or differences only in specific subdomains. In Fellingner et al.'s (2008) study, (D)HH children and adolescents reported better QoL in the subdomains of school and family than their TH peers, while they reported less satisfaction with their physical health and participation in recreational activities. Parents of (D)HH, on the other hand, reported better QoL in the subdomains of physical health and recreational activities than parents of TH children. Differences like these between self- and parent-report emphasise the importance of including self-reports as the authentic measure of QoL. Low agreement between self- and parent-reported QoL has been documented for TH (Jozefiak et al., 2012; Mattejat & Remschmidt,

2006; Upton et al., 2008) and (D)HH children and adolescents (Fellinger et al., 2008; Pardo-Guijarro et al., 2015; Roland et al., 2016; Warner-Czyz et al., 2009) in both community and clinical samples.

Several factors have been thought to influence QoL. Age, as one of them, is negatively associated with QoL in both TH (Jozefiak et al., 2009) and (D)HH children (Kushalnagar et al., 2011; Pardo-Guijarro et al., 2015; Aanondsen et al., 2018). Studies on associations between communication and QoL have not been conclusive (Haukedal et al., 2020; Haukedal et al., 2018; Kushalnagar et al., 2011). Severity of HL has not been found to be associated with QoL in (D)HH children and adolescents (Hintermair, 2010; Qi et al., 2020; Reeh et al., 2008).

#### **1.6.4 Communication**

##### *Bilingualism in children*

Bilingualism in TH children has generated both interest and debate among researchers, professionals, and lay people. This is not surprising as bilingualism is on the rise in several parts of the world (Byers-Heinlein & Lew-Williams, 2013). There are several myths associated with it, among them that early bilingualism negatively impacts language acquisition and increases the risk of developmental language impairment (Genesee, 2015; Petitto et al., 2001). This has not been proven to hold true in typically developing children (Genesee, 2015; Hammer et al., 2014; Werker & Byers-Heinlein, 2008) or children with other developmental disorders such as autism spectrum disorder (Langdon, 2015). It has also been suggested that bilingual children may show delays in vocabulary acquisition.

When assessing conceptual vocabulary across languages (Marchman et al., 2010), bilingual children have shown vocabulary acquisition at the same speed as monolingual children (Bedore et al., 2005; Petitto et al., 2001). Bilingual children's code-switching between languages raised concerns previously (Byers-Heinlein & Lew-Williams, 2013; Genesee, 2015). There is, however, evidence that bilingual children distinguish between their two languages and switch languages when they cannot retrieve the word in their other language (Byers-Heinlein & Lew-Williams, 2013; Genesee, 2015; Hammer et al., 2014). A meta-analysis has shown small to medium effect sizes for bilingual children's superior

performance in Theory of Mind tasks when adjusted for language proficiency (Schroeder, 2018). Bilingual children have also been shown to perform significantly better in tasks involving conflicting attentional demands (executive performance tasks) (Carlson & Meltzoff, 2008). Bilingualism in children is positively associated with academic and socio-emotional outcomes (Hammer et al., 2014; Siegal et al., 2010). Despite these findings, some health and education professionals have been found to provide misinformation on bilingualism (Langdon, 2015; Yu, 2013). It is, however, essential to consider that there still is a lack of research in this field and that several studies are based on case studies or small samples, which limits the number of systematic reviews and meta-analyses. Werker and Byers-Heinlein (2008) provided further cause for caution due to challenges faced by researchers in the field of bilingualism. They refer to the heterogeneity in samples, differences between the languages that are compared regarding phonetic, syntactic and pragmatic aspects, the variety of contexts, and the varying degree to which children are exposed to both languages. Other factors are differences in the social status of the languages, SES as a confounder, i.e., systematic differences have been observed for bilinguals and monolinguals in some studies based on geographic area. Varying ages at acquisition, i.e. simultaneous or sequential bilingualism, also need to be considered as earlier bilingualism has been found to lead to better language acquisition (Byers-Heinlein & Lew-Williams, 2013). Overall, caution still needs to be applied in drawing firm conclusions, and further studies on larger samples taking the factors mentioned above into account are necessary.

### *Communication in (D)HH children and adolescents*

As previously mentioned in section 1.5, mode of communication and education for (D)HH children and adolescents have been debated since the 18<sup>th</sup> century (Grønlie, 2005; Stokoe, 1960). The debate is still ongoing even though a lot more is known about bilingualism in TH and (D)HH children and adolescents. As Fitzpatrick et al. (2016) stated in their systematic review, this debate has been reignited by the advent of the cochlear implant. CIs have been found to improve (D)HH children's speech and spoken language acquisition (Fulcher et al., 2012). Despite these improvements, (D)HH children with CI are found to be delayed in spoken language development (Haukedal et al., 2020; Holzinger et al., 2021; Lund, 2016; Niparko et al., 2010; Yoshinaga-Itano et al., 2018). One also needs to consider that studies such as the one by Haukedal et al. (2020) excluded (D)HH children and

adolescents who did not have sufficient spoken language skills to participate in the study and therefore are not representative for all (D)HH children with CI.

To our best knowledge, there are only two systematic reviews that have compared spoken language approaches only with a bimodal bilingual approach. Although some single studies demonstrated that sign language could be beneficial for the acquisition of spoken language (Petitto et al., 2001; Petitto et al., 2000), both reviews (Fitzpatrick et al., 2016; Kirkehei et al., 2011) stated that there is not sufficient evidence to conclude on the matter whether a bimodal bilingual approach or a spoken language only approach is best for spoken language acquisition due to the lack of high-quality evidence. In addition to this, there is limited information in Fitzpatrick et al.'s (2016) study about the degree of access to sign language and total communication in the studies included in the review. As access to services and intervention varies significantly between countries it makes comparisons challenging. Moreover, most of the studies included were based on small sample sizes, cross-sectional data and language outcomes assessed during early childhood. Another factor that hinders reaching a consensus is the lack of studies on social and functional language, and on pragmatic skills as most focus on vocabulary, speech perception and production (Crowe & Dammeyer, 2021; Holzinger et al., 2020; Kermit, 2010). Moreover, Holzinger et al. (2021) described heterogeneity in language outcomes in (D)HH children due to child-related factors (e.g. cognitive abilities, additional disabilities, aetiology of HL), parent-related factors (e.g. SES, maternal sensitivity or cognitive stimulation) and differences in intervention (e.g. age at detection, extent of intervention).

Bailes et al. (2009) stressed the necessity of prioritising cognitive and language development, i.e. including sign language, instead of focusing solely on spoken language acquisition. As 90% to 95% of all (D)HH children have TH parents, they learn sign language from non-native speakers, potentially delaying sign language acquisition (Grønlie, 2005). Access to signing peers and adults is also decreasing due to the focus on mainstreaming, a decline in the number of deaf schools and other sign language arenas (Haualand et al., 2021; Lyxell, 2019). (D)HH children and adolescents with (D)HH parents, on the other hand, have been shown to reach language milestones at the same time as their TH peers (Grønlie, 2005; Lu et al., 2016; Schick et al., 2005).

Good communication skills independent of modality are associated with better mental health (Dammeyer, 2010; Theunissen, Rieffe, Netten, et al., 2014; VanOrmer et al., 2019), while negative associations have been found for language development and behavioural problems (Hintermair, 2013; Stevenson et al., 2010). Moreover, Fellingner, Holzinger, Beitel, et al. (2009) found associations between (D)HH children and adolescents' functional language skills in conversation with TH peers and peer problems. Several authors (du Feu & Chovaz, 2014; Holzinger et al., 2021; Marschark, Convertino, et al., 2007; Moeller & Schick, 2006; Wright, Hargate, et al., 2021) have stressed successful communication between parents and (D)HH children as critical for language, cognitive and socio-emotional development. This, in turn, emphasises the need for early intervention, including strategies for facilitating communication and interaction between (D)HH children and their TH parents (Cruz et al., 2013; Holzinger et al., 2021; Wright, Hargate, et al., 2021).

## **1.7 Methodological considerations**

### **1.7.1 Assessment of (D)HH children and adolescents**

Most psychological measures are validated and standardised for the TH population from the cultural and linguistic majority (Wilkins et al., 2021). The use of such measures by professionals from general mental health services when assessing (D)HH people may lead to misinterpretation, misdiagnosis and consequently also impact treatment choices (Black & Glickman, 2006; du Feu & Chovaz, 2014; Wilkins et al., 2021; Øhre et al., 2014). In general clinical practice, it is common to use sign language interpreters to provide ad-hoc translations, which will be influenced by the interpreters training and experience and vary across settings (Roberts et al., 2015).

Hindley et al. (1993) examined the influence of clinicians' signing ability and hearing status on (D)HH children's report of mental health symptoms in a structured diagnostic interview in a small sample. (D)HH children were found to under-report affective symptoms when interviewed by a trainee psychiatrist with limited sign language skills. (D)HH children and adolescents have also been found to report more mental health symptoms when assessed with questionnaires in sign than in written language (Cornes & Brown, 2012; Cornes et al., 2006). Challenges in using written measures have been attributed to literacy issues as several studies have found signing (D)HH high school students to perform at 4<sup>th</sup> to 5<sup>th</sup>-grade reading

level (Baines et al., 2010; Harris et al., 2017; Marschark, Rhoten, et al., 2007; Marschark et al., 2009). Several possible explanations have been proposed, such as delays in language acquisition, aetiology of HL, or lack of reading with their TH parents (du Feu & Chovaz, 2014). (D)HH children's reading abilities, in turn, affects self-reported mental health symptoms. It needs to be noted that (D)HH children and adolescents also are heterogeneous regarding their literacy outcomes.

To ensure early recognition of mental health problems and valid assessment it is recommended that (D)HH children and adolescents are assessed by culturally sensitive and skilled clinicians, who are also fluent in sign language (Fellinger et al., 2012; Sessa & Sutherland, 2013; Wilkins et al., 2021; Wright et al., 2012). Specialised mental health services can ensure that disorders such as Autism Spectrum Disorder can be diagnosed despite phenomena such as overshadowing and camouflaging (Sessa & Sutherland, 2013) or other symptoms distinguished from cultural and linguistic aspects. The current lack of such translated and validated measures emphasises the need for validated measures in sign language (Roberts et al., 2015; Øhre et al., 2014). Specific challenges in translating written measures into sign language have been pointed out by Roberts et al. (2015) due to differences in syntax, morphology and prosody and their visual nature. Studies have also shown that cultural context influences the understanding of seemingly identical wordings, especially when written text is translated into sign language (Jones et al., 2001; Mason, 2005).

Translation and validation of established standardised measures enables comparison with TH peers and across countries. The Strengths and Difficulties Questionnaire (SDQ) has been used extensively in research and clinical practice for TH children and adolescents as well as for (D)HH children and adolescents. Prior to this study, the SDQ was available and validated in the following sign languages: Australian (Cornes & Brown, 2012), British (Roberts et al., 2015) and in American (Plimmer, 2018).

The challenges in assessing (D)HH children and adolescents have not only affected clinical decision-making but research findings as well. Factors such as the use of written self-report measures for signing (D)HH children and adolescents, a possible lack of cultural or linguistic sensitivity among some researchers as well as heterogeneity within the deaf population are likely to have contributed to inconsistent findings on the prevalence of mental health problems in (D)HH children and adolescents. Translating and validating standardised



measures into sign language can improve clinical assessment and research. Issues with reliability and validity, in general, will be addressed in the following section.

### 1.7.2 Psychometrics

De Vet et al. (2011) define the quality of measurement instruments as the cornerstone of medical and psychological research and clinical practice. Due to the need of assessing non-observable characteristics of psychological constructs, psychologists have developed methods to evaluate different measures (De Vet et al., 2011). Two central concepts are reliability and validity. Reliability is the overall consistency of an instrument across different conditions (Field, 2012), such as for the same respondents across time (test-retest reliability), between different raters (interrater reliability) or different sets of items within the same instrument (internal reliability) (De Vet et al., 2011). Cronbach's  $\alpha$  has traditionally been used to assess internal consistency. Due to its inherent limitations, such as assumptions of uncorrelated errors, tau-equivalence, and normality (Yanyun & Green, 2011) alternatives for estimating composite reliability have been proposed by several authors (Aitken et al., 2015; Niclasen et al., 2013). One of these alternatives is Dillon Goldstein's rho (Mehmetoglu & Chen, 2012), which is based on the loadings of the structural model.

Validity is defined as the degree to which an instrument measures the construct it sets out to measure (Field, 2012). Three types of validity are commonly used to estimate this: content validity (including face validity), criterion validity (concurrent and predictive validity) and construct validity (structural and cross-cultural validity) (De Vet et al., 2011).

Content validity is the degree to which "the content of an instrument is an adequate reflection of the construct to be measured" (Mokkink et al., 2010) p.743. Content validity, including face validity, are based on judgement, i.e. a qualitative measure. De Vet et al. (2011) recommend that an independent expert panel should be consulted in addition to researchers or clinicians who are planning on using the instrument as they are likely to be positively biased.

Criterion validity is established by assessing the degree to which the score of the measure reflects a gold standard (De Vet et al., 2011; Evers et al., 2013). To confirm criterion validity the availability of such a gold standard is necessary. The Youth Self Report

(Achenbach & Rescorla, 2001) or a semi-structured diagnostic interview such as the Schedule for Affective Disorders and Schizophrenia – Present Life Version 2009 (Kiddie SADS; (Kaufman et al., 1997) could have served as a gold standard for the SDQ in NSL, but as there were no NSL versions available, this was not possible within the timeframe of this study. We faced the same difficulties for validating the Inventory of Life Quality in Children and Adolescents (ILC) as possible gold standards such as the KINDL (Ravens-Sieberer & Bullinger, 1998) were not available in NSL. For situations such as these, the establishment of construct validity is recommended as an alternative (De Vet et al., 2011).

Structural validity constitutes one of the aspects of construct validity (De Vet et al., 2011; Evers et al., 2013). It represents the degree to which the scores of the instrument reflect the underlying constructs, i.e., for the SDQ to which degree the five subscales (Emotional Problems, Conduct Problems, Hyperactivity-Inattention, Peer Problems, and Pro-Social Behaviour) are reflected in the measure. For validation studies, confirmatory factor analysis (CFA) is recommended for establishing structural validity (De Vet et al., 2011). As small sample size can cause problems with under-identified models and non-convergence in CFA, Partial Least Squares Structural Equation Modelling (PLS-SEM) can be performed to compensate. (Hair et al., 2016).

## **1.8 Summary**

Several factors complicate understanding mental health in (D)HH children and adolescents (1.6.1 and 1.6.2). Heterogeneity in outcomes is large for (D)HH children and adolescents because of differences in mode and level of communication, likelihood of other disabilities, aetiology of HL, access to UNHS and early intervention. Studying (D)HH children and adolescents is further complicated by the relatively low prevalence of moderate to profound PCHL, which results in small sample sizes. Technological advances and changes in education policies, such as more mainstreaming also complicate comparison across time and countries. Communication skills are associated with (D)HH children and adolescents' mental health and in turn affected by access to sign language. The right to education in sign language varies across countries. Extensive sign language programs such as the one in Norway are thought to improve overall outcomes. Linguistic and cultural factors have been shown to complicate assessment, diagnosis, and treatment of (D)HH children and adolescents

or even lead to misdiagnosis. At the time of data collection, (D)HH children and adolescents were known to be referred to specialised CAMHS later than their TH peers and with more severe symptoms. When assessing signing (D)HH children and adolescents with written measures, they have been found to under-report symptoms. Moreover, there is a lack of validated measures in sign language.

## **1.9 Contribution of this thesis**

This thesis with its three studies was designed to address several of these challenges. Prior to this study, there were no instruments available in NSL to assess (D)HH children and adolescents' mental health or QoL. This study contributed to translating the self-report of the SDQ and ILC into NSL and validating these and the original written ones. A further purpose of this study was to provide instruments in NSL that could be used to detect mental health symptoms as early as possible and ensure timely referral to specialised mental health services across the whole country. Last but not least, our intention was to gain a better understanding of Norwegian (D)HH children and adolescent's mental health and QoL and factors associated with these. Knowledge of the prevalence of mental health problems in Norwegian (D)HH children and adolescents is important for organising and improving early intervention and specialised mental health services in the future.



## **2 Aims of the study**

This thesis had two main aims. One, to translate reliable and valid assessment tools for mental health and QoL into NSL for (D)HH children and adolescents and validate these. Two, to apply these to gain a better understanding of (D)HH children and adolescents' mental health, QoL and communication as well as associations between these factors. More specifically, the following research questions were addressed:

### **Paper I: Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language**

1. What are the internal consistency and test-retest reliability of the SDQ-NSL and SDQ-NOR for (D)HH children?
2. What are the correlations between the total score, subscales, and items between the parent-report (SDQ-P) and the self-reports (SDQ-NSL and SDQ-NOR)?
3. What are the correlations between the total score, subscales, and items between the SDQ-NSL and SDQ-NOR?
4. What is the construct validity of the SDQ-NSL and SDQ-NOR for (D)HH children?
5. How do (D)HH children evaluate the usability of the SDQ-NSL and SDQ-NOR?

### **Paper II: Psychometric properties of the Inventory of Life Quality in Children and Adolescents in Norwegian Sign Language**

1. What is the internal consistency of the ILC-NSL and ILC-NOR for (D)HH children and adolescents?
2. What are the correlations between the parent-report (ILC-P) and the self-reports (ILC-NSL and ILC-NOR) for the QoL score (LQ<sub>0-28</sub>) and the individual items?
3. What are the correlations between the total scores and items between the self-report ILC-NSL and ILC-NOR?
4. What is the construct validity of the ILC-NSL and ILC-NOR for (D)HH children and adolescents?

5. How do (D)HH children and adolescents evaluate the usability of the ILC-NSL and ILC-NOR?

### **Paper III: Deaf and hard-of-hearing children and adolescents' mental health, Quality of Life and communication**

1. Are there differences in mental health between DHH, HH and TH children (self- and parent-report)?
2. Are there differences in QoL between DHH, HH and TH children (self- and parent-report)?
3. A) Is there an association between (D)HH children's degree of hearing loss and mental health?  
B) Is there an association between (D)HH children's degree of hearing loss and their QoL?
4. A) Is there an association between (D)HH children's communication (spoken and sign language; communicative competence) and mental health?  
B) Is there an association between (D)HH children's communication (spoken and sign language; communicative competence) and their QoL?

## 3 Methods

### 3.1 Participants

Fifty-eight DHH children and adolescents aged 6–17 from the part- and full-time students at A.C. Møller school, a Deaf school for central and northern Norway, were eligible for inclusion. Eleven DHH adolescents aged 15–20 attending Tiller Upper Secondary school in central Norway with NSL as their first or second language were also invited and agreed to participate. Nine declined participation, resulting in a response rate of 87%. As shown in Figure 4, 49 DHH children and adolescents were old enough ( $\geq 9$  yrs) to complete the SDQ self-report and participate in study I. All 60 were eligible for inclusion in study II. Apart from fluency in NSL and written Norwegian to ensure completion of the self-report, we did not apply any exclusion criteria to study I and II. We did this to ensure the representativeness of our sample as a reflection of the heterogeneity of the DHH population. For the parent-reported data in study III all participants were included, also those without sufficient fluency in NSL and/or written Norwegian.

For study III, HH children aged 6–19 were recruited from the Norwegian National Support System for Special Education (Statped) and the local audiology department at St. Olavs University Hospital. Of the 24 eligible HH children from Statped, one declined participation resulting in a response rate of 96%. Hundred-and-forty-seven HH children were invited through a letter by the audiology department (ENT); 124 were non-responders, while 24 agreed to participation resulting in a response rate of 16%. It is likely that several of the (D)HH children and adolescents invited by the audiology department already had participated in the study during attendance at deaf school or courses at Statped. The overall response rate for all subsamples combined was 45% (107/240) (see Fig. 5 for the separate response rates). The parents of all subsamples also took part in the study. Data were collected between November 1, 2016, and March 23, 2018.

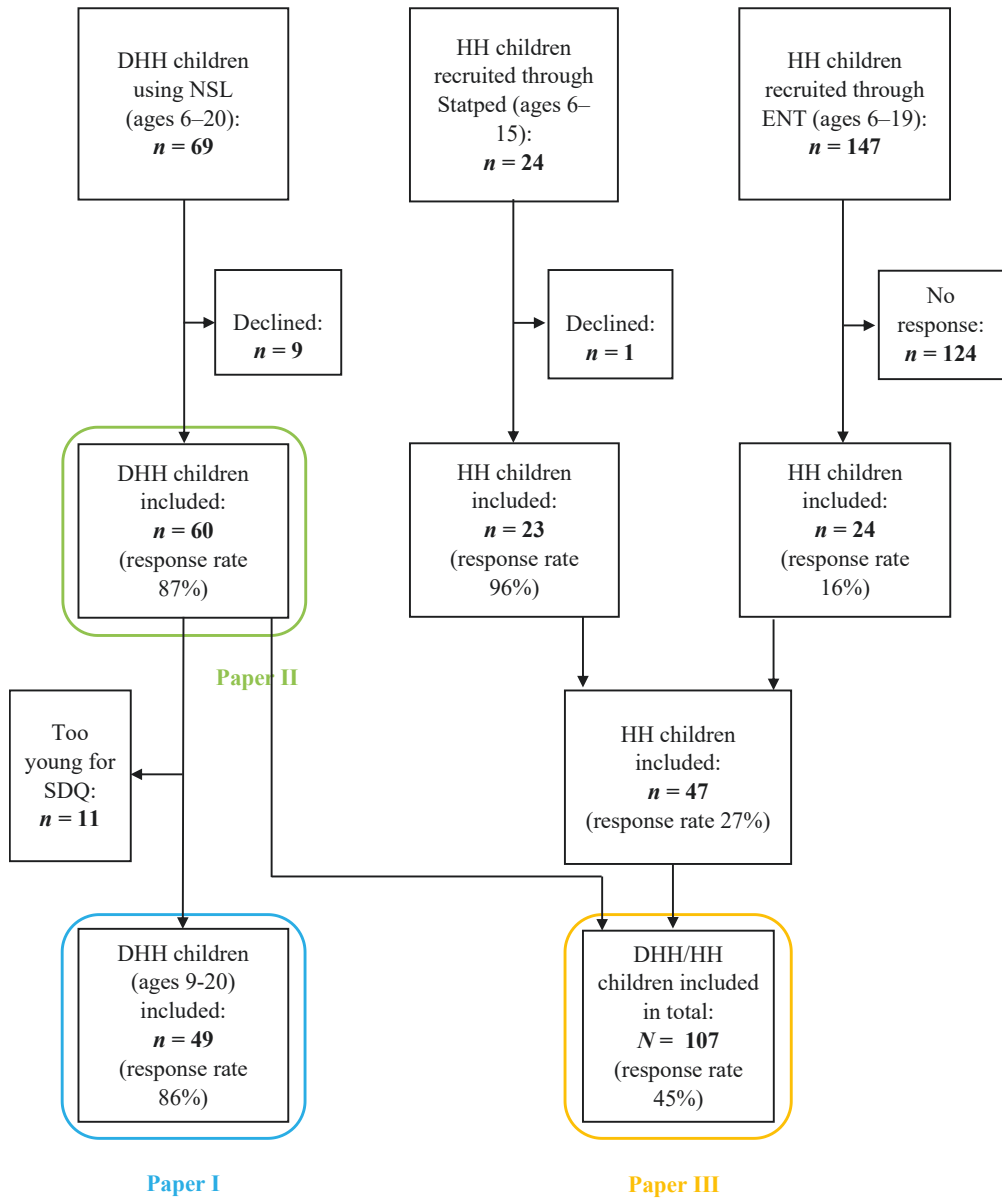


Figure 5. Participant flow chart for papers I to III

In total, 107 (D)HH children (62.6% girls) participated, with a mean age of 11.8 years (and a mean nonverbal IQ of 107.91 (SD=16.84; range=49–143). The participant with the lowest non-verbal IQ was included in further analysis despite being an extreme outlier in the IQ distribution (range excluding outlier = 74–143). Seventy-four of the 87 (85.1%) mothers



had completed 12 years or more of education, whereas 57 of the 83 (68.7%) fathers had completed 12 years or more. The majority of the DHH children (69%) mainly attended mainstream schools while spending two to six weeks at the deaf school per school year. Almost all HH children (87%) attended mainstream school full-time (see Table 1). Sixty-one % of the DHH children and adolescents had a severe to profound HL compared to 22% of the HH children and adolescents. Almost half of the DHH children used CIs compared to 7% of the HH children and adolescents. Based on parent-report, 50% of the DHH used NSL compared to 9% of the HH sample.

**Table 1** Hearing-related characteristics (parent-report) for DHH and HH children

Variable	DHH <i>n</i> =42	%	HH <i>n</i> =45	%
<b>(D)HH parent</b>				
Yes / No	8/34	19.0/81.0	5/40	11.1/88.9
<b>Time in deaf school <sup>a</sup></b>				
1-2 days a week <sup>b</sup>	8	19.0	2	4.4
5 days a week	4	9.5	0	0.0
2-6 weeks a year	29	69.0	6	13.3
> 7 weeks a year	8	19.0	0	0.0
<b>Aetiology of HL</b>				
Prenatal infection	2	4.8	0	0.0
Prelingual infection	1	2.3	0	0.0
Postlingual infection	0	0.0	1	2.2
Perinatal	5	11.9	2	4.4
Syndromic	5	11.9	3	6.7
Other hereditary	5	11.9	5	11.1
Damage to middle/inner ear	4	9.5	15	33.3
Other/unknown	18	42.8	14	31.1
Missing	2	4.8	4	8.9
<b>Degree of hearing loss</b>				
Moderate: 40-70 dB	10	23.8	23	51.1
Severe: 71-100 dB	14	33.3	7	15.6
Profound: 101+	12	28.6	3	6.7
Unknown	5	11.9	9	20
Missing	1	2.4	3	6.7
<b>Use of hearing aid (Yes / No) <sup>c</sup></b>				
CI	20/21	47.6/50.0	3/42	6.7/93.3

<b>Hearing aid</b>	33/ 8	78.6/19.0	38/7	84.4/15.6
<b>Missing</b>	1	2.4	0	0
<b>Age at detection</b>				
<b>0-2 years</b>	27	64.3	19	42.2
<b>3-5 years</b>	15	35.7	19	42.2
<b>6-12 years</b>	0	0	6	13.3
<b>Unknown</b>	0	0	1	2.2
<b>Preferred language</b>				
<b>Spoken Norwegian</b>	21	50.0	40	88.9
<b>NSL</b>	6	14.3	1	2.2
<b>Bilingual</b>	15	35.7	3	6.7
<b>Missing</b>	0	0	1	2.2
<b>Other impairment <sup>d</sup></b>				
<b>Vision</b>	14	32.6	11	24.4
<b>Motor</b>	1	2.3	2	4.4
<b>Learning</b>	4	9.3	4	8.9
<b>Other</b>	8	18.7	4	8.9
<b>Missing</b>	3	7.0	1	2.2

<sup>a</sup> All children attend both mainstream and deaf school.

<sup>b</sup> Children attending the deaf school for 1–2 days a week combine this with two or more week-long stays during the school year; that is, total number of answers is greater than the number of participants.

<sup>c</sup> Based on reports of ever having used a hearing aid.

<sup>d</sup> Some of the children had more than one impairment

Prevalence rates for (D)HH children and adolescents with moderate to profound HL (Butcher et al., 2019; Caluraud et al., 2015; Fortnum et al., 2001) would result in estimations of 190 to 390 (D)HH for children in central and northern Norway, based on population statistics at the time of data collection.

### 3.2 Measures

Table 2 provides an overview of the measures applied in this thesis. For an overview of the psychometric properties of all measures in this thesis, see Appendix A.

Table 2. Measures used in Papers I-III

Measure	Topic	Form	Paper		
			I	II	III
Self-report/child informant			I	II	III
SDQ (NOR/NSL)	Mental health	Questionnaire	■	■	■
ILC (NOR/NSL)	QoL	Questionnaire		■	■
Leiter-3	Nonverbal cognitive ability	Cognitive assessment	■	■	■
Usability of self-report	Usability of NSL and NOR	Questionnaire	■	■	
Parent-report					
SDQ-P	Mental health	Questionnaire	■		■
ILC-P	QoL	Questionnaire		■	■
CAP	Listening skills	Single item scale	■	■	■
SIR	Speech intelligibility	Single item scale	■	■	■
SUS	Sign language understanding	Single item scale	■	■	■
SPS	Sign language production	Single item scale	■	■	■
CCC-2	Communicative competence	Questionnaire			■
SES and HL information	Background information	Questionnaire	■	■	■

*Note.* *SDQ-NOR* Strengths and Difficulties Questionnaire - written Norwegian; *SDQ-NSL* Strengths and Difficulties Questionnaire – NSL; *ILC-NOR* - The Inventory of Life Quality in Children and Adolescents - written Norwegian ; *ILC-NSL* - The Inventory of Life Quality in Children and Adolescents - NSL; *Leiter 3* Leiter International Performance Scale – Third Edition; *SDQ-P* Strengths and Difficulties Questionnaire – parent-report; *ILC-P* - The Inventory of Life Quality in Children and Adolescents - parent-report; *CAP* Categories of Auditory Performance; *SIR* Speech Intelligibility Rating; *SUS* Sign Language Understanding Scale; *SPS* Sign Language Production Scale; *CCC-2* Children’s Communication Checklist Second Edition

### 3.2.1 Mental health

The Strengths and Difficulties Questionnaire - SDQ (Goodman, 1997, 2001) is a brief measure to assess emotional and behavioural problems and pro-social behaviour in children. It has been translated, validated and used in clinical and community samples across countries (Essau et al., 2012) and in Norway (Rønning et al., 2004; Sanne et al., 2009; van Roy et al., 2006; van Roy et al., 2008). The SDQ has also been used for (D)HH children in its written

original form (Dammeyer, 2010; Fellingner et al., 2008; Hintermair, 2007; Stevenson et al., 2015) and translated and validated in Australian (Cornes & Brown, 2012), British (Roberts et al., 2015), American (Plimmer, 2018) and Norwegian Sign Language (Aanondsen et al., 2019).

The SDQ is a multi-informant assessment that is completed by parents of 4–17-year-olds, teachers of 4–17-year-olds and 11–17-year-old adolescents. Even though the self-report was originally designed for adolescents aged 11 to 17 years (Goodman, 2001), other studies have provided evidence that it also can be used for children as young as 8 (Muris et al., 2004) and as old as 19 (van Roy et al., 2006). Based on the evidence of acceptable psychometric properties for both younger and older children and the need for assessment tools of mental health in NSL for children and adolescents of all ages, we included children and adolescents aged 9 to 20. The SDQ consists of 25 items grouped into five scales (Emotional Problems, Conduct Problems, Hyperactivity-Inattention, Peer Problems, and Pro-Social Behaviour). Each item is scored on a three-point Likert Scale (0 = “Not true,” 1 = “Somewhat true” and 2 = “Certainly true”). A Total Difficulties score is calculated based on the sum score of the four problem subscales, with higher scores indicating more difficulties.

The original validation demonstrated satisfactory reliability (internal consistency  $\alpha=.73$ ; test-retest reliability  $r=.62$ ) and construct validity for both self- and proxy-reports (Goodman, 2001). The reliability and validity of the written Norwegian SDQ self-, parent- and teacher-reports were acceptable (Rønning et al., 2004; Sanne et al., 2009; van Roy et al., 2006; van Roy et al., 2008). The reliability and validity of the SDQ-NSL were also found to be acceptable even though they are based on a small sample size (Aanondsen et al., 2019). For this study, we use the terms SDQ-NOR to refer to the written Norwegian self-report and SDQ-NSL for the self-report in NSL. DHH children completed the SDQ-NOR and SDQ-NSL, HH children the SDQ-NOR. Parents completed the parent-report, SDQ-P.

### **3.2.2 Quality of Life (QoL)**

The Inventory of Life Quality in Children and Adolescents – ILC (Mattejat & Remschmidt, 2006) is a brief measure to assess QoL in children and adolescents. The original German version has been validated and then translated into written Norwegian (Jozefiak et al., 2012) and NSL (Aanondsen et al., 2021) and validated (Jozefiak et al., 2012; Aanondsen

et al., 2021). The measure is based on the concept of the individual's perception of their position in life, including their health, functioning, and participation in routines and activities compared to their peers. The ILC has been used to study QoL in (D)HH children and adolescents in Germany (Hintermair, 2010), Austria (Fellinger et al., 2008) and Norway (Overgaard et al., 2021; Aanondsen et al., 2018; Aanondsen et al., 2021).

The ILC is a multi-informant assessment that can be completed by children, adolescents, and young adults aged 6–21 and their parents. For children aged 6–11, the self-report is administered as an interview. The ILC has seven items that assess the child's physical and mental health, school and family functioning, social contact with peers, play/hobbies when alone and overall QoL. Items are rated on a 5-point Likert scale from 1="Very Good" to 5="Very Bad." The QoL score (LQ<sub>0-28</sub>) is calculated by multiplying the mean of the seven items by seven and subtracting 35, thus obtaining absolute values with a range of 0 to 28; higher scores representing better QoL (LQ<sub>0-28</sub>).

The original German validation found acceptable internal consistency ( $\alpha=.63$  self-report;  $\alpha=.76$  parent report) and test-retest reliability ( $r=.72$  self-report;  $r=.80$  parent report) for the QoL score (LQ<sub>0-28</sub>) for community samples. Convergent validity with the Kinder Lebensqualität Fragebogen (KINDL) was shown to be moderate. Construct validity based on Principal Component Analysis was acceptable for a community and a clinical sample. For more details on construct validity, see Mattejat and Remschmidt (2006). The validation of the Norwegian self and parent report (Jozefiak et al., 2012) found satisfactory internal consistency for adolescents aged 11 and older. For children aged ten and younger, internal consistency was somewhat lower. The two-week test-retest reliability for the self-report was found to be high. The one-factor model of the ILC based on confirmatory factor analysis demonstrated good fit in several samples. Moderate correlations between the KINDL and ILC self-report were found, supporting convergent validity. A systematic Norwegian review based on five studies of the psychometric properties of the ILC confirmed these findings (Kristensen & Hove, 2013). Internal consistency of the ILC-NSL self-report was established as acceptable to good and construct validity as acceptable in a small sample (Aanondsen et al., 2021).

In the current study, we administered the written parent report (ILC-NOR) and the self-report versions for children (6–11) and adolescents (12 and older) in both written Norwegian and NSL (ILC-NOR and ILC-NSL)

### **3.2.3 Non-verbal cognitive ability**

The non-verbal cognitive ability of participants recruited through Statped, Tiller Upper Secondary School and A.C. Møller School was assessed using the Leiter International Performance Scale – Third Edition - Leiter-3 (Roid et al., 2013). It consists of the following subtests: Figure Ground, Form Completion, Classification/Analogies, and Sequential Order. The composite score for nonverbal IQ is based on the sum of the scaled scores for these subtests. Internal consistency ( $\alpha=.79$  to  $.95$ ) and test-retest reliability ( $r=.94$  to  $.98$ ) of the nonverbal IQ composite score were found to be good (Roid & Koch, 2017; Roid et al., 2013). Criterion, concurrent, and construct validity were found to be acceptable to good (Hooper & Mee Bell, 2006; Roid & Koch, 2017; Roid et al., 2013). A study by Svensson et al. (2019) found significantly higher nonverbal IQ scores in a Scandinavian sample compared to the original standardisation ( $M=108.6$ ,  $SD=8.4$ ).

### **3.2.4 Communication**

At the time of data collection, no validated assessment tools for pragmatic and communicative NSL skills were available that could have been completed within the timeframe allocated to data collection. The scales and questionnaire described below were therefore used as they were feasible. In addition to these, parents were asked to indicate their child's preferred mode of communication (spoken Norwegian, NSL, other spoken or sign language or bilingual) in and outside the family.

#### ***Spoken language skills***

Auditory performance (speech intelligibility and listening skills) was assessed by parents completing Categories of Auditory Performance (CAP; (Archbold et al., 1995) and Speech Intelligibility Rating (SIR; Allen et al. (2001)). CAP and SIR were frequently used in research on follow-up in (D)HH with CIs. The CAP is a single-item scale with a range of 0 to 7. Level 0 is “no awareness of environmental sounds”, and Level 7 “uses a telephone with a known speaker.” The SIR is also a single-item scale and has a range of 1 to 5. Level 1 is

“connected speech is unintelligible.” and 5 “connected speech is intelligible to all listeners”. Interrater reliability for the Danish version was reported as good (CAP: kappa = .785; SIR: kappa = .848; Dammeyer (2010)). The sum of CAP and SIR was calculated for each child as the spoken language skills score, higher scores indicating better performance.

### *Sign language skills*

Sign language skills were assessed with the Norwegian version of the Sign Language Production Scale (SPS) and the Sign Language Understanding Scale (SUS). Dammeyer (2010) designed the SPS and SUS as a short screening of sign language skills for research purposes. The structure and range of the SUS and SPS correspond to that of the CAP and SIR scales. The SPS is based on the SIR scales, i.e., a single-item scale with a range of 1 to 5. Level 1 is “the child does not produce real signs” and Level 5 “the child uses fluent and almost conventional correct sign language.” The SUS is based on the CAP, i.e., a single-item scale with a range of 0 to 7. Level 0 is “does not react to or does not comprehend signs” and Level 7 “is able to participate in long and complex conversations in sign language.” The interrater reliability of the Danish version was reported to be good (SUS: kappa = .944; SPS: kappa = .921; (Dammeyer, 2010)). Criterion validity of the Danish version of the SUS was found to be good ( $r = .905$ ,  $p < .001$ ; Dammeyer (2010)). No corresponding test was available for sign language production. The sum of SUS and SPS was calculated for each child as the sign language skills score, higher scores indicating better performance.

### *Communicative competence*

Communicative competence was assessed using the validated Norwegian version (Bishop, 2011) for the Children’s Communication Checklist Second Edition (CCC-2), which was developed by Bishop (Bishop, 1998; Bishop, 2003). The CCC-2 is completed by parents and/or teachers. It consists of 10 subscales (7 items per subscale): (A) speech, (B) syntax, (C) semantics, (D) coherence, (E) inappropriate initiation, (F) stereotyped language, (G) use of context, (H) non-verbal communication, (I) social relations, and (J) interests. Items are rated on a 4-point Likert scale from 0=“less than once a week (or never)” to 3=“several times a day (or always)”. The first four scales (A-D) assess vocabulary, discourse, and language structure; scales E, G, H, and I assess pragmatic language. The General Communication Composite (GCC) is based on the sum of the scaled scores for subscales A to H. Cut-off for the GCC at 55 (10th percentile of the UK sample) is recommended in the British (Bishop,

2003) and Norwegian (Bishop, 2011) manuals. One Norwegian study, however, suggests applying a cut-off at 60 (Hollund-Mollerhaug, 2010) and two other studies at 64 (10th percentile of the Norwegian sample; (Akselberg et al., 2021; Helland et al., 2009) to increase specificity. The internal consistency of the Norwegian CCC-2 is reported as good for the subscales ((Cronbach's  $\alpha$  .73 to .89; (Helland et al., 2009)). Specificity of 69.8% and sensitivity of 98.1% was found for the cut-off score at 55. For the cut-off score at 64, specificity was 86% and sensitivity 90.7% (Helland et al., 2009). A recent systematic review on the use of the CCC-2 in Scandinavian countries recommended further research to clarify the appropriate cut-off for identification (Reindal et al., under review).

### **3.2.5 Background information**

Parents completed a questionnaire about their children's age, sex, HL, language preferences, type of schooling and residence, and attendance of sign language classes/intervention programs.

### **3.2.6 Translation procedure**

The translation process of the SDQ and ILC self-report were based on the guidelines for cross-cultural adaptation of written self-report measures by Beaton et al. (2000). Due to differences in syntax, morphology and prosody of sign languages and their visual nature, the necessary adaptations suggested by Roberts et al. (2015) were made. The SDQ and ILC were put through several cycles of independent forward and backward translations from written Norwegian to NSL and adaptations based on a panel discussion, feedback from a focus group and the authors of SDQ and ILC. After the final approval from the respective authors, the SDQ-NSL and ILC-NSL were filmed professionally and prepared for interactive online administration using Select Survey. For a more detailed description of the translation process see paper I (Aanondsen et al., 2019) for the SDQ and paper II (Aanondsen et al., 2021) for the ILC. Two independent forward and backwards translations were conducted for the Danish SPS and SUS. The author, Jesper Dammeyer, then approved these.

## **3.3 Procedure**

Information about participating in the study was provided in writing, NSL and spoken Norwegian for DHH children and their parents during their first attendance at the deaf school



and Tiller Upper Secondary School after the survey had been initiated. According to the study's survey procedures, written informed consent was obtained from parents and adolescents  $\geq 16$  years prior to inclusion. Parents of adolescents  $\geq 16$  were only invited to participate if the adolescents consented to their parents' participation. The participating DHH children responded to the web-based SDQ-NSL, SDQ-NOR, ILC-NSL and ILC-NOR. They also answered a question about the usability of the two versions and completed a nonverbal cognitive assessment. When the children asked for help with the NSL versions, they received support in NSL, whereas the children replying to the NOR versions were assisted in spoken Norwegian or sign-supported speech. The administration of the NSL and NOR versions of the SDQ and ILC was conducted on two separate occasions with an interval of two days. The order of these two administrations was randomised. Parents completed the parent-report of the SDQ, ILC and CCC-2. They also completed the single-item scales for the spoken and sign language skills and responded to a questionnaire assessing children's age, sex, HL, language preferences, type of schooling and residence, and attendance of sign language classes/intervention programs.

The HH children and their parents received information in written and spoken Norwegian while attending a course at Statped. The audiology department sent information about the study, forms of consent as well as questionnaires to the other group of HH children and their parents. According to the study's survey procedures, written informed consent was obtained from parents and adolescents  $\geq 16$  years before inclusion. The participating HH children responded to the paper and pencil version of the SDQ-NOR and ILC-NOR. Parents also responded to the same questionnaire as the DHH group's parents.

### **3.4 Ethics**

The Regional Committee for Medical and Health Research Ethics approved the study (reference number: 2015/1739/REK midt). Written informed consent was obtained from all parents and adolescents older than 16 years prior to inclusion. Verbal informed consent was obtained from children under the age of 16 years. The participants were informed that they could withdraw from the study at any time. Appropriate support and counselling were available to participants who experienced stress during data collection.

### 3.5 Statistical analysis

For the study in paper I, 17 of the 49 parent-reports (34.7%), nine of the 49 SDQ-NSL self-reports (18.4%) and three of the 49 SDQ-NOR reports (6.1%) were not completed. These missing cases were excluded from analyses. There were no missing items as YouthInMind requires a response to all items on the SDQ in web-based administrations. For the study in paper II, eight of 51 parent-reports (15.7%) and seven of the 56 ILC-NSL self-reports (12.5%) were not completed. These missing cases were excluded from analyses. Missing values on five cases were substituted using expectation maximisation (Dempster et al., 1977). In paper III, we handled missing values using multiple imputation. Details on both missing cases and values for all variables involved can be found in Table B1 in Appendix B in paper III. We assumed data to be missing at random (MAR) when they were not structurally missing. Examples of structurally missing data were CCC-2 GCC for those who did not speak in complete sentences, SDQ-NSL, ILC-NSL and sign language skills for those not using sign language. First, we imputed all missing values; then we deleted the imputed values in the positions where they were structurally missing.

Independent samples t-tests were used to examine boys' and girls' mean score differences on the SDQ in paper I, gender differences in item and scale mean scores for the ILC scores in paper II and for group differences between (D)HH and TH children for SDQ and ILC scores in paper III. Differences between (D)HH children's spoken and sign language skills were analysed using paired sample t-tests in paper II. Bootstrapped confidence intervals were calculated using the bias corrected and accelerated method and B=1000 bootstrap samples for paper II. Dillon–Goldstein's rho (DG rho) was used to assess internal consistency (papers I and II) because of the limitations of Cronbach's  $\alpha$ , such as assumptions of uncorrelated errors, tau-equivalence, and normality (Aitken et al., 2015; Niclasen et al., 2013; Yanyun & Green, 2011). DG rho was interpreted as acceptable at .6 to .7 and as good when  $> .7$ . We also calculated Cronbach's  $\alpha$ , including bootstrapped confidence intervals for comparison with other studies for paper II. Test-retest reliability based on intraclass correlations (ICC) was calculated using a two-way random effects model (paper I). ICCs were also used to evaluate associations between the scale and item scores of the two self-reports (ILC-NSL and ILC-NOR) in paper II. ICC values of less than .5 were considered

poor, .5–0.75 was acceptable, .75–0.9 was good and greater than .90 was considered excellent reliability (Koo & Li, 2016). Spearman’s rank correlation coefficient was used to compare total score, subscales and items between the SDQ-NSL and SDQ-NOR (paper I) and to assess multi-informant correlations between parent- and self-reports of the SDQ and ILC (papers I and II).

To handle the small sample sizes and estimate construct validity of the SDQ and ILC self-report versions (papers I and II), we performed Partial Least Squares Structural Equation Modelling (PLS-SEM). PLS-SEM is regarded as a robust method when dealing with small sample sizes as it is nonparametric and makes fewer distributional assumptions. PLS-SEM, however, is mostly used for exploratory purposes because it lacks goodness of fit measures. We established factor loadings and discriminant validity (average variance extracted - AVE) as suggested by Hair et al. (2016). Standardized factor loadings greater than .4 were considered acceptable (Mehmetoglu & Jakobsen, 2017). Factors with AVE scores greater than .5 were regarded as satisfactory for convergent/discriminant validity. However, Fornell and Larcker (1981) argue that  $AVE > .4$  can be treated as acceptable if composite reliability is above .6. We also performed CFA with the weighted least squares means and variances (WLSMV) estimation method for categorical variables to confirm the original factor structure of the SDQ and ILC for both self-report language versions (papers I and II). The chi-squared test, the normed chi-square ( $\chi^2/df$ ), the root mean square error of approximation (RMSEA), comparative fit index (CFI) and Tucker-Lewis Index (TLI) were used to assess model fit. A non-significant chi-square test, CFI and TFI  $> .9$ , RMSEA  $< .1$  were considered indicators of acceptable goodness of fit according to Mehmetoglu and Jakobsen (2017), whereas CFI and TFI  $> .95$  and RMSEA  $< .05$  were considered as indicators of good model fit (Hu & Bentler, 1999). A normed chi-square of  $< 2.0$  was considered acceptable for this study, although others have reported acceptable ratios as high as 5.0 (Hooper et al., 2008). Standardized factor loadings greater than .4 were considered acceptable (Mehmetoglu & Jakobsen, 2017).

A contingency table was computed for comparing the total score of DHH children within the normal, sub-clinical and clinical ranges for the SDQ-NSL and SDQ-NOR (paper I), as well as the concordance between the two self-reports. Based on Fagerland et al.’s (2017) recommendation, we computed a contingency table and used Fisher’s exact test to examine the association between the DHH children’s preferred mode of communication in

everyday life and their preference for the SDQ-NSL or SDQ-NOR. Further contingency tables, including Kruskal-Wallis equality-of-populations rank tests, were computed for the DHH children's spoken as well as their NSL skills and their preference for the SDQ-NSL or SDQ-NOR.

Associations between HL, communication, mental health and QoL were investigated using linear regression with mental health and QoL as dependent variable and communication and HL as independent variables (paper III). All regression analyses were adjusted for age and gender.

Descriptive analyses in paper I were conducted in IBM SPSS Statistics version 25. Confirmatory Factor Analysis (CFA) for paper I and II were performed in MPlus version 8. All other analyses were conducted in Stata/SE for Windows, versions 14.2 and 17.0. PLS-SEM, including AVE, was conducted in Stata by applying the module for PLS-SEM Venturini and Mehmetoglu (2017). Two-sided p-values < .05 were taken to indicate statistical significance, and 95% confidence intervals (95% CI) were reported where relevant. However, p-values between 0.01 and 0.05 should be interpreted with caution due to multiple hypotheses.

## 4 Results

### Paper I

#### *Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language*

The main aim of the study was to examine the psychometric properties (internal consistency, test-retest reliability and construct validity) of the SDQ self-report in written Norwegian and NSL for (D)HH children and adolescents. In addition to this, we studied the usability of the two language versions according to the children and adolescents.

A descriptive summary of the mean scores for the SDQ total scores and subscale scores can be found in Figure 6 for self-reports (NOR and NSL) and the parent-report.

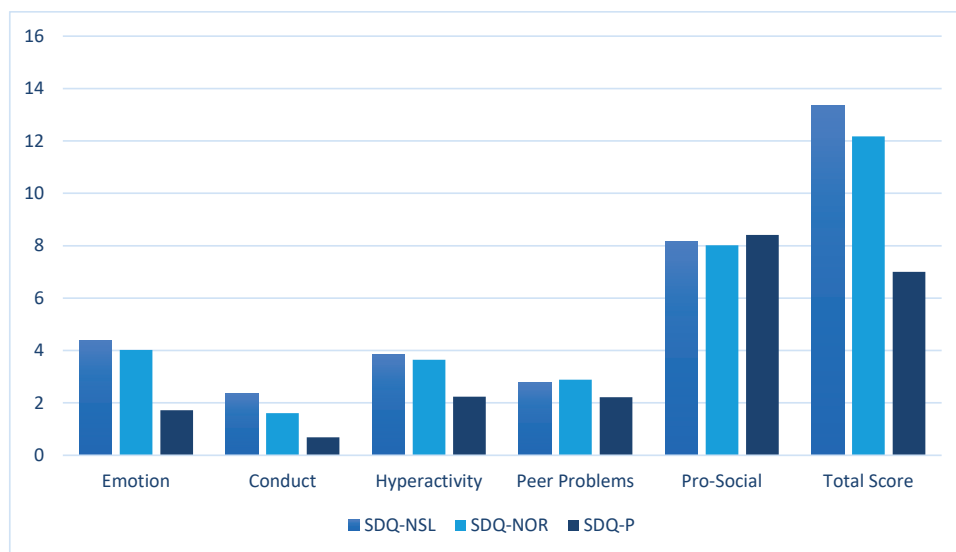


Fig. 6. Mean scores for total score and subscale scores for self-reports (NOR and NSL) and parent-report. *SDQ* Strengths and Difficulties Questionnaire possible range of score 0-40 for total score and 0-10 for each subscale. Norwegian cut-off scores for self-report ( $\geq 90$  percentile): Emotion = 6, Conduct = 5, Hyperactivity = 7, Peer Problems = 5, Pro-social = 4, Total score = 18; *SDQ-NSL* SDQ self-report in Norwegian Sign Language; *SDQ-NOR* SDQ self-report in written Norwegian; *SDQ-P* parent-report.

Internal consistency was established as acceptable to good for all subscales of the SDQ-NOR and SDQ-NSL (Paper I, Table 4). The lowest, but still acceptable internal consistency based on DG rho was found for Peer Problems (SDQ-NSL and SDQ-NOR) and

Pro-Social Behaviour (SDQ-NSL). Test-retest reliability for the SDQ-NSL was found to be acceptable based on ICCs for all subscales as well as Total Difficulties (Paper I, Table 5). Test-retest reliability for the SDQ-NOR ranged from poor (Pro-Social Behaviour), to acceptable (Hyperactivity-Inattention and Peer Problems) and good (Emotional Problems, Conduct Problems and Total Difficulties) based on ICCs.

Spearman rank correlations between parent-report and the two self-report versions varied from  $r = -.029$  (SDQ-NOR)/ $r = .026$  (SDQ-NSL) for Pro-Social Behaviour to  $r = .400$  (SDQ-NOR)/ $r = .521$  (SDQ-NSL) for Emotional Problems and were all non-significant except for Emotional Problems (Paper I, Table 10). Spearman rank correlations between the two language versions for Total Difficulties and all subscales were highly significant at  $p < .001$  (Paper I, Table 9). The correlations for Emotional Problems, Peer Problems, and Total Difficulties were in the “good” range, while Conduct Problems, Hyperactivity-Inattention and Pro-Social Behaviour demonstrated acceptable correlations.

Construct validity was based on CFA and PLS-SEM. Best fit was obtained for the proposed five-factor model for both language versions, although not all fit indices reached acceptable levels (Paper I, Table 8).

Forty-four-point nine percent (22/40) of the DHH children indicated a preference for the SDQ-NOR. The SDQ-NSL or a combination of the signed and written self-report were the preferred choice of 30.6% (15/40).

## **Paper II**

### ***Psychometric properties of the Inventory of Life Quality in Children and Adolescents in Norwegian Sign Language***

The main aim of the study was to examine the psychometric properties (internal consistency and construct validity) of the ILC self-report in written Norwegian and NSL for DHH children. We also wanted to study the usability of the two versions according to the children and multi-informant correlations.

A descriptive summary of the mean scores for the QoL score (LQ0-28) and item scores can be found in Figure 7 for the self-reports (NOR and NSL) and the parent-report.

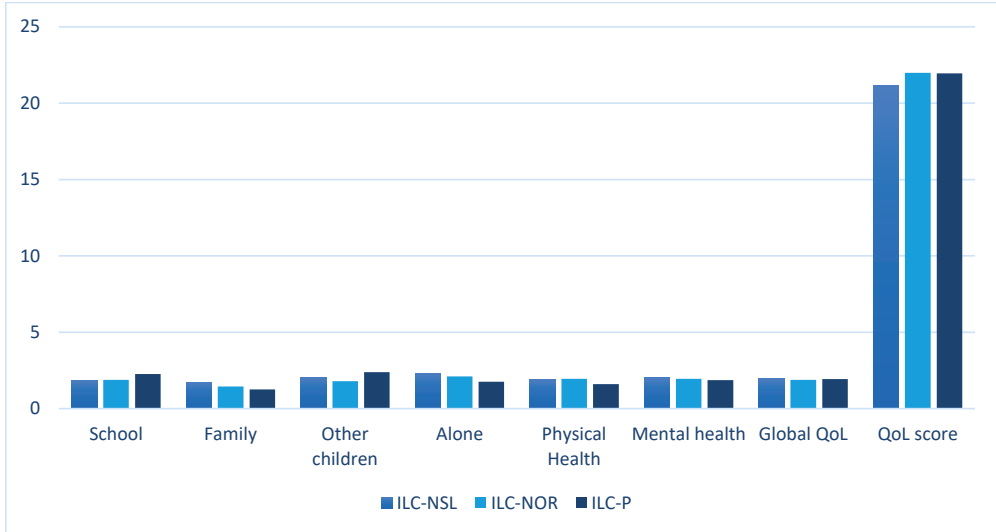


Fig. 7. Mean scores for the QoL score and item scores for self-reports (NOR and NSL) and parent-report. *ILC* the Inventory of Life Quality in Children and Adolescents: range of item scores 1–5, 1=high QoL; QoL score ( $LQ_{0-28}$ ): range 0–28, 28=high QoL; *ILC-NSL* ILC self-report in Norwegian Sign Language; *ILC-NOR* SDQ self-report in written Norwegian; *ILC-P* parent-report

Internal consistency based on DG rho and Cronbach’s  $\alpha$  was found to be acceptable to good for both language and age version (Paper II, Table 4). The ICCs between the  $LQ_{0-28}$  of the ILC-NSL and ILC-NOR were highly significant at  $p < .001$  for the complete sample, as well as for the adolescent version, but not for the child version (Paper II, Table 5). The items on the adolescent versions were all significantly correlated, moderately to strongly (.441–.867), while none of the items on the child versions correlated significantly. For construct validity all factor loadings ( $\lambda$ ) of the PLS-SEM were above the recommended .4 for both adolescent versions and the complete sample (Paper II, Table 6), but not for the child versions. AVE was above the recommended .4 while composite reliability was above .6 for both language versions and ages, thereby indicating an acceptable fit. Supplementary CFA analyses supported these findings (Paper II, Appendix C).

Spearman rank correlations varied from  $r = -.281$  (ILC-NOR)/ $r = -.245$  (ILC-NSL) for the child self- and parent-reports to  $r = .319$  (ILC-NOR;)/ $.511$  (ILC-NSL) for the adolescent self- and parent-reports (Paper II, Table 7a and b). Fifty-four-point nine percent (26/48) of the

DHH children indicated a preference for the ILC-NOR. The ILC-NSL or a combination of the signed and written self-report were the preferred choice of 39.9% (19/48).



## Paper III

### *Deaf and hard-of-hearing children and adolescents' mental health, Quality of Life and communication*

The main aims of this study were to compare the mental health and QoL of DHH, HH and TH children to each other based on self- and parent-report and to examine associations between HL/communication and mental health/QoL.

A descriptive summary of the mean scores for mental health, QoL and communicative competence can be found in Figure 8 for DHH, HH and TH children and adolescents and their parents.

We found no significant differences between DHH and HH children for self-reported ( $\beta$  -.548; CI: -4.25 to 3.15;  $p$ :.767) and parent-reported mental health ( $\beta$  -.704; CI: -3.17 to 1.76;  $p$ :.572) or self-reported ( $\beta$  .232; CI: -1.54 to 2.00;  $p$ :.795) and parent-reported QoL ( $\beta$  1.15; CI: -.64 to 2.94;  $p$ : 0.205). DHH and HH children and adolescents and their parents reported significantly more mental health problems on the SDQ than TH children and adolescents. Parents of both DHH and HH children and adolescents reported significantly lower QoL than parents of TH children (Paper III, Tables 3 and 5). Based on the Norwegian cut-off score for the self-reported SDQ, 17.2% of the HH and 19.0% of the DHH children and adolescents were within the clinical range on the SDQ-NOR, while 15.9% of the DHH children and adolescents were in the clinical range on the SDQ-NSL, compared to 8.7% of the TH children and adolescents in van Roy et al.'s (2006) study. Significant regression coefficients were found for communicative competence and parent-reported mental health ( $\beta$  -.98; CI: -.15 to -.05;  $p$ :<.001) and QoL  $\beta$  .10; CI: .07 to .13;  $p$ :<.001; Paper III, Table 4).

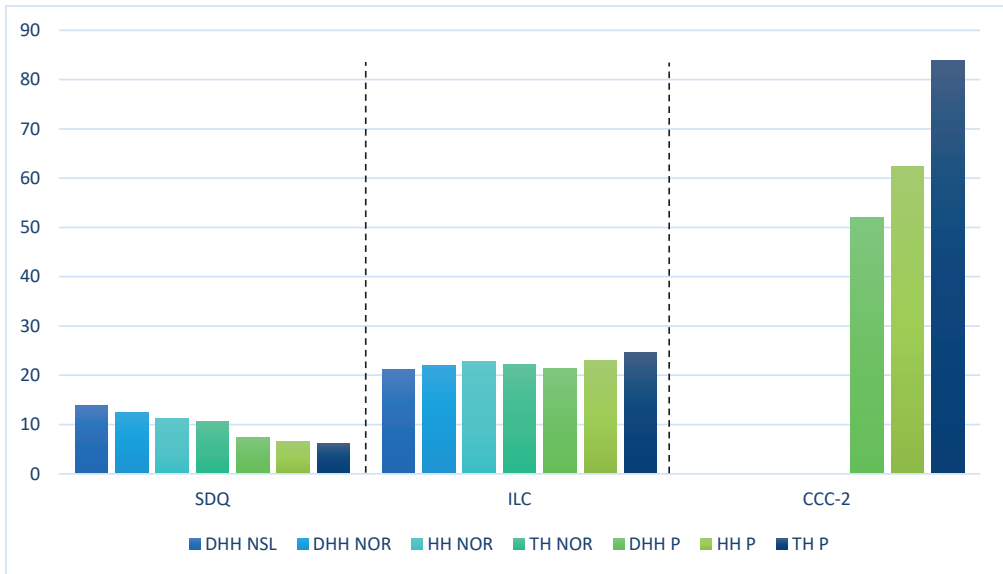


Fig. 8. Mean scores for DHH, HH and TH children and their parents on the SDQ, ILC and CCC-2. *SDQ* Strengths and Difficulties Questionnaire, range of score 0-40 for total score, Norwegian cut-off score for the total score of the self-report ( $\geq 90$  percentile): 18; *ILC* the Inventory of Life Quality in Children and Adolescents: range of QoL score ( $LQ_{0-28}$ ): range 0-28, 28=high QoL; *CCC-2* Children's Communication Checklist version 2 based on the General Communication Composite; range 0-168; a GCC score of 83 equals the mean or 51st percentile, while a GCC score of 61 equals the 15th percentile; DHH NSL deaf and hard-of-hearing children and adolescents' scores on the NSL self-reports; DHH NOR deaf and hard-of-hearing children and adolescents' scores on the written self-reports; HH NOR hard-of-hearing children and adolescents' scores on the written self-reports; TH NOR typically hearing children and adolescents scores on the written self-reports; DHH P parents of DHH children and adolescents; HH P parents of HH children and adolescents; TH P parents of typically hearing children and adolescents

## **5 Discussion**

### **5.1 Main findings**

This thesis aimed to translate generic measures for mental health and QoL into NSL for (D)HH children and adolescents and to study the psychometric properties of both the written and NSL versions. Both written and NSL measures were then used to gain a better understanding of both DHH and HH children and adolescents' mental health and QoL compared to TH children and adolescents. In addition to this, associations between communication, degree of HL, mental health and QoL were explored.

To summarise, so far, internal consistency and test-retest reliability of the written and NSL self-report of the SDQ seem promising despite some issues concerning the Pro-Social subscale. Even though construct validity of the proposed five-factor model was confirmed, acceptable levels were not reached for all fit indices. The two self-report versions correlated significantly with each other except for the subscale Pro-Social behaviour. Regarding the written and NSL self-report versions of the ILC, composite reliability and construct validity were also promising for both the child and adolescent versions. Agreement between self- and parent-report on QoL was low, especially for the child versions. More DHH adolescents indicated a preference for the written versions of the SDQ and ILC than for the NSL version or a proposed combination of the two. The majority of DHH children, however, preferred the NSL version of the ILC. DHH and HH children and adolescents and their parents reported more mental health problems than TH children and adolescents. Furthermore, a prevalence for mental health problems about twice as high as for TH children and adolescents was found for DHH and HH children and adolescents based on both self-report versions. Parents of DHH and HH children reported significantly lower QoL in their children than parents of TH children, while DHH and HH children did not rate themselves differently from their TH peers. Degree of HL was not associated with either mental health or QoL for self- and parent-reports. Communicative competence, however, was found to be associated with parent-reported mental health and QoL.

## 5.2 General discussion

### 5.2.1 Validation of the SDQ

Acceptable levels of internal consistency based on composite reliability (DG rho) were found for the total problem scale and all subscales for both the written and NSL self-report. Internal consistency was somewhat higher than in other studies based on Cronbach's  $\alpha$  but more similar to that found in Aitken et al.'s (2015) study based on composite reliability (Raykov's correlation coefficient). This is likely due to the known tendency of Cronbach's  $\alpha$  to underestimate internal consistency due to its limitations ((assumptions of uncorrelated errors, tau-equivalence, and normality; (Aitken et al., 2015; Niclasen et al., 2013; Yanyun & Green, 2011)). Internal consistency for Peer Problems in our study was higher than in both the original validation and the validation of the SDQ in British Sign Language(BSL). Roberts et al. (2015) suggested that peer problems due to communication barriers are more common and could explain the low internal consistency of the subscale (Peer Problems) found in their validation of the SDQ in BSL. As composite reliability for Peer Problems was higher in our study, it does not seem likely that challenging communication with peers has impacted on the reliability of the Peer Problem scale in our sample. A possible explanation might be that the data in our study were collected while all DHH children and adolescents attended deaf school, i.e. were in a deaf environment where they could communicate easily. This is supported by the queries of several participants, who asked if they were to answer the questions based on their experience at home in a mainstream setting or during their stay at the deaf school. Overall, internal consistency for the SDQ-NSL and SDQ-NOR were found to be acceptable and, to some degree, even better than those found in the original validation (Goodman, 2001).

Test-retest reliability was established as acceptable for the total scale and all subscales of the SDQ-NSL. Test-retest reliability for the SDQ-NOR, however, was somewhat higher than for the SDQ-NSL for the total score and all subscales except for the Pro-Social Scale, which was poor. A reason for this might be that the written version is more neutral than the NSL version, which is dependent on the presenter's speed, intensity of articulation and facial expressions (Roberts et al., 2015). This, in turn, might have affected the DHH children and adolescents' responses even though the SDQ-NSL was presented by the same online survey. As Cornes and Brown (2012) only administered the SDQ in Australian Sign Language for

retest reliability in their study, but not the written SDQ, we cannot compare our results to other studies. Test-retest reliability in our study was lower than that found by Cornes and Brown (2012). Their retest was administered with an interval of 2 days compared to our 15 weeks, which is a likely explanation. The lower test-retest reliability in our study might reflect actual changes in mental health symptoms as the participants are instructed to base their replies on the last six months. However, even with the 15-week interval, the test-retest reliability was acceptable.

Cross-informant correlations in our study were lower than those reported for the original validation (Goodman, 2001) and those reported by Cornes and Brown (2012) for DHH adolescents. We did, however, find the same pattern of cross-informant correlations, with correlations between parent- and self-report being lower for the self-report in NSL than that in written Norwegian. A reason for this could be the differences in neutrality between NSL and written Norwegian, mentioned previously. The wording of the parent-report and written self-report is, therefore, more similar than the parent-report and SDQ-NSL. The lower correlations found for our DHH sample compared to TH children and their parents might also be an indication of the TH parents' lack of awareness of the experiences of their DHH children. This is supported by Roberts et al.s (2015) study reporting higher correlations between DHH children and their DHH parents than between DHH children and their TH parents. It is also essential to keep in mind that we do not expect mean correlations higher than .25 (Achenbach et al., 1987) for parents and children, as symptoms and behaviour are influenced by differences in settings. This in turn reinforces the necessity of the multi-informant perspective. Correlations between the SDQ-NOR and SDQ-NSL demonstrated a close correspondence between the two versions for the total score and subscale scores. Correlations found in our study were higher than those reported by Cornes and Brown (2012). Construct validity of the proposed five-factor model received the most support, although it did not reach acceptable levels for all goodness of fit indices. The small sample size might be an explanation for this. However, other validation studies have reported similar goodness of fit indices, especially for the self-report (Roberts et al., 2015).

Almost 45% of the DHH children and adolescents indicated a preference for the written SDQ, whereas about 30% stated a preference for the NSL version or a potentially combined version. The remaining 25% did not answer the question or did not have a personal

preference. In addition, the DHH children and adolescents' spoken or sign language skills or preferred language as indicated by their parents were not associated with their preference for either the written or NLS versions. During administration, however, several DHH children commented on the time-consuming nature of the video presentation in NSL, which is likely to have affected their choice.

To summarise, the SDQ self-report was successfully translated into NSL while taking linguistic and cultural aspects into account that are specific to translations from a written to a visual language. Further, the reliability and validity of the SDQ-NSL are broadly similar to other translated versions. Overall, this supports usability and the possibility of administering the written and NSL reports simultaneously without limiting reliability or construct validity.

### **5.2.2 Validation of the ILC**

Internal consistency was confirmed as good for both language and age versions based on DG rho and Cronbach's  $\alpha$ . Cronbach's  $\alpha$  demonstrated lower consistency for both language and age versions than DG rho, hereby confirming the known tendency to underestimate internal consistency due to its limitations (assumptions of uncorrelated errors, tau-equivalence, and normality ((Aitken et al., 2015; Niclasen et al., 2013; Yanyun & Green, 2011)). As we estimated internal consistency using both measures, we were able to attribute differences to methodological choices. Internal consistency was lowest but still good for both the child versions (written and NSL) and especially low for the NSL version. This accords with the validation of the Norwegian version (Jozefiak et al., 2012). Relative cognitive immaturity in younger children and less age-appropriate formulation of items have been suggested as possible explanations. (Jozefiak et al., 2008; le Coq et al., 2000). Conijn et al. (2020) found that children as young as seven could provide valid and consistent self-report on a QoL measure with a 3-point-scale, whereas 8-year-olds struggled more on a version with a 5-point-scale. As the ILC is rated on a 5-point-scale, this might have affected internal consistency for the child versions. For our study, less familiarity with NSL might be another factor that could explain the difference in internal consistency between the NSL and written version for children, which is also visible in the lower sign language skills scores for the children compared to the adolescents.

Cross-informant correlations for parent-report and adolescents' written self-report were similar to those found in the original Norwegian validation (Jozefiak et al., 2012) and somewhat higher for the NSL self-report. Whereas we found the opposite for the SDQ, where cross-informant correlations were higher for the written SDQ than for the SDQ-NSL. This could be due to the inherent differences between the neutrality of the two languages previously mentioned. Alternatively, as the adolescents in this study (study II) were older than the children and adolescents in study I, they are likely to have had better sign language skills as they have spent more time in settings where NSL is used. Cross-informant correlations between DHH adolescents and their parents were somewhat higher in Overgaard et al.'s (2021) study than ours and the original validation (Jozefiak et al., 2012). For children, however, the cross-informant correlations were negative and non-significant for both language versions. None of the cross-informant correlations at item level were significant in contrast to the original Norwegian validation (Jozefiak et al., 2012). Several other authors report low agreement between DHH children and their parents (Chmiel et al., 2000; Fellingner et al., 2008; Warner-Czyz et al., 2009). Others have suggested that as parents and DHH children and adolescents do not necessarily share the same mode of communication, this might affect the parents' insight into their children's mental and physical health as well as their situation in school, with friends and during leisure activities (Fellinger et al., 2008). Several aspects of QoL, such as self-esteem, friends and family, seem less observable to parents (Warner-Czyz et al., 2009), which emphasises QoL as a subjective concept. Others have suggested that TH parents might rate their (D)HH children and adolescents' QoL based on their own experiences, values and expectations (Pardo-Guijarro et al., 2015). Overall, the low cross-informant correlations combined with the validity of self-reports even in young children highlight the importance of the self-report as the authentic QoL measure (Conijn et al., 2020; Holte et al., 2014; Landgraf et al., 2018).

Correlations between the two language versions for adolescents were high for both item and QoL scores indicating a close correspondence between the two versions for this age group. Associations in the study were higher than expected based on comparisons of written and sign language questionnaires on mental health (Cornes & Brown, 2012; Cornes et al., 2006). Associations between the two language versions were, however, non-existent for children. A reason for this might be the significantly lower sign language skills in this age group. As the child version is designed for individual administration as a conversation, the

items are wordier, resulting in longer sign language utterances. The combination of these two facts might have made the ILC-NSL version especially difficult to understand, although the children themselves expressed a preference for this language version. A different reason could be the inconsistency found in 8-year-old children's answers to QoL measures on a 5-point-scales (Conijn et al., 2020), which may have affected the results of our study. During administration, several DHH children asked if they were to answer the items related to school and friends as they were at their local school or the deaf school. As they rated their QoL shortly after arrival and then again, a couple of days later, the low correlations may be due to an actual change in QoL on some of the domains. Problems with the translation of the ILC child version could be another reason. Still, as rigorous forward and backward translations and an expert panel and focus group were employed, this is not very likely.

Construct validity of the proposed one-factor model was acceptable based on PLS-SEM for both language and age versions. In contrast, some of the goodness of fit indices on the CFA did not reach acceptable levels. Differences between the fit indices for the PLS-SEM and the CFA are likely due to the small sample size (Hair et al., 2016).

Even though the DHH children had lower sign language skills than the adolescents, 47.6% indicated a preference for the sign language version or the possibility of a combined version; 38.1% preferred the written version. On the other hand, among the adolescents, 66.7% preferred the written version, and 33.3% the NSL version or the possibility of a combined option. We assume that this might be due to the time-consuming nature of the video presentation in the NSL versions and the likely higher level of literacy in adolescents. However, as associations between the child self-reports were low and the majority indicated a preference for the NSL version, it is also possible that the children were struggling more with the written than the NSL version.

To summarise, the ILC self-report was successfully translated into NSL while taking into account linguistic and cultural aspects specific to translations from a written to a visual language. Further, composite reliability and construct validity of the child and adolescent versions in both NSL and written Norwegian have been confirmed, supporting applicability. However, the non-existent associations between the two language versions for children make a combination of the two language versions questionable. A focus group with DHH children aged six to eleven should be established and consulted to address this issue. One could also



consider administering the adolescent version with its simpler language to see if this would improve the psychometric properties in another validation.

### **5.2.3 Mental health, QoL and communication in DHH and HH children**

We found no significant differences between the mental health of DHH and HH children and adolescents in our study, which is in accordance with previous studies (Dammeyer, 2010; Fellingner et al., 2008; Fellingner, Holzinger, Sattel, et al., 2009; Hintermair, 2007; Theunissen, Rieffe, Kouwenberg, et al., 2014). The lack of difference is further supported by the lack of associations between degree of HL and mental health found in this study. Both DHH and HH children and adolescents and their parents reported more mental health problems than TH children and adolescents and their parents. This is in accordance with several studies and systematic reviews (Fellinger et al., 2008; Stevenson et al., 2015; Theunissen, Rieffe, Netten, et al., 2014) as well as a recent Norwegian study (Overgaard et al., 2021).

We estimated the prevalence of mental health problems only based on the cut-off scores for the self-report, as to the best of our knowledge, there are no Norwegian cut-off scores available for the parent-report. The Norwegian cut-off scores commonly used are based on the self-report (Rønning et al., 2004). As others have shown differences for cut-off scores between both parent- and self-reports on the SDQ (van Roy et al., 2010) and differences between countries (Stevanovic et al., 2017), we did not want to apply cut-off scores from other countries or informants. The tendency of Norwegian parents to report fewer symptoms than parents in other countries has been reported on several measures (Helland et al., 2009; Reindal et al., under review; Rescorla et al., 2007). DHH and HH children and adolescents reported a prevalence of mental health problems about twice as high as their TH peers (van Roy et al., 2006) on both the written and NSL self-report versions. The elevated prevalence is in accordance with several international studies (Dammeyer, 2010; Fellingner, Holzinger, Sattel, et al., 2009; Stevenson et al., 2015; Theunissen, Rieffe, Netten, et al., 2014; van Gent et al., 2007), if not quite as high as in some of these. The extent of parental support in the Nordic countries has previously been suggested as a protective factor for (D)HH children's mental health (Mejstad et al., 2009) and might have contributed to a lower

prevalence in our sample. The prevalence of mental health problems in the clinical range also accords with a recent Norwegian registry study (Oerbeck et al., 2021).

The higher prevalence of mental health problems in (D)HH children and adolescents continues despite changes in education policies, technological advances, UNHS and early intervention (Roberts et al., 2015), which were thought to improve outcomes. Therefore, the elevated prevalence of mental health problems and challenges in using written measures emphasise the need for targeted early intervention, specialised mental health services and assessment in sign language.

The DHH and HH children and adolescents in our study rated their QoL as similar to their TH peers. The lack of differences between the DHH and HH children and adolescents in our studies are not surprising as other studies comparing QoL in DHH with HH (Fellinger et al., 2008) and those examining the degree of HL on QoL (Hintermair, 2010; Qi et al., 2020; Reeh et al., 2008) reach similar conclusions. The lack of differences observed between (D)HH and TH children in our study accords with some studies (Fellinger et al., 2008; Hintermair, 2010; Qi et al., 2020), but is in contrast to others, among them two recent Norwegian studies (Haukedal et al., 2020; Overgaard et al., 2021). In Haukedal et al.'s (2020) study, (D)HH children with CI reported significantly lower QoL than TH children; however, they did rate their QoL as better than their parents (Haukedal et al., 2018). The (D)HH children in Haukedal et al.'s (2020) study rated their QoL especially low on the social and school subscales. As most of our data were collected while the participants were in settings with other (D)HH children, adolescents and adults, their school and social subscale ratings might have been positively influenced. The (D)HH adolescents in Overgaard et al.'s (2021) study were older than the (D)HH children and adolescents included in our study. As age and QoL are negatively correlated (Jozefiak et al., 2009; Pardo-Guijarro et al., 2015; Aanonsen et al., 2018), this is likely to have impacted their ratings. In accordance with some studies, the parents rated their (D)HH children and adolescents' QoL as lower than parents of TH children and adolescents (Fellinger et al., 2008; Haukedal et al., 2018; Haukedal et al., 2022; Overgaard et al., 2021). As explanations for these observed differences between informants, the subjective and less observable aspects of QoL have been suggested as well as possible communication problems or differences in perspective (Fellinger et al., 2008; Pardo-Guijarro et al., 2015; Warner-Czyz et al., 2009). Upton et al. (2008) found that parents of TH children

from community samples report higher QoL than their TH children, whereas parents of TH children from clinical samples report lower QoL than their children. It may therefore seem that differences observed between TH parents and their DHH children can be understood within this framework.

We found associations between mental health and communicative competence. Associations were only found for the parent-report of mental health. A possible explanation for the differences in associations between communicative competence and other language measures might be that spoken and sign language skills are based on the sum of two single-item scales. They are, therefore, very rough measures and might not distinguish well between different levels of language skills. The high mean average score and small standard deviation on spoken language skills support this hypothesis. Parents may also overestimate their (D)HH children's spoken language skills on these single-item scales. On measures of communicative competence, however, parents rated their DHH children and adolescents at the 8<sup>th</sup> percentile and HH at the 16<sup>th</sup> percentile (Bishop, 2011), respectively, compared to TH norms indicating a significant delay compared to their TH peers. Others have also found associations between both sign and spoken language skills and parent-reported mental health (Dammeyer, 2010; Hintermair & Korneffel, 2013; Stevenson et al., 2010; Theunissen, Rieffe, Kouwenberg, et al., 2014; VanOrmer et al., 2019). Associations between communicative competence and QoL were also found for parent-reported QoL only. Positive associations like these have also been reported for spoken (Haukedal et al., 2020; Haukedal et al., 2018; Haukedal et al., 2022) and sign language skills (Kushalnagar et al., 2011) in some studies. Several authors point out the difficulties in assessing (D)HH children and adolescents' communication and language. Early studies have focused mainly on the acquisition of vocabulary or other standardized tests conducted in one-to-one settings, not representing language use in real-life settings. Several authors, however, now stress the importance of assessing social communication, including pragmatic and nonverbal skills (Crowe & Dammeyer, 2021; Haukedal et al., 2022; Holzinger et al., 2020; Kermit, 2010)}. The necessity to do so is supported by Yoshinaga-Itano et al.'s (2015) study that (D)HH with age-appropriate vocabulary still were delayed in their pragmatic language skills. Inclusion criteria for samples vary across studies regarding cognitive ability, mode of communication, additional disability, parental SES, aetiology of HL, which makes it challenging to conclude.

### 5.3 Strengths and limitations

A major strength of this thesis is the representative sample of signing DHH children and adolescents from central and northern Norway, even though it is small. Further strengths are the use of well-established and validated generic measures for mental health and QoL and their translation into NSL based on thorough procedures while taking linguistic and cultural aspects into account. The validated NSL-versions of the SDQ and ILC are now available free of charge for clinical and research purposes according to agreements with the copyright holders. Moreover, the SDQ has been used in several studies on (D)HH children and adolescents' mental health as well as in a meta-analysis (Stevenson et al., 2015), which enabled us to compare our findings. Further, using the SDQ and ILC with both self- and parent-report ensured a multi-informant perspective and provided access to self-reported QoL as a "gold" standard for QoL research. Besides, including measures of communicative competence and non-verbal cognitive ability, as well as information about aetiology and degree of HL, age at detection, additional disabilities, and type of school, provided a thorough description of the participants. A strength of paper III is the comparison of a DHH and HH sample, as research on HH children and adolescents with less severe HL is especially scarce. As we did not exclude (D)HH children and adolescents with additional disabilities or low cognitive functioning, our samples are representative of the heterogeneity in the (D)HH population. It could, however, be argued that the heterogeneity is a limitation as it makes it more challenging to conclude due to the complexity of variables affecting outcomes.

A major limitation is the small sample size owing to the small Norwegian population and the low prevalence of moderate to profound PCHL. The small sample size affected the choice of statistical analyses, as well as statistical precision and generalisability. Measures were taken to compensate for this, such as including PLS-SEM for analysis of factor structure and providing 95%-CIs. The need to limit the number of variables because of the small sample size also hindered the analyses of subscales on both the SDQ and ILC in study III. These subscales could have provided valuable insight into important subdomains such as school, friends and physical health (Fellinger et al., 2008; Haukedal et al., 2020; Haukedal et al., 2018). Another issue concerning our sample is the overrepresentation of girls, especially in studies I and II, as gender is associated with score differences for mental health and QoL and might have influenced our results. Therefore, age and gender were included as covariates

in paper III. In paper I, independent sample t-tests demonstrated no gender differences for either total scores or subscale scores on the SDQ. In paper II, however, girls were found to rate their QoL significantly lower than boys on the written ILC. As the (D)HH children and adolescents did not rate their QoL significantly lower than TH peers, this does not seem to have affected the results. Yet another issue related to our sample is the low response rate of 16% in the sample recruited by post through the audiology department, compared to 96% for the other HH sample and 87% for the DHH sample. A possible reason for this is that several non-responders might already have been included while attending deaf school or the course at Statped. Another reason could be that parents received invitations to participate in another national study on mental health and QoL in (D)HH children around the same time using some of the same measures. They might have either thought they had participated already or felt overwhelmed by the number of invitations.

A further limitation is the amount of time passed since data were collected between 2016 and 2018. In the meantime, several factors have changed that might influence mental health and QoL outcomes. The deaf school has been re-organised after data collection with part-time students no longer attending school in the same building as the full-time students, hereby no longer having the same access to other signing peers. The pandemic has also impacted the mental health of both TH and (D)HH children and adolescents (Wright, H., et al., 2021). The results of our study are, therefore, not representative of (D)HH children's current situation.

For study III, the lack of a group of matched TH children and adolescents for comparison is another limitation. In addition, the data of the TH samples we used for comparison were collected 12 and 15 years before our study, respectively, for the ILC and SDQ. Again, this might have caused secular effects. However recent research (Jozefiak et al., in press) showed stable QoL on the ILC over a span of 13 years in TH Norwegian adolescents.

Concerning the translation of the ILC and SDQ, a major limitation is the lack of including (D)HH children in the focus group. With the considerable heterogeneity in mind regarding sign language skills, it was especially challenging to reach a consensus on a version that would be accessible to as many of the (D)HH children and adolescents as possible. Including (D)HH children and adolescents with varying NSL skills in the focus group could

have supported this process. It might also have helped shed light on the lack of associations between the written and NSL child versions of the ILC or avoid it altogether. Unfortunately, including (D)HH children and adolescents in the focus group would have excluded them from participation in our study, further reducing the number of potential participants in this small population. Establishing a focus group at this point to re-examine the child versions of the ILC is, however, highly recommended.

In addition, all assessment of language and communicative competence was parent-reported. As almost all parents in our sample were TH, they started with NSL acquisition at the same time as their DHH children. As DHH children's sign language skills often are better than their parents, this might have led to the parents overestimating their children's NSL skills. We tried to compensate for this by collecting teacher-reports from the children's local mainstream schools and the deaf school. We thought that teachers at the deaf school were less likely to overestimate the DHH children's sign language skills. Unfortunately, the participation of teachers was too low to be able to use these data. Information about the DHH children's preferred language should have been assessed not only based on parent-report, but on self-report, as parents' own hearing status might have influenced their choice. The DHH children's language choice is also likely to have varied across different settings (Arnesen et al., 2008).

A further limitation is the use of single-item scales (CAP, SIR, SUS and SPS) to assess spoken and sign language skills. Interrater reliability is the only psychometric property reported for CAP, SIR and SPS, while criterion validity was explored for SUS. As other researchers have emphasised the need for assessment of both pragmatic aspects as well as social communication, we attempted to develop a version of the CCC-2 tailored to assessing communicative competence in NSL. After more thorough consultation of linguists specialised in NSL and BSL, this was deemed impossible because of inherent differences in modality. In addition, difficulties in literacy in (D)HH children have been reported (Harris et al., 2017; Marschark et al., 2009) and may have impacted the participants' scores on the written self-reports. As we did not include literacy assessment in our study, this cannot be addressed.

Another methodological limitation is the lack of a gold standard to establish criterion validity for the SDQ-NSL and ILC-NSL. As there are no other validated measures of mental

health or QoL in NSL, we would have had to conduct a clinical assessment with or without a structured diagnostic interview to establish a gold standard for mental health. Although this would also have enabled us to establish both point and lifetime prevalence of psychiatric disorders, this was not possible due to time constraints.

Moreover, the short test-retest interval between administration of the written and NSL measures might have created a bias as participants may have remembered their answers. We tried to handle this by the randomised order of administration. However, the presentation of the measures in two different modalities may have reduced the risk of bias. During administration, several of the participants suggested that their stay at the deaf school had an impact on items related to friends, school and activities. Therefore, our results may not reflect the actual situation of (D)HH children and adolescents while they are in mainstream settings. To better understand this possible effect, one could collect data both during their stay at the deaf school and in their mainstream setting in a future study.

Another limitation is the lack of medical journals, including audiograms or registry data, to provide more reliable information on aetiology and degree of HL, age at detection and additional disabilities. Therefore, background information in this study is based on parent-report only and might not be exact.

## **5.4 Practical and clinical implications**

### **5.4.1 Early intervention**

The elevated prevalence of mental health problems in (D)HH children and adolescents, found in both our and other studies (Fellinger, Holzinger, Sattel, et al., 2009; Stevenson et al., 2015; van Gent et al., 2007), emphasises the need for early intervention and prevention as well as intervention targeting other developmental areas in addition to language acquisition (Holzinger et al., 2021; Wright, Hargate, et al., 2021). The importance of communication for mental health and QoL is confirmed in our study III (Dammeyer, 2010; Theunissen, Rieffe, Kouwenberg, et al., 2014). Moreover, the influence of factors such as access to sign language and deaf environment, aetiology of HL, and additional disabilities have been discussed. Holzinger et al. (2021) propose a conceptual model that encompasses the complexity of development in (D)HH children, including child characteristics, biological

factors related to HL, parent-child interactions and communication based on the understanding of developmental psychopathology (Figure 9).

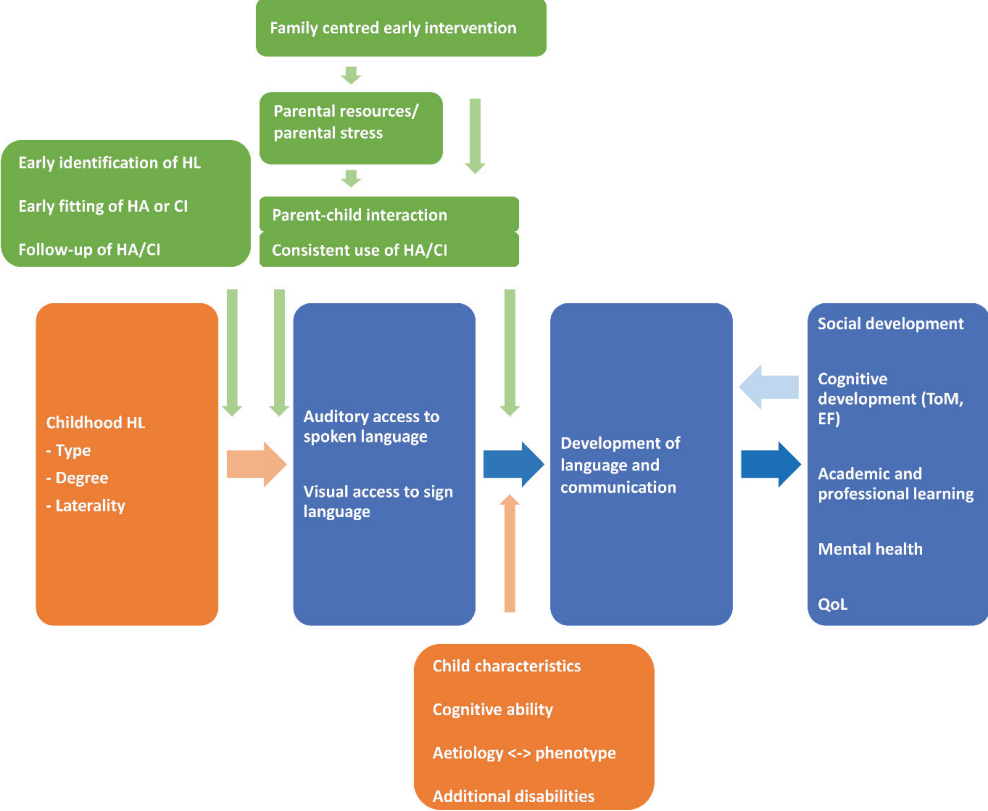


Fig. 9. Conceptual model for influences on language and overall development in (D)HH children. Translated and adapted from Holzinger et al. (2021)

In addition to the complexity of factors and outcomes, the model points to the malleable factors to improve outcomes, highlighted in green. Holzinger et al. (2021) emphasise early access to language, which is as unrestricted as possible, as the most influential factor. To ensure positive outcomes for the overall development, the authors focus on early amplification and access to sign language at an age-appropriate level according to their cognitive level. While some studies have pointed to parents' SES as an important factor for language development, a meta-analysis found that parents' SES was only mildly



associated with (D)HH children's language development, whereas parents' use of higher-level facilitative language techniques was (Holzinger et al., 2020). Therefore, parent-child interactions are of particular importance and should be supported by early intervention tailored to the individual family's needs. Factors to be kept in mind for this are parents' own needs and access to both private and systemic support. This, in turn, can ensure parents' emotional availability and sensitivity to improve parent-child interactions and benefit the child's emotional development as well. Wright, Hargate, et al. (2021) emphasise the need to address socio-emotional development and parent-child interactions especially in early intervention as a lot of early intervention is tailored solely towards language acquisition.

Other factors influencing children and parents within the microsystem are preschool and school settings. Mainstream and deaf schools will provide different settings for access to deaf peers, (D)HH role models and communication in both spoken and sign language. This, in turn, is likely to influence language acquisition, social communication and development, and identity. Several researchers have pointed to school, peers and physical health being arenas where (D)HH children and adolescents report lower scores than in TH children. Our (D)HH participants reporting similar QoL compared to TH peers while data were collected in settings with other (D)HH children and adolescents, is in contrast to (D)HH children reporting lower QoL in other Norwegian studies (Haukedal et al., 2020; Overgaard et al., 2021). Data in the other two Norwegian studies, however, were collected in mainstream settings. This emphasises the importance of school and social settings for QoL outcomes in (D)HH children and adolescents. Attitudes and ideologies in the macro-system will impact schools, parents, and children. An example is the recognition of sign languages as natural languages. Consequently, there is an increasing number of countries that have recognised their national sign language as an official language. However, almost all research presented has been conducted in western countries so far. A culture's understanding of HL as a punishment or something shameful will seriously affect parent-child interactions in some countries or cultures. Therefore, gaining insight into parents' beliefs and attitudes is an essential part of tailoring early intervention to the individual child and family's needs.

Another example of attitudes affecting developmental outcomes is the ongoing debate on whether early intervention for (D)HH children with CI should include learning sign language. Parents will meet professionals with opposing views while trying to make their

own decisions that will affect their child's future. So far, no systematic reviews or meta-analyses have concluded that sign language has a negative impact on spoken language acquisition. In fact, several authors have emphasised the unrestricted access to sign language as a visual language, hereby ensuring age-appropriate language and psychosocial development. Besides, in intervention programmes, it is important to enhance the joy of communication in parent-child interactions, which will improve socio-emotional development and attachment, not only the acquisition of vocabulary in spoken and sign language. To ensure positive overall outcomes, not only spoken language outcomes, professionals should work towards a consensus on intervention. A consensus would also reduce the burden placed on parents in their decision making.

Another aspect for consideration is the involvement of fathers in intervention. Parent organisations and practitioners have pointed out the importance of including fathers and the challenge of engaging fathers in intervention (Panter-Brick et al., 2014; Pedersen & Olthoff, 2019). They also point to the lack of studies on the topic and encourage considering alternatives to traditional home visits and programmes as well as ensuring that fathers are included in appointments, and their participation acknowledged during these (Hintermair & Sarimski, 2018; Panter-Brick et al., 2014; Pedersen & Olthoff, 2019). Access to FCEI should be provided to (D)HH children and their families independent of severity of HL as consequences for mental health and QoL are just as severe for (D)HH children with mild to moderate HL (Holzinger et al., 2020; Laugen et al., 2016). Haukedal et al. (2020) have reported that only 1 in 4 parents of HH received regular support. Regular follow-up of (D)HH children's language acquisition (with an emphasis on pragmatic language and social communication), socio-emotional and cognitive development, mental health and QoL should be carried out. Assessment of pragmatic skills should be carried out in natural conversational settings with an observational approach, while taking into account differences in the (D)HH children's conversational partners' conversation skills (Crowe & Dammeyer, 2021). The validation of the SDQ and ILC in written Norwegian and NSL enables the use of these measures to facilitate early intervention based on both self- and parent-reported mental health and QoL. This would provide an opportunity to target areas of concern early on and prevent further negative development.

#### **5.4.2 Practical and clinical implications**

Problems in assessing and treating (D)HH children and adolescents due to the complexity that requires linguistic, cultural, audiological and systemic knowledge have been mentioned previously. These can also result in late or misdiagnosis. Signing DHH children report fewer symptoms and less differentiated symptoms on written measures than sign language measures. This emphasises the need for assessment based on measures in sign language.

This study confirmed the elevated prevalence of mental health problems found in other countries for Norwegian DHH and HH children and adolescents. The prevalence of mental health problems in our study is similar to the number of (D)HH children and adolescents referred to CAMHS (Oerbeck et al., 2021). Oerbeck et al. (2021) also found (D)HH children to be referred earlier than their TH peers and diagnosed with anxiety disorders more frequently, although few were referred for anxiety disorders. The combination of elevated prevalence, the need for expertise and challenges in assessment are the main reasons for specialised mental health services advocated by several researchers and practitioners (Kuenburg et al., 2016; van Gent et al., 2012).

However, in the Netherlands and Norway, specialised services receive fewer referrals than expected based on the prevalence reported in this study. It is, therefore, essential to close the gap between the number of referrals to general CAMHS and specialised CAMHS. This would ensure that (D)HH children and adolescents receive the assessment and treatment they need. Possible steps that could be taken are the following: ensure that professionals from the regional deaf CAMHS are present at deaf schools on a regular basis, are present in parent education and early intervention, attend conferences for professionals from the general CAMHS to present services, and accept direct referrals to regional deaf CAMHS from teachers, parents and adolescents. Being present at deaf schools on a regular basis would let (D)HH children and adolescents drop in and provide teachers with an opportunity to discuss cases and ensure timely referral, assessment and treatment when needed. It could also help reduce stigma (D)HH children and adolescents might experience related to visiting CAMHS due to lower health literacy.

Although the national deaf CAMHS have made several attempts at visiting general CAMHS across the country, this has not had an impact on referrals to our services yet.

Attending the national CAMHS conference annually and being allocated time for presentation in plenary sessions might have an effect. Due to the significant turnover of professionals in general CAMHS, efforts to promote the specialised services need to be repeated regularly. Accepting referrals directly from (D)HH adolescents, their families and teachers may lead to earlier referrals with less severe symptoms and better prognosis. This could also compensate for lower health literacy among (D)HH people. Co-operating more with the Norwegian association of the deaf and the Norwegian association for the hard of hearing and being present in other deaf arenas would be another way to increase visibility.

Heiling and Eidevall (2011) have pointed out the vulnerability of small specialised CAMHS. Insufficient funding of the regional deaf CAMHS needs to be addressed as today these services are marginal and vulnerable in both Norway and other European countries apart from a few exceptions. One should look to the national deaf CAMHS established in the UK over the past 15 years to ensure sufficient availability and resources to follow up on all these suggestions. Less vulnerable services would also provide better opportunities for the training of new staff.

The validated NSL measures of QoL and mental health are recommended for regular assessment in (D)HH children and adolescents in both school and community settings. The video format enables local use independent of the administrators sign language skills. Even though the SDQ-NSL and SDQ-NOR can be used for early identification of (D)HH children and adolescents at risk, they cannot substitute diagnostic assessment or more specific instruments. Therefore, one should design better instruments for assessing mental health problems in (D)HH children and adolescents tailored to settings and challenges unique to (D)HH children. As this is time-consuming and requires access to a larger population for validation, it should be carried out across services in several countries and culturally adapted to each country. The lack of validated measures to assess pragmatic and communication skills in NSL in (D)HH is a challenge for assessment of overall language development as well as potential language disorders and differential diagnosis. This should be addressed as soon as possible. Looking to recent measures for assessing different aspects of BSL and adapting these to NSL might be a possibility. Regarding QoL, it is necessary to repeat that assessing QoL in (D)HH children and adolescents in both community and clinical settings has to be

based on self-report. It is the only authentic measure due to the subjective nature of QoL. Parent-report can be used as supplementary information only.

Furthermore, steps should be taken to ensure that the Norwegian government follows up on their stated intention of incorporating the CRPD (United Nations Convention on the Rights of Persons with Disabilities, 2006) into Norwegian law. Securing ratification of the optional protocol would grant Norwegians the right to submit a complaint to the CRPD committee when these rights are violated. In addition, the incorporation of the CRPD would strengthen (D)HH children and adolescents' rights regarding equal access to health services, education in sign language, and participation in cultural and leisure activities.

## **5.5 Future research**

There is a severe lack of longitudinal studies on mental health and QoL in (D)HH children and adolescents. Risk and protective factors reported in all studies referred here are based on cross-sectional studies. Therefore, it is not possible to come to a conclusion regarding the causality of factors. Longitudinal studies need to be carried out to address this. As the prevalence of PCHL is relatively low, national and multi-national studies should be encouraged to ensure large enough samples, especially when considering attrition. To draw conclusions for the whole population of (D)HH children and adolescents, it is necessary to include children with multiple disabilities (deafPLUS) and children from differing cultural backgrounds and parental SES. Large longitudinal national and multi-national studies with heterogeneous samples would allow analysis of group differences as well as making predictions for developmental outcomes for the whole (D)HH population. The planned Norwegian registry for HL in (D)HH children and adolescents should be put in place as soon as possible. This will provide the opportunity to recruit representative national samples in future studies.

Validated measures in sign and written language need to be included in studies and should assess not only mental health and QoL but also pragmatic skills, social communication, and literacy. In addition, information on type, aetiology and severity of HL needs to be collected, preferably based on patient registry or medical records. Previously QoL in audiology settings was often assessed based on ad-hoc-measures. The use of generic QoL measures has increased over the past years; a lot of the studies, however, have assessed QoL based on parent-report only. More studies on self-reported QoL are, therefore, needed.

Several researchers have also addressed the need to examine subdomains of QoL for (D)HH children and adolescents. These include physical health, school settings and relations to peers.

The majority of studies on risk and protective factors for mental health problems in (D)HH children and adolescents cited in this thesis have reported associations between mental health and static factors such as cognitive functioning, additional disabilities, aetiology of HL, etc. Future studies need to examine malleable protective factors that can be targeted and included in early intervention. As 63% to 74% of all (D)HH children and adolescents in our study reported good mental health a starting point could be to assess potential protective factors that are malleable in this group.

Most of the existing studies on mental health in (D)HH children and adolescents are based on questionnaires. More studies using diagnostic structured or semi-structured interviews are needed to gain insight into specific disorders and their developmental path in (D)HH children and adolescents. The importance of positive parent-child interaction and communication for overall development has been addressed previously in this thesis. However, there are very few studies on family functioning in families of (D)HH children and adolescents, which should also be addressed.

Conducting longitudinal multi-national studies with heterogeneous samples, generic measures, and medical records would allow Structural Equation Modelling-analyses that reflect the complexity and interaction of factors in this field. To ensure the necessary knowledge in this complex field, studies should be carried out by multi-disciplinary teams, including psychologists, psychiatrists, otolaryngologists, linguists and educationalists. (D)HH children and their parents, deaf professionals and service users should be included when designing future studies and interpreting results.

Multi-national and multi-disciplinary studies could help to work towards a consensus regarding intervention ensuring optimal overall development for (D)HH children. The last systematic reviews and meta-analyses addressing mental health in (D)HH children were published seven to eight years ago. Several studies have been published since, and new systematic reviews and meta-analyses are therefore needed.

## 6 Conclusion

The self-report version of the SDQ and ILC were successfully translated into NSL, taking into account linguistic and cultural aspects specific to translations from written to visual language. The copyright holders approved the SDQ-NSL and ILC-NSL, now available free of charge. The reliability and validity of the SDQ-NSL and ILC-NSL are acceptable and similar to the original versions and other translations. However, the lack of associations between the two language versions of the child ILC needs to be examined. Establishing a focus group with young children is recommended to address this issue.

DHH and HH children and adolescents and their parents reported more mental health problems than TH children and their parents. Moreover, the prevalence of self-reported mental health problems in the clinical range was about twice as high for DHH and HH children and adolescents as their TH peers. The SDQ-NSL seemed to differentiate better between mental health problems in the normal, borderline and clinical range for DHH children and adolescents than the SDQ-NOR. (D)HH children and adolescents reporting similar QoL to their TH peers is a positive indication of their overall experience of life despite challenges related to communication and HL. Associations between parent-reported communicative competence and parent-reported mental health and QoL indicate the importance of communication. However, future studies need to address social communication and pragmatic skills in both spoken and sign language and their associations with mental health and QoL.

Specialised CAMHS need to become more accessible by increasing visibility and by establishing more robust services, which requires more funding. Specialised CAMHS are necessary to ensure timely and correct assessment and treatment of (D)HH children and adolescents and provide equal access to mental health services. Developing validated language and communication measures for assessing both spoken and sign language in (D)HH children is necessary for examining co-morbidity and improving future research. To address the complex interactions of protective and risk factors and compensate for the low prevalence of PCHL, longitudinal and multi-national studies are needed.





## 7 References

- Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity [Peer Reviewed]. *Psychological Bulletin*, 101(2), 213-232. <https://doi.org/10.1037/0033-2909.101.2.213> 3562706
- Achenbach, T. M., & Rescorla, L. (2001). *Manual for the ASEBA school-age forms & profiles: child behavior checklist for ages 6-18, teacher's report form, youth self-report : an integrated system of multi-informant assessment*. ASEBA.
- Ainsworth, M. S., & Bowlby, J. (1991). An ethological approach to personality development. *American Psychologist*, 46(4), 333-341. <https://doi.org/10.1037/0003-066X.46.4.333>
- Aitken, M., Martinussen, R., Wolfe, R. G., & Tannock, R. (2015). Factor Structure of the Strengths and Difficulties Questionnaire in a Canadian Elementary School Sample. *Assessment for Effective Intervention*, 40(3), 155-165. <https://doi.org/10.1177/1534508414560347>
- Akselberg, E. T., Karlsen, J., Valand, S., & Torkildsen, J. v. K. (2021). Hvor godt kan CELF-4 og CCC-2 identifisere utviklingsmessige språkforstyrrelser? *Norsk Tidsskrift for Logopedi*, 2.
- Allen, C., Nikolopoulos, T. P., Dyar, D., & O'Donoghue, G. M. (2001). Reliability of a rating scale for measuring speech intelligibility after pediatric cochlear implantation. *Otology & Neurotology*, 22(5), 631-633. <https://doi.org/10.1097/00129492-200109000-00012>
- Anderson, V., Anderson, P., Grimwood, K., & Nolan, T. (2004). Cognitive and executive function 12 years after childhood bacterial meningitis: effect of acute neurologic complications and age of onset. *Journal of Pediatric Psychology*, 29(2), 67-81. <http://www.ncbi.nlm.nih.gov/pubmed/15096529>
- Anderson, V., Bond, L., Catroppa, C., Grimwood, K., Keir, E., & Nolan, T. (1997). Childhood bacterial meningitis: impact of age at illness and acute medical complications on long term outcome. *Journal of the International Neuropsychological Society*, 3(2), 147-158. <http://www.ncbi.nlm.nih.gov/pubmed/9126856>
- Andrews, J. F., Leigh, I., & Weiner, M. T. (2004). *Deaf people : evolving perspectives from psychology, education and sociology*. Allyn and Bacon.
- Anmyr, L., Larsson, K., Olsson, M., & Freijd, A. (2012). Strengths and difficulties in children with cochlear implants--comparing self-reports with reports from parents and teachers. *International Journal of Pediatric Otorhinolaryngology*, 76(8), 1107-1112. <https://doi.org/10.1016/j.ijporl.2012.04.009>
- Arbeiderpartiet, & Senterpartiet. (2021). *Hurdalsplattformen. For en regjering utgått fra arbeiderpartiet og senterpartiet 2021-2025* <https://www.regjeringen.no/contentassets/cb0adb6c6fee428caa81bd5b339501b0/no/pdfs/hurdalsplattformen.pdf>
- Archbold, S., Lutman, M. E., & Marshall, D. H. (1995). Categories of auditory performance. *Annals of Otology, Rhinology, and Laryngology. Supplement*, 166, 312-314. <http://www.ncbi.nlm.nih.gov/pubmed/7668685>
- Archbold, S., Lutman, M. E., & Nikolopoulos, T. (1998). Categories of Auditory Performance: Inter-User Reliability. *British Journal of Audiology*, 32(1), 7-12. <https://doi.org/10.3109/030053640000000045>
- Arnesen, K., Enerstvedt, R. T., Engen, E. A., Engen, T., Høie, G., & Vonen, A. M. (2008). The linguistic milieu of Norwegian children with hearing loss. *American Annals of the Deaf*, 153(1), 65-77. <https://doi.org/10.1353/aad.0.0000>
- Bailes, C. N., Erting, C. J., Erting, L. C., & Thumann-Prezioso, C. (2009). Language and Literacy Acquisition through Parental Mediation in American Sign Language. *Sign Language Studies*, 9(4), 417-456,483. <https://doi.org/http://dx.doi.org/10.1353/sls.0.0022>
- Baines, D., Patterson, N., & Austen, S. (2010). An Investigation Into the Length of Hospital Stay for Deaf Mental Health Service Users. 179-184. <https://doi.org/10.1093/deafed/enq003>
- Basilier, T. (1964). Surdophrenia. The psychic consequences of congenital or early acquired deafness. Some theoretical and clinical considerations. *Acta Psychiatrica Scandinavica*, 39(S180), 363-372. <https://doi.org/10.1111/j.1600-0447.1964.tb04948.x>
- Basilier, T. (1973). *Hearing loss and original deafness in a socialpsychiatric perspective. [Hørselstap og egentlig døvhet i sosialpsykiatrisk perspektiv]*. Universitetsforlaget. <https://www.nb.no/nbsok/nb/c7ff149ce750e57b0f7b18bfe4a7d43b?lang=no#7>

- Bastiaansen, D., Koot, H. M., & Ferdinand, R. F. (2005). Psychopathology in children: improvement of quality of life without psychiatric symptom reduction? *European Child and Adolescent Psychiatry*, *14*(7), 364-370. <https://doi.org/10.1007/s00787-005-0481-8>
- Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(24), 3186–3191. <https://doi.org/10.1097/00007632-200012150-00014>
- Bedore, L. M., Peña, E. D., García, M., & Cortez, C. (2005). Conceptual versus monolingual scoring: when does it make a difference? *Lang Speech Hear Serv Sch*, *36*(3), 188-200.
- Bishop, D. (2011). *The Children's Communication Checklist - Second Edition. Norwegian Version*. Åtta.45 Tryckeri AB.
- Bishop, D. V. (1998). Development of the Children's Communication Checklist (CCC): a method for assessing qualitative aspects of communicative impairment in children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *39*(6), 879-891. <https://doi.org/10.1111/1469-7610.00388>
- Bishop, D. V. M. (2003). *The Children's Communication Checklist - 2*. Psychological Corporation.
- Black, P. A., & Glickman, N. S. (2006). Demographics, Psychiatric Diagnoses, and Other Characteristics of North American Deaf and Hard-of-Hearing Inpatients. *Journal of deaf studies and deaf education*, *.11*(3), 303-321. <https://doi.org/10.1093/deafed/enj042>
- Boudewyns, A., van den Ende, J., Declau, F., Wuyts, W., Peeters, N., Brandt, A. H. D., & Van Camp, G. (2020). Etiological Work-up in Referrals From Neonatal Hearing Screening: 20 Years of Experience. *Otology & Neurotology*, *41*(9), 1240-1248. <https://doi.org/10.1097/mao.0000000000002758>
- Bowlby, J. (1969). *Attachment and loss: vol. 1: Attachment (Vol. no. 79)*. Hogarth Press.
- Bronfenbrenner, U. (1979). *The ecology of human development : experiments by nature and design*. Harvard University Press.
- Brown, A. S., Cohen, P., Greenwald, S., & Susser, E. (2000). Nonaffective psychosis after prenatal exposure to rubella. *The American Journal of Psychiatry*, *157*(3), 438-443. <https://doi.org/10.1176/appi.ajp.157.3.438>
- Bussé, A. M. L., Hoeve, H. L. J., Nasserinejad, K., Mackey, A. R., Simonsz, H. J., & Goedegebure, A. (2020). Prevalence of permanent neonatal hearing impairment: systematic review and Bayesian meta-analysis. *International Journal of Audiology*, *59*(6), 475-485. <https://doi.org/10.1080/14992027.2020.1716087>
- Butcher, E., Dezateux, C., Cortina-Borja, M., & Knowles, R. L. (2019). Prevalence of permanent childhood hearing loss detected at the universal newborn hearing screen: Systematic review and meta-analysis. *PLoS One*, *14*(7), e0219600. <https://doi.org/10.1371/journal.pone.0219600>
- Byers-Heinlein, K., & Lew-Williams, C. (2013). Bilingualism in the Early Years: What the Science Says. *LEARNING landscapes*, *7*(1), 95-112.
- Caluraud, S., Marcolla-Bouchetemplé, A., de Barros, A., Moreau-Lenoir, F., de Sevin, E., Rerolle, S., Charrière, E., Lecler-Scarcella, V., Billet, F., Obstoy, M.-F., Amstutz-Montadert, I., Marie, J.-P., & Lerosey, Y. (2015). Newborn hearing screening: Analysis and outcomes after 100,000 births in Upper-Normandy French region. *International Journal of Pediatric Otorhinolaryngology*, *79*(6), 829–833. <https://doi.org/10.1016/j.ijporl.2015.03.012>
- Carlson, S. M., & Meltzoff, A. N. (2008). Bilingual experience and executive functioning in young children. *Developmental Science*, *11*(2), 282-298. <https://doi.org/https://doi.org/10.1111/j.1467-7687.2008.00675.x>
- Chmiel, R., Sutton, L., & Jenkins, H. (2000). Quality of Life in children with cochlear implants. *Annals of Otology, Rhinology and Laryngology*, *109*, 103-105. <https://doi.org/https://doi.org/10.1177%2F0003489400109S1245>
- Chovaz, C. (2017). Mental Health Care of Deaf People. *Psynopsis*, *39*(3).
- Cicchetti, D., & Rogosch, F. A. (2002). A developmental psychopathology perspective on adolescence. *Journal of Consulting and Clinical Psychology*, *70*(1), 6-20. <https://doi.org/10.1037//0022-006x.70.1.6>
- Conijn, J. M., Smits, N., & Hartman, E. E. (2020). Determining at What Age Children Provide Sound Self-Reports: An Illustration of the Validity-Index Approach. *Assessment*, *27*(7), 1604-1618. <https://doi.org/10.1177/1073191119832655>
- Cornes, A. J., & Brown, P. M. (2012). Mental health of Australian deaf adolescents: An investigation using an Auslan version of the Strengths and Difficulties Questionnaire [Peer Reviewed]. *Deafness & Education International*, *14*(3), 161–175. <https://doi.org/10.1179/1557069X12Y.0000000009>

- Cornes, A. J., Rohan, M. J., Napier, J., & Rey, J. M. (2006). Reading the signs: Impact of signed versus written questionnaires on the prevalence of psychopathology among deaf adolescents. *Australian and New Zealand Journal of Psychiatry, 40*(8), 665–673. <https://doi.org/10.1111/j.1440-1614.2006.01866.x>
- Crowe, K., & Dammeyer, J. (2021). A Review of the Conversational Pragmatic Skills of Children With Cochlear Implants. *The Journal of Deaf Studies and Deaf Education, 26*(2), 171-186. <https://doi.org/10.1093/deafed/enab001>
- Cruz, I., Quittner, A. L., Marker, C., & DesJardin, J. L. (2013). Identification of Effective Strategies to Promote Language in Deaf Children With Cochlear Implants. *Child Development, 84*, 543-559. <https://doi.org/10.1111/j.1467-8624.2012.01863.x>
- Dammeyer, J. (2010). Psychosocial development in a Danish population of children with cochlear implants and deaf and hard-of-hearing children. *Journal of deaf studies and deaf education, 15*(1), 50–58. <https://doi.org/10.1093/deafed/enp024>
- Das, V. K. (1996). Aetiology of bilateral sensorineural hearing impairment in children: a 10 year study. *Archives of Disease in Childhood, 74*(1), 8-12. <https://doi.org/10.1136/adc.74.1.8>
- De Vet, H. C. W., Terwee, C. B., Mokkink, L. B., & Knol, D. L. (2011). *Measurement in Medicine*. Clays, St. Ives plc.
- Dempster, A. P., Laird, N. M., & Rubin, D. B. (1977). Maximum Likelihood from Incomplete Data via the EM Algorithm. *Journal of the Royal Statistical Society. Series B (Methodological), 39*(1), 1-38. <http://www.jstor.org/stable/2984875>
- DesGeorges, J. (2016). Avoiding Assumptions: Communication Decisions Made by Hearing Parents of Deaf Children. *AMA J Ethics, 18*(4), 442-446. <https://doi.org/10.1001/journalofethics.2016.18.4.sect1-1604>
- DesJardin, J. L., Ambrose, S. E., & Eisenberg, L. S. (2009). Literacy skills in children with cochlear implants: the importance of early oral language and joint storybook reading. *J Deaf Stud Deaf Educ, 14*(1), 22-43. <https://doi.org/10.1093/deafed/enn011>
- DesJardin, J. L., & Eisenberg, L. S. (2007). Maternal contributions: supporting language development in young children with cochlear implants. *Ear and Hearing, 28*(4), 456-469. <https://doi.org/10.1097/AUD.0b013e31806dc1ab>
- du Feu, M., & Chovaz, C. (2014). *Mental Health and Deafness*. Oxford University Press.
- Eiser, C., & Jenney, M. (2007). Measuring quality of life. *Archives of Disease in Childhood, 92*(4), 348-350. <https://doi.org/10.1136/adc.2005.086405>
- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*(4286), 129-136. <https://doi.org/10.1126/science.847460>
- Essau, C. A., Olaya, B., Anastassiou-Hadjicharalambous, X., Pauli, G., Gilvarry, C., Bray, D., O'Callaghan, J., & Ollendick, T. H. (2012). Psychometric properties of the Strengths and Difficulties Questionnaire from five European countries. *International Journal of Methods in Psychiatric Research, 21*(3), 232–245. <https://doi.org/10.1002/mpr.1364>
- Evers, A., Hagemester, C., Høstmælingen, A., Lindley, P., Muñiz, J., & Sjöberg, A. (2013). *EFPA Review Model for the Description and Evaluation of Psychological and Educational Tests. Test Review Form and Notes for Reviewers. Version 4.2.6*. EFPA.
- Fagerland, M. W., Lydersen, S., & Laake, P. (2017). *Statistical Analysis of Contingency Tables* (1 ed.). Chapman & Hall/CRC.
- Fellinger, J., Holzinger, D., Beitel, C., Laucht, M., & Goldberg, D. P. (2009). The impact of language skills on mental health in teenagers with hearing impairments. *Acta Psychiatrica Scandinavica, 120*(2), 153-159. <https://doi.org/10.1111/j.1600-0447.2009.01350.x>
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet, 379*(9820), 1037–1044. [https://doi.org/10.1016/S0140-6736\(11\)2961143-4](https://doi.org/10.1016/S0140-6736(11)2961143-4)
- Fellinger, J., Holzinger, D., Sattel, H., & Laucht, M. (2008). Mental health and quality of life in deaf pupils. *European Child and Adolescent Psychiatry, 17*(7), 414–423. <https://doi.org/10.1007/s00787-008-0683-y>
- Fellinger, J., Holzinger, D., Sattel, H., Laucht, M., & Goldberg, D. (2009). Correlates of mental health disorders among children with hearing impairments. *Developmental Medicine and Child Neurology, 51*(8), 635–341. <https://doi.org/10.1111/j.1469-8749.2008.03218.x>
- Field, A. (2012). *Discovering statistics using IBM SPSS statistics*. SAGE Publications Ltd.

- Fitzpatrick, E. M., Hamel, C., Stevens, A., Pratt, M., Moher, D., Doucet, S. P., Neuss, D., Bernstein, A., & Na, E. (2016). Sign Language and Spoken Language for Children With Hearing Loss: A Systematic Review. *Pediatrics*, *137*(1). <https://doi.org/10.1542/peds.2015-1974>
- Folkehelseinstituttet. (2015). *Fakta om livskvalitet og trivsel hos barn og unge*. Retrieved 10/06/2015 from <http://www.fhi.no/artikler/?id=114346>
- Fornell, C., & Larcker, D. F. (1981). Structural equation models with unobservable variables and measurement error: Algebra and statistics [Article]. *Journal of Marketing Research*, *18*(3), 382–388. <https://doi.org/10.2307/3150980>
- Fortnum, H., & Davis, A. (1993). Hearing impairment in children after bacterial meningitis: Incidence and resource implications. *British Journal of Audiology*, *27*(1), 43-52. <https://doi.org/10.3109/03005369309077889>
- Fortnum, H. M., Summerfield, A. Q., Marshall, D. H., Davis, A. C., & Bamford, J. M. (2001). Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. *BMJ*, *323*(7312), 536-540. <https://doi.org/10.1136/bmj.323.7312.536>
- Frosch, C. A., Cox, M. J., & Goldman, B. D. (2001). Infant-parent attachment and parental child behavior during parent-toddler storybook interaction. *Merrill-Palmer Quarterly*, *47*(4), 445-474. <https://doi.org/10.1353/mpq.2001.0022>
- Fulcher, A., Purcell, A. A., Baker, E., & Munro, N. (2012). Listen up: children with early identified hearing loss achieve age-appropriate speech/language outcomes by 3 years-of-age. *International Journal of Pediatric Otorhinolaryngology*, *76*(12), 1785-1794. <https://doi.org/10.1016/j.ijporl.2012.09.001>
- Gallaudet Research Institute. (2013). *Regional and National Summary Report of Data from the 2011-12 Annual Survey of Deaf and Hard of Hearing Children and Youth*.
- Genesee, F. (2015). Myths about early childhood bilingualism. *Canadian Psychology/Psychologie canadienne*, *56*(1), 6-15. <https://doi.org/10.1037/a0038599>
- Glickman, N. (2007). Do you hear voices? Problems in assessment of mental status in deaf persons with severe language deprivation [Peer Reviewed]. *Journal of deaf studies and deaf education*, *12*(2), 127-147. <https://doi.org/10.1093/deafed/enm001>
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Child Psychology & Psychiatry & Allied Disciplines*, *38*(5), 581–586. <https://doi.org/10.1111/j.1469-7610.1997.tb01545.x>
- Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry*, *40*, 1337–1345. <https://doi.org/10.1097/00004583-200111000-00015>
- Grønlie, S. M. (2005). *Uten hørsel? En bok om hørselshemming*. Fagbokforlaget.
- Hair, J. F., Hult, G. T. M., Ringle, C. M., & Sarstedt, M. (2016). *A primer on partial least squares structural equation modeling* (2nd ed.). Sage.
- Hall, W. C., Levin, L. L., & Anderson, M. L. (2017). Language deprivation syndrome: a possible neurodevelopmental disorder with sociocultural origins. *Social Psychiatry and Psychiatric Epidemiology*, *52*(6), 761-776. <https://doi.org/10.1007/s00127-017-1351-7>
- Hammer, C. S., Hoff, E., Uchikoshi, Y., Gillanders, C., Castro, D. C., & Sandilos, L. E. (2014). The language and literacy development of young dual language learners: A critical review. *Early Childhood Research Quarterly*, *29*(4), 715-733. <https://doi.org/https://doi.org/10.1016/j.ecresq.2014.05.008>
- Harris, M. S., Terlektsi, E., & Kyle, F. E. (2017). Concurrent and longitudinal predictors of reading for deaf and hearing children in primary school. *Journal of deaf studies and deaf education*, *22*(2), 233–242. <https://doi.org/10.1093/deafed/enw101>
- Hualand, H., & Holmström, I. (2019). When language recognition and language shaming go hand in hand – sign language ideologies in Sweden and Norway. *Deafness & Education International*, *21*(2-3), 99-115. <https://doi.org/10.1080/14643154.2018.1562636>
- Hualand, H., Kermit, P. S., Hjulstad, J., & Ødemark, I. L. (2021). *Children and adolescents' access to sign language in the Nordic countries. A review [Barn og unges tilgang til tegnspråk i Norden. En litteraturstudie]*. Språkrådet.
- Haukedal, C. L., Lyxell, B., & Wie, O. B. (2020). Health-Related Quality of Life With Cochlear Implants: The Children's Perspective. *Ear and Hearing*, *41*(2), 330-343. <https://doi.org/10.1097/AUD.0000000000000761>

- Haukedal, C. L., von Koss Torkildsen, J., Lyxell, B., & Wie, O. B. (2018). Parents' Perception of Health-Related Quality of Life in Children With Cochlear Implants: The Impact of Language Skills and Hearing. *Journal of Speech, Language, and Hearing Research*, *61*(8), 2084-2098. [https://doi.org/10.1044/2018\\_jslhr-h-17-0278](https://doi.org/10.1044/2018_jslhr-h-17-0278)
- Haukedal, C. L., Wie, O. B., Schaubert, S. K., Lyxell, B., Fitzpatrick, E. M., & von Koss Torkildsen, J. (2022). Social communication and quality of life in children using hearing aids. *International Journal of Pediatric Otorhinolaryngology*, *152*, 111000. <https://doi.org/https://doi.org/10.1016/j.ijporl.2021.111000>
- Heiling, K. (1995). *The development of deaf children: Academic achievement levels and social processes* (Vol. 30). Signum.
- Heiling, K., & Eidevall, L. (2011). Deaf and hard-of-hearing children with mental health problems. Challenges and resources in Europe. *International Journal on Mental Health and Deafness*, *1*(1), 37-45.
- Helland, W. A., Biringner, E., Helland, T., & Heimann, M. (2009). The usability of a Norwegian adaptation of the Children's Communication Checklist Second Edition (CCC-2) in differentiating between language impaired and non-language impaired 6- to 12-year-olds [Peer Reviewed]. *Scandinavian Journal of Psychology*, *50*(3), 287-292. <https://doi.org/10.1111/j.1467-9450.2009.00718.x>
- Hindley, P. (1997). Psychiatric Aspects of Hearing Impairments. *Journal of Child Psychology and Psychiatry*, *38*, 101-117. <https://doi.org/10.1111/j.1469-7610.1997.tb01507.x>
- Hindley, P., Hill, P., & Bond, D. (1993). Interviewing deaf children, the interviewer effect: a research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *34*(8), 1461-1467. <https://doi.org/10.1111/j.1469-7610.1993.tb02103.x>
- Hindley, P. A., Hill, P. D., McGuigan, S., & Kitson, N. (1994). Psychiatric Disorder in Deaf and Hearing Impaired Children and Young People: A Prevalence Study. *Journal of Child Psychology and Psychiatry* *35*, 917-934. <https://doi.org/10.1111/j.1469-7610.1994.tb02302.x>
- Hintermair, M. (2007). Prevalence of socioemotional problems in deaf and hard of hearing children in Germany [Peer Reviewed]. *American Annals of the Deaf*, *152*(3), 320-330. <https://doi.org/10.1353/aad.2007.0028>
- Hintermair, M. (2010). Quality of life of mainstreamed hearing-impaired children-Results of a study with the Inventory of Life Quality of Children and Youth (ILC) [Peer Reviewed]. *Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie*, *38*(3), 189-199. <https://doi.org/10.1024/1422-4917/a00003220464660> (Lebensqualität integriert beschulter Kinder mit einer Hörschädigung: Ergebnisse einer Studie mit dem Inventar zur Erfassung der Lebensqualität bei Kindern und Jugendlichen (ILK). May 2010)
- Hintermair, M. (2011). Health-related quality of life and classroom participation of deaf and hard-of-hearing students in general schools. *Journal of deaf studies and deaf education*, *16*(2), 254-271. <https://doi.org/10.1093/deafed/enq045>
- Hintermair, M. (2013). Executive functions and behavioral problems in deaf and hard-of-hearing students at general and special schools. *Journal of deaf studies and deaf education*, *18*(3), 344-359. <https://doi.org/10.1093/deafed/ent003>
- Hintermair, M., & Korneffel, D. (2013). On the relationship between executive functioning and social-emotional problems of deaf and hard-of-hearing students at general schools [Peer Reviewed]. *Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie*, *41*(5), pp. <https://doi.org/10.1024/1422-4917/a000249> (Zum Zusammenhang exekutiver Funktionen und sozial-emotionaler Auffälligkeiten bei integriert beschulter Kindern mit einer Hörschädigung. )
- Hintermair, M., & Sarimski, K. (2018). Fathers of Deaf and Hard-of-Hearing Infants and Toddlers – Experiences, Needs, and Challenges. *The Journal of Deaf Studies and Deaf Education*, *24*(2), 84-94. <https://doi.org/10.1093/deafed/eny040>
- Hollund-Møllerhaug, L. (2010). Children's Communication Checklist (CCC-2): A comparison of General Communication Composite scores in Norway and the United Kingdom. *Tidsskrift for Norsk Psykologforening*, *47*(9), 824-826. (Children's Communication Checklist (CCC-2): En sammenligning av GCC-skårenes persentilfordeling i et britisk og norsk utvalg.)
- Holte, A., Barry, M. M., Bekkhus, M., Borge, A. I. H., Bowes, L., Casas, F., Friborg, O., Grinde, B., Headey, B., Jozefiak, T., Lekhal, R., Marks, N., Muffels, R., Nes, R. B., Røysamb, E., Thimm, J. C., Torgersen, S., Trommsdorff, G., Veenhoven, R., Vittersø, J., Waaktaar, T., Wagner, G. G., Wang, C. E. A., Wold, B., & Zachrisson, H. D. (2014). Psychology of Child Well-Being. In A. Ben-Arieh, F. Casas, I. Frønes, & J. E.

- Korbin (Eds.), *Handbook of Child Well-Being: Theories, Methods and Policies in Global Perspective* (pp. 555-631). Springer Netherlands. [https://doi.org/10.1007/978-90-481-9063-8\\_13](https://doi.org/10.1007/978-90-481-9063-8_13)
- Holzinger, D., Dall, M., Sanduvete-Chaves, S., Saldaña, D., Chacón-Moscoso, S., & Fellingner, J. (2020). The Impact of Family Environment on Language Development of Children With Cochlear Implants: A Systematic Review and Meta-Analysis. *Ear and Hearing, 41*(5), 1077-1091. <https://doi.org/10.1097/aud.0000000000000852>
- Holzinger, D., Hofer, J., & Dall, M. (2021). Frühe Prädiktoren der Sprachentwicklung von Kindern mit permanenter Hörstörung. *Kindheit und Entwicklung, 30*(1), 25-36. <https://doi.org/10.1026/0942-5403/a000325>
- Hooper, D., Coughlan, J., & Mullen, M. R. (2008). Evaluating model fit: A synthesis of the structural equation modelling literature. 7th European Conference on Research Methodology for Business and Management Studies, Regent's College, London, United Kingdom.
- Hooper, V. S., & Mee Bell, S. (2006). Concurrent validity of the universal nonverbal intelligence test and the Leiter international performance scale-revised. *Psychology in the Schools, 43*(2), 143-148. <https://doi.org/10.1002/pits.20136>
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives [Peer Reviewed] [Structural Equation Modeling-a Multidisciplinary Journal]. *Structural Equation Modeling-a Multidisciplinary Journal, 6*(1), 1-55. <https://doi.org/10.1080/10705519909540118>
- Huber, M., & Kipman, U. (2011). The mental health of deaf adolescents with cochlear implants compared to their hearing peers. *International Journal of Audiology, 50*(3), 146-154. <https://doi.org/10.3109/14992027.2010.533704>
- Ingber, S., & Most, T. (2012). Fathers' involvement in preschool programs for children with and without hearing loss. *American Annals of the Deaf, 157*(3), 276-288. <https://doi.org/10.1353/aad.2012.1620>
- Israelite, N., Ower, J., & Goldstein, G. (2002). Hard-of-Hearing Adolescents and Identity Construction: Influences of School Experiences, Peers, and Teachers. *J Deaf Stud Deaf Educ, 7*(2), 134-148. <https://doi.org/10.1093/deafed/7.2.134>
- Jones, P. S., Lee, J. W., Phillips, L. R., Zhang, X. E., & Jaceldo, K. B. (2001). An adaptation of Brislin's translation model for cross-cultural research. *Nursing Research, 50*(5), 300-304. <https://doi.org/10.1097/00006199-200109000-00008>
- Jozefiak, T., Larsson, B., & Wichstrom, L. (2009). Changes in quality of life among Norwegian school children: a six-month follow-up study [Research Support, Non-U.S. Gov't]. *Health & Quality of Life Outcomes, 7*, 7. <https://doi.org/10.1186/1477-7525-7-7>
- Jozefiak, T., Larsson, B., Wichstrom, L., Mattejat, F., & Ravens-Sieberer, U. (2008). Quality of Life as reported by school children and their parents: a cross-sectional survey. *Health & Quality of Life Outcomes, 6*, 34. <https://doi.org/10.1186/1477-7525-6-34>
- Jozefiak, T., Mattejat, F., & Remschmidt, H. (2012). *Inventory of Life Quality in Children and Adolescents Manual, Norwegian Version*. Hogrefe.
- Jozefiak, T., Wallander, J., & Lydersen, S. (in press). Change over 11-13 year periods in Quality of life, emotional problems and negative stressful life events among 13-17 year old students. *Child Psychiatry and Human Development*.
- Kaufman, J., Birmaher, B., Brent, D., Rao, U., Flynn, C., Moreci, P., Williamson, D., & Ryan, N. (1997). Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version (K-SADS-PL): Initial reliability and validity data. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*(7), 980-988. <https://doi.org/10.1097/00004583-199707000-00021>
- Kermit, P. S. (2010). 'Hearing' or 'Deaf'? Discussing epistemological and methodological issues related to the bioethical discourse on paediatric cochlear implantation. *Scandinavian Journal of Disability Research, 12*(2), 91-107. <https://doi.org/doi:10.1080/15017410903338838>
- Kirkehei, I., Myrhaug, H. T., Garm, N., Simonsen, E., & O, B. W. (2011). NIPH Systematic Reviews: Executive Summaries. In *Communication Modes for Children with Cochlear Implant*. Knowledge Centre for the Health Services at The Norwegian Institute of Public Health (NIPH).
- Klim, S., Andersen, G., Mortensen, O. B., Dyhr, E., & Pedersen, T. (1991). *Deaf children are children. [Døve børn er børn]*. Bonaventura.

- Koo, T. K., & Li, M. Y. (2016). A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research. *Journal of Chiropractic Medicine, 15*(2), 155–163.  
<https://doi.org/10.1016/j.jcm.2016.02.012>
- Kral, A., & O'Donoghue, G. M. (2010). Profound deafness in childhood. *New England Journal of Medicine, 363*, 1438-1450. <https://doi.org/10.1056/NEJMra0911225>
- Kristensen, H., & Hove, P. (2013). Måleegenskaper ved den norske versjonen av Inventory of Life Quality in Children and Adolescents. *PsykTestBarn, 1*(5). <https://doi.org/10.21337/0022>
- Kuenburg, A., Fellinger, P., & Fellinger, J. (2016). Health Care Access Among Deaf People. *The Journal of Deaf Studies and Deaf Education, 21*(1), 1-10. <https://doi.org/10.1093/deafed/env042>
- Kushalnagar, P., Topolski, T. D., Schick, B., Edwards, T. C., Skalicky, A. M., & Patrick, D. L. (2011). Mode of communication, perceived level of understanding, and perceived quality of life in youth who are deaf or hard of hearing. *J Deaf Stud Deaf Educ, 16*(4), 512-523. <https://doi.org/10.1093/deafed/enr015>
- Landgraf, J. M., van Grieken, A., & Raat, H. (2018). Giving voice to the child perspective: psychometrics and relative precision findings for the Child Health Questionnaire self-report short form (CHQ-CF45). *Quality of Life Research, 27*(8), 2165-2176. <https://doi.org/10.1007/s11136-018-1873-9>
- Langdon, H. W. (2015). Raising children bilingually [journal article]. *Health Psychology Report, 3*(3), 260-268. <https://doi.org/10.5114/hpr.2015.50884>
- Laugen, N. J., Jacobsen, K. H., Rieffe, C., & Wichstrom, L. (2016). Predictors of psychosocial outcomes in hard-of-hearing preschool children. *Journal of deaf studies and deaf education, 21*(3), 259-267. <https://doi.org/10.1093/deafed/enw005>
- Laugen, N. J., Jacobsen, K. H., Rieffe, C., & Wichstrom, L. (2017a). Emotion understanding in preschool children with mild-to-severe hearing loss. *Journal of deaf studies and deaf education, 22*(2), 155–163. <https://doi.org/10.1093/deafed/enw069>
- Laugen, N. J., Jacobsen, K. H., Rieffe, C., & Wichstrom, L. (2017b). Social skills in preschool children with unilateral and mild bilateral hearing loss. *Deafness & Education International, 19*(2), pp. <https://doi.org/10.1080/14643154.2017.1344366>
- le Coq, E. M., Boeke, A. J., Bezemer, P. D., Colland, V. T., & van Eijk, J. T. (2000). Which source should we use to measure quality of life in children with asthma: the children themselves or their parents? *Quality of Life Research, 9*(6), 625-636. <https://doi.org/10.1023/a:1008977200176>
- Lederberg, A. R., Schick, B., & Spencer, P. E. (2013). Language and literacy development of deaf and hard-of-hearing children: successes and challenges. *Developmental Psychology, 49*(1), 15-30. <https://doi.org/10.1037/a0029558>
- Lewis, C., & Lamb, M. E. (2003). Fathers' influences on children's development: The evidence from two-parent families. *European Journal of Psychology of Education, 18*(2), 211-228. <https://doi.org/10.1007/BF03173485>
- Liddle, K., Beswick, R., Fitzgibbons, E. J., & Driscoll, C. (2021). Aetiology of permanent childhood hearing loss at a population level. *Journal of Paediatrics and Child Health, n/a*. <https://doi.org/https://doi.org/10.1111/jpc.15738>
- Lin, F. R., & Niparko, J. K. (2006). Measuring health-related quality of life after pediatric cochlear implantation: A systematic review. *International Journal of Pediatric Otorhinolaryngology, 70*(10), 1695-1706. <https://doi.org/https://doi.org/10.1016/j.ijporl.2006.05.009>
- Lin, P.-H., Hsu, C.-J., Lin, Y.-H., Lin, Y.-H., Yang, S.-Y., Yang, T.-H., Chen, P.-L., Wu, C.-C., & Liu, T.-C. (2020). An integrative approach for pediatric auditory neuropathy spectrum disorders: revisiting etiologies and exploring the prognostic utility of auditory steady-state response. *Scientific Reports, 10*(1), 9816. <https://doi.org/10.1038/s41598-020-66877-y>
- Lu, J., Jones, A., & Morgan, G. (2016). The impact of input quality on early sign development in native and non-native language learners. *Journal of Child Language, 43*, 537-552. <https://doi.org/10.1017/S0305000915000835>
- Lund, E. (2016). Vocabulary Knowledge of Children With Cochlear Implants: A Meta-Analysis. *J Deaf Stud Deaf Educ, 21*(2), 107-121. <https://doi.org/10.1093/deafed/env060>
- Lyxell, T. (2019). *Med blick på modersmålet – om språksituationen för hörande barn till döva och modersmålsundervisningen i svensk teckenspråk*. Språkrådet.

- Marchman, V. A., Fernald, A., & Hurtado, N. (2010). How vocabulary size in two languages relates to efficiency in spoken word recognition by young Spanish–English bilinguals. *Journal of Child Language*, 37(4), 817–840. <https://doi.org/10.1017/S0305000909990055>
- Marschark, M., Convertino, C. M., Macias, G., Monikowski, C. M., Sapere, P., & Seewagen, R. (2007). Understanding communication among deaf students who sign and speak: A trivial pursuit? *American Annals of the Deaf*, 152(4), 415–424. <https://doi.org/10.1353/aad.2008.0003>
- Marschark, M., Rhoten, C., & Fabich, M. (2007). Effects of cochlear implants on children's reading and academic achievement. *Journal of deaf studies and deaf education*, 12(3), 269–282. <https://doi.org/10.1093/deafed/enm013>
- Marschark, M., Sapere, P., Convertino, C. M., Mayer, C., Wauters, L., & Sarchet, T. (2009). Are deaf students' reading challenges really about reading? *American Annals of the Deaf*, 154(4), 357–370. <https://doi.org/10.1353/aad.0.0111>
- Mason, T. C. (2005). Cross-cultural instrument translation: assessment, translation, and statistical applications. *American Annals of the Deaf*, 150(1), 67–72. <https://doi.org/10.1353/aad.2005.0020>
- Masten, A. S., & Cicchetti, D. (2010). Developmental cascades. *Development and Psychopathology*, 22(3), 491–495. <https://doi.org/10.1017/S0954579410000222>
- Mattejat, F., & Remschmidt, H. (2006). *Das Inventar zur Erfassung der Lebensqualität bei Kindern und Jugendlichen (ILK) [The Inventory of Quality of Life in Children and Adolescents ILC]* Verlag Hans Huber.
- McKee, M. M., Paasche-Orlow, M. K., Winters, P. C., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. (2015). Assessing Health Literacy in Deaf American Sign Language Users. *J Health Commun*, 20 Suppl 2(0 2), 92–100. <https://doi.org/10.1080/10810730.2015.1066468>
- Meadow-Orlans, K., & Erting, C. (2000). Deaf people in society. In P. Hindley & N. Kitson (Eds.), *Mental health and deafness* (pp. 3–24). Whurr Publishers.
- Mehmetoglu, M., & Chen, J. S. (2012). Partial Least Squares Approach to Structural Equation Modeling for Tourism Research. In *Advances in Hospitality and Leisure* (Vol. 8, pp. 43–61). [https://doi.org/10.1108/S1745-3542\(2012\)0000008007](https://doi.org/10.1108/S1745-3542(2012)0000008007)
- Mehmetoglu, M., & Jakobsen, T. G. (2017). *Applied statistics using stata*. Sage Publications Ltd.
- Mejstad, L., Heiling, K., & Svedin, C. G. (2009). Mental health and self-image among deaf and hard of hearing children. *American Annals of the Deaf*, 153(5), 504–515. <https://doi.org/10.1353/aad.0.0069>
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106(3), E43. <https://doi.org/10.1542/peds.106.3.e43>
- Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: an international consensus statement. *J Deaf Stud Deaf Educ*, 18(4), 429–445. <https://doi.org/10.1093/deafed/ent034>
- Moeller, M. P., & Schick, B. (2006). Relations between maternal input and theory of mind understanding in deaf children. *Child Development*, 77(3), 751–766. <https://doi.org/10.1111/j.1467-8624.2006.00901.x>
- Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., Bouter, L. M., & de Vet, H. C. (2010). The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology*, 63(7), 737–745. <https://doi.org/10.1016/j.jclinepi.2010.02.006>
- Mosand, N. E., & Malmquist, A. K. (1996). *Look at my language! [Se mitt språk!]*. Døves Forlag AS.
- Muris, P., Meesters, C., Eijkelenboom, A., & Vincken, M. (2004). The self-report version of the Strengths and Difficulties Questionnaire: Its psychometric properties in 8- to 13-year-old non-clinical children. *British Journal of Clinical Psychology*, 43(Part 4), 437–448. <https://doi.org/10.1348/0144665042388982>
- Nagel, A., Dimitrakopoulou, E., Teig, N., Kern, P., Lücke, T., Michna, D., Korn, K., Steininger, P., Shahada, K., Neumann, K., & Überla, K. (2020). Characterization of a universal screening approach for congenital CMV infection based on a highly-sensitive, quantitative, multiplex real-time PCR assay. *PLoS One*, 15(1), e0227143. <https://doi.org/10.1371/journal.pone.0227143>
- Neumann, K., Euler, H. A., Chadha, S., & White, K. R. (2020). A Survey on the Global Status of Newborn and Infant Hearing Screening. *The Journal of Early Hearing Detection and Intervention*, 5(2), 63–84. <https://doi.org/10.26077/a221-cc28>
- Neumann, K., Mathmann, P., Chadha, S., Euler, H. A., & White, K. R. (2022). Newborn Hearing Screening Benefits Children, But Global Disparities Persist. *Journal of Clinical Medicine*, 11(1), 271. <https://doi.org/10.3390/jcm11010271>



- Niclasen, J., Skovgaard, A. M., Andersen, A.-M. N., Sømshovd, M. J., & Obel, C. (2013). A Confirmatory Approach to Examining the Factor Structure of the Strengths and Difficulties Questionnaire (SDQ): A Large Scale Cohort Study. *Journal of Abnormal Child Psychology*, 41(3), 355-365. <https://doi.org/10.1007/s10802-012-9683-y>
- Niparko, J. K., Tobey, E. A., Thal, D. J., Eisenberg, L. S., Wang, N. Y., Quittner, A. L., & Fink, N. E. (2010). Spoken language development in children following cochlear implantation. *JAMA*, 303(15), 1498-1506. <https://doi.org/10.1001/jama.2010.451>
- Oerbeck, B., Ohre, B., Zeiner, P., Pripp, A. H., Wagner, K., & Overgaard, K. R. (2021). What can a national patient registry tell us about psychiatric disorders and reasons for referral to outpatient services in youth with hearing loss? *Nordic Journal of Psychiatry*, 1-7. <https://doi.org/10.1080/08039488.2021.1979095>
- Overgaard, K. R., Oerbeck, B., Wagner, K., Friis, S., Øhre, B., & Zeiner, P. (2021). Youth with hearing loss: Emotional and behavioral problems and quality of life. *International Journal of Pediatric Otorhinolaryngology*, 145, 110718. <https://doi.org/https://doi.org/10.1016/j.ijporl.2021.110718>
- Panter-Brick, C., Burgess, A., Eggerman, M., McAllister, F., Pruett, K., & Leckman, J. F. (2014). Practitioner Review: Engaging fathers – recommendations for a game change in parenting interventions based on a systematic review of the global evidence. *Journal of Child Psychology and Psychiatry*, 55(11), 1187-1212. <https://doi.org/https://doi.org/10.1111/jcpp.12280>
- Pardo-Guijarro, M. J., Martínez-Andrés, M., Notario-Pacheco, B., Solera-Martínez, M., Sánchez-López, M., & Martínez-Vizcaíno, V. (2015). Self-Reports Versus Parental Perceptions of Health-Related Quality of Life Among Deaf Children and Adolescents. *Journal of deaf studies and deaf education*, 20(3), 275-282. <https://doi.org/10.1093/deafed/env018>
- Pedersen, H. F., & Olthoff, J. (2019). Listen to Us: Dad-Endorsed Strategies for EHDI Professionals. *The Journal of Early Hearing Detection and Intervention*, 4(1), 62-72.
- Petitto, L. A., Katerelos, M., Levy, B. G., Gauna, K., Tétreault, K., & Ferraro, V. (2001). Bilingual signed and spoken language acquisition from birth: implications for the mechanisms underlying early bilingual language acquisition. *Journal of Child Language*, 28(2), 453-496. <https://doi.org/10.1017/s0305000901004718>
- Petitto, L. A., Zatorre, R. J., Gauna, K., Nikelski, E. J., Dostie, D., & Evans, A. C. (2000). Speech-like cerebral activity in profoundly deaf people processing signed languages: implications for the neural basis of human language. *Proceedings of the National Academy of Sciences of the United States of America*, 97(25), 13961-13966. <https://doi.org/10.1073/pnas.97.25.13961>
- Pham, N. S. (2017). The management of pediatric hearing loss caused by auditory neuropathy spectrum disorder. *Current Opinion in Otolaryngology & Head and Neck Surgery*, 25(5), 396-399. <https://doi.org/10.1097/moo.0000000000000390>
- Plimmer, C. (2018). *Translating the Strengths and Difficulties Questionnaire into American Sign Language: A pilot study* Kings's University College, Western University]. London, Ontario.
- Qi, L., Zhang, H., Nie, R., Xiao, A., Wang, J., & Du, Y. (2020). Quality of Life of Hearing-Impaired Middle School Students: a Cross-Sectional Study in Hubei Province, China. *Journal of Developmental and Physical Disabilities*, 32(5), 821-837. <https://doi.org/10.1007/s10882-019-09722-z>
- Ravens-Sieberer, U., & Bullinger, M. (1998). Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Quality of Life Research*, 7(5), 399-407. <https://doi.org/10.1023/A:1008853819715>
- Reeh, M., Kroner-Herwig, B., & Kiese-Himmel, C. (2008). Health-related quality of life in children with hearing loss in their parents' perspective. *Zeitschrift für Medizinische Psychologie*, 17(4), 161-168. <https://doi.org/info:doi/>
- Reindal, L., Brøndbo, P. H., & Jozefiak, T. (under review). Måleegenskaper ved den norske versjonen av The Children's Communication Checklist - Second Edition (CCC-2). *PsykTestBarn*.
- Rescorla, L., Achenbach, T., Ivanova, M. Y., Dumenci, L., Almqvist, F., Bilenberg, N., Bird, H., Chen, W., Dobrea, A., Döpfner, M., Erol, N., Fombonne, E., Fonseca, A., Frigerio, A., Grietens, H., Hannesdottir, H., Kanbayashi, Y., Lambert, M., Larsson, B., Leung, P., Liu, X., Minaei, A., Mulatu, M. S., Novik, T. S., Oh, K.-J., Roussos, A., Sawyer, M., Simsek, Z., Steinhausen, H.-C., Weintraub, S., Weisz, J., Metzke, C. W., Wolanczyk, T., Yang, H.-J., Zilber, N., Zukauskienė, R., & Verhulst, F. (2007). Behavioral and Emotional Problems Reported by Parents of Children Ages 6 to 16 in 31 Societies. *Journal of Emotional and Behavioral Disorders*, 15(3), 130-142. <https://doi.org/10.1177/10634266070150030101>

- Roberts, S., Wright, B., Moore, K., Smith, S., Allgar, V., Tennant, A., Doherty, C., Hughes, E., Moore, D. C., Ogden, R., Phillips, H., Beese, L., & Rogers, K. (2015). Translation into British Sign Language and validation of the Strengths and Difficulties Questionnaire. *Health Services and Delivery Research, 3*(2).  
<https://doi.org/10.3310/hsdr03020>
- Robinson, E. L., StGeorge, J., & Freeman, E. E. (2021). A Systematic Review of Father-Child Play Interactions and the Impacts on Child Development. *Children (Basel, Switzerland), 8*(5), 389.  
<https://doi.org/10.3390/children8050389>
- Roid, G. H., & Koch, C. (2017). Leiter-3: Nonverbal Cognitive and Neuropsychological Assessment. In R. S. McCallum (Ed.), *Handbook of Nonverbal Assessment* (pp. 127-150). Springer International Publishing.  
[https://doi.org/10.1007/978-3-319-50604-3\\_8](https://doi.org/10.1007/978-3-319-50604-3_8)
- Roid, G. H., Miller, L. J., Pomplun, M., & Koch, C. (2013). *Leiter International Performance Scale Manual (3rd ed.)*. Stoelting.
- Roland, L., Fischer, C., Tran, K., Rachakonda, T., Kallogjeri, D., & Lieu, J. E. (2016). Quality of Life in Children with Hearing Impairment: Systematic Review and Meta-analysis. *Otolaryngology and Head and Neck Surgery, 155*(2), 208-219. <https://doi.org/10.1177/0194599816640485>
- Rouillon, I., de Lamaze, A., Ribot, M., Collet, G., de Bollardière, T., Elmir, R., Parodi, M., Achard, S., Denoyelle, F., & Loundon, N. (2021). Auditory processing disorder in children: the value of a multidisciplinary assessment. *European Archives of Oto-Rhino-Laryngology, 278*(12), 4749-4756.  
<https://doi.org/10.1007/s00405-020-06601-8>
- Rutter, M., & Sroufe, L. A. (2000). Developmental psychopathology: concepts and challenges. *Development and Psychopathology, 12*(3), 265-296. <https://doi.org/10.1017/s0954579400003023>
- Rønning, J. A., Handegaard, B. H., Sourander, A., & Mørch, W. T. (2004). The Strengths and Difficulties Self-Report Questionnaire as a screening instrument in Norwegian community samples. *European Child and Adolescent Psychiatry, 13*(2), 73-82. <https://doi.org/10.1007/s00787-004-0356-4>
- Sameroff, A. J. (2009). *The transactional model of development : how children and contexts shape each other*. American Psychological Association.
- Sanne, B., Torsheim, T., Heiervang, E., & Stormark, K. M. (2009). The Strengths and Difficulties Questionnaire in the Bergen Child Study: A conceptually and methodically motivated structural analysis. *Psychological Assessment, 21*(3), 352-364. <https://doi.org/10.1037/a0016317>
- Sarkadi, A., Kristiansson, A., Oberklaid, F., & Bremberg, S. (2008). Fathers' involvement and children's developmental outcomes: a systematic review of longitudinal studies. *Acta Paediatrica, 97*(2), 153-158.  
<https://doi.org/https://doi.org/10.1111/j.1651-2227.2007.00572.x>
- Schick, B., Marschark, M., & Spencer, P. E. (2005). *Advances in the Sign-Language Development of Deaf Children*. Oxford University Press. <https://doi.org/DOI:10.1093/acprof:oso/9780195180947.001.0001>
- Schore, J. R., & Schore, A. N. (2008). Modern attachment theory: The central role of affect regulation in development and treatment. *Clinical Social Work Journal, 36*(1), 9-20. <https://doi.org/10.1007/s10615-007-0111-7>
- Schroeder, S. R. (2018). Do Bilinguals Have an Advantage in Theory of Mind? A Meta-Analysis. *Frontiers in Communication, 3*, 36. <https://doi.org/10.3389/fcomm.2018.00036>
- Sessa, B., & Sutherland, H. (2013). Addressing mental health needs of deaf children and their families: the National Deaf Child and Adolescent Mental Health Service. *The Psychiatrist 37*, 175-178.  
<https://doi.org/10.1192/pb.bp.112.038604>
- Siegal, M., Surian, L., Matsuo, A., Geraci, A., Iozzi, L., Okumura, Y., & Itakura, S. (2010). Bilingualism Accentuates Children's Conversational Understanding. *PloS One, 5*(2), e9004.  
<https://doi.org/10.1371/journal.pone.0009004>
- Smith, R. J., Bale, J. F., Jr., & White, K. R. (2005). Sensorineural hearing loss in children. *Lancet, 365*(9462), 879-890. [https://doi.org/10.1016/s0140-6736\(05\)71047-3](https://doi.org/10.1016/s0140-6736(05)71047-3)
- Språklova. (2021). *Lov om språk*. (LOV-2021-05-21-42). Retrieved from  
<https://lovdata.no/dokument/NL/lov/2021-05-21-42>
- Sroufe, L. A. (2013). The promise of developmental psychopathology: past and present. *Development and Psychopathology, 25*(4 Pt 2), 1215-1224. <https://doi.org/10.1017/s0954579413000576>
- Sroufe, L. A., Carlson, E. A., Levy, A. K., & Egeland, B. (1999). Implications of attachment theory for developmental psychopathology. *Development and Psychopathology, 11*(1), 1-13.  
<https://doi.org/10.1017/s0954579499001923>

- St. meld. nr. 25 (1996-97). (1997). *Åpenhet og helhet. Om psykiske lidelser og tjenestetilbudene*. Oslo: Departementenes servicesenter
- Stach, B. A. (1998). *Clinical audiology. An Introduction*. Singular Publishing Group.
- Statens helsetilsyns utredningsserie. (2001). *Tjenestetilbudene til døve med psykiske lidelser: en utredning med forslag om å styrke tilbudene fra psykisk helsevern til døve barn, ungdommer og voksne*. Oslo Retrieved from <https://www.nb.no/nbsok/nb/4b14186ab11186ab1d82f5fc310c0918#0>
- Statped. (2016). *Se mitt språk. Tegnspråkopplæring for foreldre*. Statped. <https://www.statped.no/globalassets/publikasjoner/brosjyrer-horsel/se-mitt-sprak-ver-6.pdf>
- Stevanovic, D., Jafari, P., Knez, R., Franic, T., Atilola, O., Davidovic, N., Bagheri, Z., & Lakić, A. (2017). Can we really use available scales for child and adolescent psychopathology across cultures? A systematic review of cross-cultural measurement invariance data. *Transcultural Psychiatry*, 54(1), 125-152. <https://doi.org/10.1177/1363461516689215>
- Stevenson, J., Kreppner, J., Pimperton, H., Worsfold, S., & Kennedy, C. (2015). Emotional and behavioural difficulties in children and adolescents with hearing impairment: A systematic review and meta-analysis [Peer Reviewed]. *European Child and Adolescent Psychiatry*, 24(5), 477-496. <https://doi.org/10.1007/s00787-015-0697-1>
- Stevenson, J., McCann, D., Watkin, P., Worsfold, S., Kennedy, C., & Hearing Outcomes Study, T. (2010). The relationship between language development and behaviour problems in children with hearing loss. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 51(1), 77-83. <https://doi.org/10.1111/j.1469-7610.2009.02124.x>
- Stevenson, J., McCann, D. C., Law, C. M., Mullee, M., Petrou, S., Worsfold, S., Yuen, H. M., & Kennedy, C. R. (2011). The effect of early confirmation of hearing loss on the behaviour in middle childhood of children with bilateral hearing impairment. *Developmental Medicine and Child Neurology*, 53(3), 269-274. <https://doi.org/10.1111/j.1469-8749.2010.03839.x>
- Stevenson, J., Pimperton, H., Kreppner, J., Worsfold, S., Terleksi, E., Mahon, M., & Kennedy, C. (2017). Language and reading comprehension in middle childhood predicts emotional and behaviour difficulties in adolescence for those with permanent childhood hearing loss. *Journal of Child Psychology and Psychiatry*, 59(2), 180-190. <https://doi.org/10.1111/jcpp.12803>
- Stokoe, W. C. J. (1960). Sign language structure: An outline of the visual communication system for the deaf. *Studies in Linguistics*, 8, 1-78.
- Subbiah, K., Mason, C. A., Gaffney, M., & Grosse, S. D. (2018). Progress in Documented Early Identification and Intervention for Deaf and Hard of Hearing Infants: CDC's Hearing Screening and Follow-up Survey, United States, 2006-2016. *J Early Hear Detect Interv*, 3(2), 1-7. <https://doi.org/10.26077/6sj1-mw42>
- Svensson, L., Syzdek, B. M., & Roid, G. H. (2019). Leiter-3 generalizability in Scandinavia. *Scandinavian Journal of Psychology*(Pagination). <https://doi.org/10.1111/sjop.12607>
- Taylor, H. G., Schatschneider, C., & Minich, N. M. (2000). Longitudinal outcomes of Haemophilus influenzae meningitis in school-age children. *Neuropsychology*, 14(4), 509-518. <http://www.ncbi.nlm.nih.gov/pubmed/11055253>
- Theunissen, S. C., Rieffe, C., Kouwenberg, M., Raeve, L. J. I., Soede, W., Briaire, J. J., & Frijns, J. H. M. (2014). Behavioral problems in school-aged hearing-impaired children: The influence of sociodemographic, linguistic, and medical factors [Peer Reviewed]. *European Child and Adolescent Psychiatry*, 23(4), 187-196. <https://doi.org/10.1007/s00787-013-0444-4>
- Theunissen, S. C., Rieffe, C., Netten, A. P., Briaire, J. J., Soede, W., Schoones, J. W., & Frijns, J. H. (2014). Psychopathology and its risk and protective factors in hearing-impaired children and adolescents: A systematic review. *JAMA Pediatr*, 168(2), 170-177. <https://doi.org/10.1001/jamapediatrics.2013.3974>
- Titus, J. C., Schiller, J. A., & Guthmann, D. (2008). Characteristics of youths with hearing loss admitted to substance abuse treatment. *Journal of deaf studies and deaf education*, 13(3), 336-350. <https://doi.org/10.1093/deafed/enm068>
- United Nations Convention on the Rights of Persons with Disabilities. (2006). United Nations. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of Life Research*, 17(6), 895-913. <https://doi.org/10.1007/s11136-008-9350-5>

- van Beeck Calkoen, E. A., Engel, M. S. D., van de Kamp, J. M., Yntema, H. G., Goverts, S. T., Mulder, M. F., Merkus, P., & Hensen, E. F. (2019). The etiological evaluation of sensorineural hearing loss in children. *European Journal of Pediatrics, 178*(8), 1195-1205. <https://doi.org/10.1007/s00431-019-03379-8>
- van Eldik, T. (2005). Mental health problems of Dutch youth with hearing loss as shown on the Youth Self Report. *American Annals of the Deaf, 150*(1), 11–16. <https://doi.org/10.1353/aad.2005.0024>
- van Eldik, T., Treffers, P. D. A., Veerman, J. W., & Verhulst, F. C. (2004). Mental health problems of deaf Dutch children as indicated by parents' responses to the Child Behavior Checklist. *American Annals of the Deaf, 148*(5), 390–394. <https://doi.org/10.1353/aad.2004.0002>
- van Gent, T., Goedhart, A. W., Hindley, P. A., & Treffers, P. D. A. (2007). Prevalence and correlates of psychopathology in a sample of deaf adolescents. *Journal of Child Psychology and Psychiatry, 48*(9), 950–958. <https://doi.org/10.1111/j.1469-7610.2007.01775.x> 17714380
- van Gent, T., Goedhart, A. W., & Treffers, P. D. A. (2012). Characteristics of children and adolescents in the Dutch national in- and outpatient mental health service for deaf and hard of hearing youth over a period of 15 years. *Research in Developmental Disabilities, 33*(5), 1333–1342. <https://doi.org/10.1016/j.ridd.2012.02.012>
- van Roy, B., Groholt, B., Heyerdahl, S., & Clench-Aas, J. (2006). Self-reported strengths and difficulties in a large Norwegian population 10-19 years: Age and gender specific results of the extended SDQ-questionnaire. *European Child and Adolescent Psychiatry, 15*(4), 189–198. <https://doi.org/10.1007/s00787-005-0521-4>
- van Roy, B., Groholt, B., Heyerdahl, S., & Clench-Aas, J. (2010). Understanding discrepancies in parent-child reporting of emotional and behavioural problems: Effects of relational and socio-demographic factors. *BMC Psychiatry, 10*(56). <https://doi.org/10.1186/1471-244X-10-56>
- van Roy, B., Veenstra, M., & Clench-Aas, J. (2008). Construct validity of the five-factor Strengths and Difficulties Questionnaire (SDQ) in pre-, early, and late adolescence *Journal of Child Psychology and Psychiatry, 49*, 1304–1312. <https://doi.org/10.1111/j.1469-7610.2008.01942.x>
- VanOrmer, J. L., Rossetti, K. G., & Zlomke, K. R. (2019). The Development of Behavioral Difficulties in Hard-of-Hearing and Deaf Youth. *Child & Family Behavior Therapy, 41*(4), 179-200. <https://doi.org/10.1080/07317107.2019.1659537>
- Venturini, S., & Mehmetoglu, M. (2017). PLSSEM: Stata module to implement partial least squares structural equation modelling (PLS-SEM). <https://EconPapers.repec.org/RePEc:boc:bocode:s458291>.
- Vostanis, P., Hayes, M., Du Feu, M., & Warren, J. (1997). Detection of behavioural and emotional problems in deaf children and adolescents: comparison of two rating scales. *Child: Care, Health and Development, 23*, 233-246. <https://doi.org/10.1111/j.1365-2214.1997.tb00966.x>
- Warner-Czyz, A. D., Loy, B., Roland, P. S., Tong, L., & Tobey, E. A. (2009). Parent versus child assessment of quality of life in children using cochlear implants. *International Journal of Pediatric Otorhinolaryngology, 73*(10), 1423-1429. <https://doi.org/10.1016/j.ijporl.2009.07.009>
- Werker, J. F., & Byers-Heinlein, K. (2008). Bilingualism in infancy: first steps in perception and comprehension. *Trends in Cognitive Sciences, 12*(4), 144-151. <https://doi.org/10.1016/j.tics.2008.01.008>
- Wilkins, A. M., Morere, D. A., Pick, L. H., Day, L. A., & Anderson, M. L. (2021). Characteristics of Psychologists Assessing Deaf and Hard of Hearing Clients. *J Deaf Stud Deaf Educ.* <https://doi.org/10.1093/deafed/enab039>
- World Health Organization. (1995). The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine, 41*(10), 1403-1409. [https://doi.org/10.1016/0277-9536\(95\)00112-k](https://doi.org/10.1016/0277-9536(95)00112-k)
- World Health Organization. (2016). *Childhood hearing loss: Strategies for prevention and care* <https://www.who.int/publications/i/item/childhood-hearing-loss-strategies-for-prevention-and-care>
- World Health Organization. (2018a). *Addressing the rising prevalence of hearing loss*. World Health Organization. <http://apps.who.int/iris/bitstream/handle/10665/260336/9789241550260-eng.pdf?sequence=1&ua=1>
- World Health Organization. (2018b, 01/12/2002). *Deafness and hearing loss - Key facts*. World Health Organization. <https://www.who.int/en/news-room/fact-sheets/detail/deafness-and-hearing-loss>
- World Health Organization. (2021). *World report on hearing*. World Health Organization, . <https://www.who.int/publications/i/item/world-report-on-hearing>

- Wright, B., H., C., Garside, M., Hargate, R., Noon, I., & Eggleston, R. (2021). The impact of COVID-19 on deaf children in the United Kingdom *International Journal on Mental Health and Deafness*, 5(1), 26-36.
- Wright, B., Hargate, R., Garside, M., Carr, G., Wakefield, T., Swanwick, R., Noon, I., & Simpson, P. (2021). A systematic scoping review of early interventions for parents of deaf infants. *BMC Pediatrics*, 21(1), 467. <https://doi.org/10.1186/s12887-021-02893-9>
- Wright, B., Walker, R., Holwell, A., Gentili, N., Barker, M., Rhys-Jones, S., Leach, V., Hindley, P., Gascon-Ramos, M., & Moore, K. (2012). A new dedicated mental health service for deaf children and adolescents. *Advances in Mental Health*, 11(1), 95-105. <https://doi.org/10.5172/jamh.2012.11.1.95>
- Yanyun, Y., & Green, S. B. (2011). Coefficient alpha: A reliability coefficient for the 21st century? *Journal of Psychoeducational Assessment*, 29(4), 377–392. <https://doi.org/10.1177/0734282911406668>
- Yoshinaga-Itano, C. (2015). The missing link in language learning of children who are deaf or hard of hearing: pragmatics. *Cochlear Implants Int*, 16 Suppl 1, S53-54. <https://doi.org/10.1179/1467010014z.000000000237>
- Yoshinaga-Itano, C., Sedey, A. L., Wiggin, M., & Mason, C. A. (2018). Language Outcomes Improved Through Early Hearing Detection and Earlier Cochlear Implantation. *Otology & Neurotology*, 39(10), 1256-1263. <https://doi.org/10.1097/mao.0000000000001976>
- Yu, B. (2013). Issues in Bilingualism and Heritage Language Maintenance: Perspectives of Minority-Language Mothers of Children With Autism Spectrum Disorders. *American Journal of Speech-Language Pathology*, 22(1), 10-24. [https://doi.org/doi:10.1044/1058-0360\(2012/10-0078\)](https://doi.org/doi:10.1044/1058-0360(2012/10-0078))
- Øhre, B., & Saltnes, H. (2018). *Guidelines. Guidelines for referral of people with severe hearing loss and mental health disorders. [Retningslinje. Retningslinje for henvisning av personer med betydelig hørselstap og psykisk lidelse]* Nasjonal behandlingstjeneste for hørsel og psykisk helse.
- Øhre, B., Saltnes, H., von Tetzchner, S., & Falkum, E. (2014). Psychometric properties of a sign language version of the Mini International Neuropsychiatric Interview (MINI). *BMC Psychiatry*, 14(148), 1–10. <https://doi.org/10.1186/1471-244x-14-148>
- Øhre, B., Von Tetzchner, S., & Falkum, E. (2011). Deaf adults and mental health: A review of recent research on the prevalence and distribution of psychiatric symptoms and disorders in the prelingually deaf adult population. *International Journal on Mental Health and Deafness*, 1(1), 3-22.
- Aanonsen, C. M., Heiling, K., Nøvik, T. S., & Jozefiak, T. (2018). Quality of Life, family function and mental health of deaf and hard-of-hearing adolescents in mental health services in Norway – a pilot study. *International Journal on Mental Health and Deafness*, 4(1), 3–13.
- Aanonsen, C. M., Jozefiak, T., Heiling, K., Lydersen, S., & Rimehaug, T. (2021). Psychometric properties of the Inventory of Life Quality in children and adolescents in Norwegian Sign Language. *BMC Psychology*, 9(1), 89. <https://doi.org/10.1186/s40359-021-00590-x>
- Aanonsen, C. M., Jozefiak, T., Heiling, K., & Rimehaug, T. (2019). Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language. *The Journal of Deaf Studies and Deaf Education*, 1-14. <https://doi.org/10.1093/deafened/enz026>



# Appendix

## Appendix A

**Table A1 Psychometric properties of measures used in this thesis**

Measure	Description	Age	Use	Scores	Psychometric properties	References
SDQ	Ratings of mental health symptoms	Self-report: 11-17 (8 <sup>1</sup> -19 <sup>2</sup> ) Parent-report: 4-17	Self-report for children and adolescents and parent-report in research, clinical and community settings	Subscale scores (Emotional Problems, Conduct Problems, Hyperactivity-Inattention, Peer Problems, Pro-Social Behaviour) and Total Difficulties score	<p><b>Reliability</b></p> <p>Internal consistency (subscales): Cronbachs <math>\alpha</math>=.41 to .66 (self) Cronbachs <math>\alpha</math>=.55 to .77 (parent) Test-retest reliability: <math>r</math>=.51 to .62 (self) <math>r</math>=.57 to .72 (parent)</p> <p><b>Validity</b></p> <p>Construct validity: satisfactory for five-factor model (EFA) Specificity: 94% (self/parent) Sensitivity: self: 23%; parent 47% NPV: self: 92%; parent 96% PPV: self: 35%; parent 46%</p>	Goodman (2001)
SDQ-NOR	Written self-report	9-20			<p><b>Reliability</b></p> <p>Internal consistency (subscales): Cronbachs <math>\alpha</math>=.44 to .71</p> <p><b>Validity</b></p> <p>Construct validity: satisfactory for five-factor model (CFA)</p>	van Roy et al. (2008)
SDQ-NSL	NSL self-report	9-20			<p><b>Reliability</b></p> <p>Internal consistency (subscales): DG <math>\rho</math>=.51 to .66</p> <p><b>Validity</b></p> <p>Construct validity: satisfactory for five-</p>	Aanondsen et al. (2019)

					factor model (CFA and PLS-SEM)	
SDQ-P	Parent-report	6-20			<p><b>Reliability</b> Internal consistency (subscales): Cronbach's <math>\alpha</math>=.50 to .76</p> <p><b>Validity</b> Construct validity: satisfactory for five-factor model (CFA)</p>	van Roy et al. (2008)
ILC	Rating of QoL	6-11 (child) 12+ (adol.)  6-11 (parent)	Self-report for children and adolescents and parent-report in research, clinical and community settings	Item scores (physical and mental health, school and family functioning, social contact with peers, play/hobbies when alone and QoL score (LQ <sub>0-28</sub> ))	<p><b>Reliability</b> Internal consistency: Cronbach's <math>\alpha</math>=.63 (self) Cronbach's <math>\alpha</math>=.76 (parent) Test-retest reliability: r=.72 (self) r=.80 (parent)</p> <p><b>Validity</b> Convergent validity: moderate Construct validity: acceptable for one-factor model (PCA)</p>	Mattejat and Remschmidt (2006)
ILC-NOR	Written self-report	6-11 12+			<p><b>Reliability</b> Internal consistency: Cronbach's <math>\alpha</math>=.64 (child) Cronbach's <math>\alpha</math>=.82 (adol.) Test-retest reliability: r=.86</p> <p><b>Validity</b> Construct validity: satisfactory for one-factor model (CFA) Convergent validity: moderate</p>	Jozefiak et al. (2012)
ILC-NSL	NSL self-report	6-11 12+			<p><b>Reliability</b> Internal consistency: Cronbach's <math>\alpha</math>=.70 (child) Cronbach's <math>\alpha</math>=.81 (adol.)</p>	Aanonsen et al. (2021)



					DG rho=.83 (child) DG rho=.86 (adol.)  <b>Validity</b> Construct validity: satisfactory for one-factor model (CFA and PLS-SEM)	
ILC-P	Parent-report	6-21			<b>Reliability</b> Internal consistency: Cronbach's $\alpha$ =.78  <b>Validity</b> Construct validity: satisfactory for one-factor model (CFA) Convergent validity: moderate	Jozefiak et al. (2012)
Leiter-3	Nonverbal cognitive assessment	3-75	Applicable to both research and clinical settings	Subtest and composite scores	<b>Reliability</b> Internal consistency: Cronbach's $\alpha$ =.79 to .95 Test-retest reliability: r=.94 to .98  <b>Validity</b> Satisfactory criterion, concurrent and construct validity	Roid and Koch (2017); Roid et al. (2013)
CAP	Parent rating of listening skills	0-	Outcome rating after paediatric cochlear implantation; also used for research purposes	Single item score	<b>Reliability</b> Interrater reliability (UK): r=.97  Interrater reliability (DK): kappa=.76	Archbold et al. (1995); Archbold et al. (1998); Dammeyer (2010)
SIR	Parent rating of speech intelligibility	0-	Outcome rating after paediatric cochlear implantation; also used for research purposes	Single item score	<b>Reliability</b> Interrater reliability (UK) r=.82 (Spearman and ICC) kappa=.53  Interrater reliability (DK)	Allen et al. (2001); Dammeyer (2010)

					kappa=.85	
SUS	Parent rating of sign language understanding	0-	Developed for research purposes	Single item score	<p><b>Reliability</b> Interrater reliability kappa=.94</p> <p><b>Validity</b> Criterion validity r=.91</p>	Dammeyer (2010)
SPS	Parent rating of sign language production	0-	Developed for research purposes	Single item score	<p><b>Reliability</b> Interrater reliability kappa=.92</p>	Dammeyer (2010)
CCC-2	Parent-rating of communicative competence	4-	Rating scale for communicative competence; screening of general and pragmatic language	Subscale scores and General Communication Composite (GCC)	<p><b>Reliability</b> Internal consistency (subscales; UK) Cronbach's <math>\alpha</math>=.66 to .80</p> <p>Internal consistency (subscales; N) Cronbach's <math>\alpha</math>=.73 to .89</p> <p>Interrater reliability (subscales; N) r=.44 to .76</p> <p><b>Validity</b> Cut-off: 55 (N) Specificity: 69.8% Sensitivity of 98.1%</p> <p>Cut-off: 64 (N) Specificity: 86% Sensitivity: 91%</p>	Bishop (2003); Helland et al. (2009)

Notes. *SDQ-NOR* Strengths and Difficulties Questionnaire - written Norwegian; *SDQ-NSL* Strengths and Difficulties Questionnaire – NSL; *ILC-NOR* - The Inventory of Life Quality in Children and Adolescents - written Norwegian ; *ILC-NSL* - The Inventory of Life Quality in Children and Adolescents - NSL; *Leiter 3* Leiter International Performance Scale – Third Edition; *SDQ-P* Strengths and Difficulties Questionnaire – parent-report; *ILC-P* - The Inventory of Life Quality in Children and Adolescents - parent-report; *CAP* Categories of Auditory Performance; *SIR* Speech Intelligibility Rating; *SUS* Sign Language Understanding Scale; *SPS* Sign Language Production Scale; *CCC-2* Children's Communication Checklist Second Edition; *EFA* – Exploratory factor Analysis; *NPV*- Negative Predictive Value; *PPV* - Positive Predictive Value; *CFA* – Confirmatory Factor Analysis; *DG rho* – Dillon Goldstein's rho; *PLS-SEM* – Partial Least Squares Structural Equation Modelling; *PCA* – Principal Component Analysis;

<sup>1</sup> Validation of self-report in 8 to 13-year-old children (Muris et al., 2004)

<sup>2</sup> Validation of self-report in 10 to 19-year-old children (van Roy et al., 2006)

## Appendix B1

### Norwegian version of the Sign Language Understanding Scale (SUS)

#### VTF - Vurdering av tegnspråklig forståelse

Sett et kryss ved nivået, som passer best på barnet:

0		Registrerer ikke eller oppfatter ikke tegn.
1		Registrerer tegn.
2		Forstår enkle tegn, mest konkrete tegn. (F.eks. forstår tegnet for bil, ball eller spise.)
3		Forstår tegn uten at konteksten hjelper til (F.eks. at barnet ikke kan se tingen som det snakkes om.) Forstår abstrakte tegn. (F.eks. tegnene "tisse", "pause" mv.)
4		Forstår korte setninger på tegnspråk. (F.eks. beskjeder, ordre.)
5		Kan inngå i korte dialoger om ting som ikke er konkret nærværende og hverdagssetninger.
6		Kan uten vansker delta i vanlig samtale på tegnspråk.
7		Kan fullt ut delta i lengre og komplekse samtaler på tegnspråk om et kjent emne, forstå fortellinger på tegnspråk, aldersadekvate TV-programmer på tegnspråk og lignende uten problemer.

Jesper Dammeyer, 2006.

Norsk oversettelse: Chris M. Aanonsen, 2013

## Appendix B2

### Norwegian version of the Sign Language Production Scale (SUS)

#### VTP - Vurdering av tegnspråklig produksjon

Sett et kryss ved nivået, som passer best på barnet:

1		Barnet produserer ikke egentlige tegn. Bruker enkelte gester og pekninger.
2		Barnet kan produsere enkelte vanlige tegn når konteksten hjelper til.
3		Barnet kan tegne enkle handlingsforløp av minimum to-tre tegn. Tegnspråket er forståelig for personer som kjenner barnet godt.
4		Barnet kan tegne setninger med flere enn tre tegn som ikke nødvendigvis er grammatisk korrekte. Enkel bruk av proformer. Tegnspråket er forståelig for personer som kan tegnspråk, men som ikke kjenner barnet.
5		Barnet har et flytende og nesten konvensjonelt korrekt tegnspråk. Tegnspråket er lett forståelig for alle som kan tegnspråk. (Bruker f.eks. proformer og grammatisk ansiktsuttrykk kreativt.)

Jesper Dammeyer, 2006

Norsk oversettelse: Chris M. Aanonsen, 2013.

## **Papers I-III**



# Paper I





## EMPIRICAL MANUSCRIPT

# Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language

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## Abstract

The majority of studies on mental health in deaf and hard-of-hearing (DHH) children report a higher level of mental health problems. Inconsistencies in reports of prevalence of mental health problems have been found to be related to a number of factors such as language skills, cognitive ability, heterogeneous samples as well as validity problems caused by using written measures designed for typically hearing children. This study evaluates the psychometric properties of the self-report version of the Strengths and Difficulties Questionnaire (SDQ) in Norwegian Sign Language (NSL; SDQ-NSL) and in written Norwegian (SDQ-NOR). Forty-nine DHH children completed the SDQ-NSL as well as the SDQ-NOR in randomized order and their parents completed the parent version of the SDQ-NOR and a questionnaire on hearing and language-related information. Internal consistency was examined using Dillon–Goldstein’s rho, test–retest reliability using intraclass correlations, construct validity by confirmatory factor analysis (CFA), and partial least squares structural equation modeling. Internal consistency and test–retest reliability were established as acceptable to good. CFA resulted in a best fit for the proposed five-factor model for both versions, although not all fit indices reached acceptable levels. The reliability and validity of the SDQ-NSL seem promising even though the validation was based on a small sample size.

Two reviews and a meta-analysis have reported an elevated prevalence of emotional and behavioral problems in deaf and hard-of-hearing (DHH) children and adolescents across countries, informants, and measures (Fellinger, Holzinger, & Pollard, 2012; Stevenson, Kreppner, Pimperton, Worsfold, & Kennedy, 2015; Theunissen et al., 2014). For brevity, the term “children” will be used to describe both children and adolescents in this paper. The majority of studies have reported that 20–50% of DHH children suffer from mental health problems (Dammeyer, 2010b; Fellinger, Holzinger, Sattel, & Laucht, 2008; Hintermair, 2007; van Eldik, 2005; van Eldik, Treffers, Veerman, & Verhulst, 2004; van Gent, Goedhart, Hindley, & Treffers, 2007) whereas Sinkkonen (1994) reported rates comparable to those of typically hearing (TH) children based on teacher reports. Mejsstad, Heiling, and

Svedin (2009) found equivalent rates of emotional and behavioral problems in DHH and TH boys based on the self-report version of the Strengths and Difficulties Questionnaire (SDQ).

Fellinger, Holzinger, Sattel, Laucht, and Goldberg (2009) found point and lifetime prevalence rates of 32.6% and 45.3%, respectively, for any psychiatric disorder in a representative Austrian DHH sample of children. Theunissen et al. (2014) concluded in their systematic review that DHH were more likely to suffer from depression, aggression, oppositional defiant disorder, and conduct disorder than their TH peers. A possible cause for differences in prevalence rates found for DHH children are heterogeneous samples as well as different inclusion criteria across studies such as different degrees of hearing loss (HL) and modes of communication. Additional disabilities, communica-

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tive skills, and intellectual functioning have been shown to affect DHH children's mental health whereas the degree of HL has not (Dammeyer, 2010b; Fellingner et al., 2009; Hintermair, 2006; Mejstad, Heiling, & Svedin, 2009; Stevenson et al., 2017; van Gent et al., 2007). Mejstad et al. (2009) suggested that the extent of parental support provided in Sweden and Finland may ensure better mental health. This is in accordance with Dammeyer's (2010b) study, which found no increased risk of mental health problems in DHH children with good signing or oral communication skills.

## The Strengths and Difficulties Questionnaire

The SDQ is a brief measure to assess emotional and behavioral problems and prosocial behavior in children. It consists of 25 items that are grouped into five scales (emotional problems, conduct problems, hyperactivity-inattention, peer problems, and prosocial behavior). The SDQ is a multi-informant assessment and can be completed by parents of 4-17-year-old children, teachers of 4-17-year-old children, and 11-17-year-old adolescents. Achenbach, McConaughy, and Howell (1987) have emphasized the importance of multi-informant assessments for capturing the unique perspectives held by each informant. The original validation demonstrated satisfactory reliability (internal consistency and test-retest reliability) and validity for all informants. The peer problems scale showed the lowest internal consistency ( $\alpha = .41$ ) for the self-report (R. Goodman, 2001).

The SDQ is available free of charge in over 80 languages and has been used in community and clinical samples across the world. Essau et al. (2012) compared the psychometric properties of the self-report SDQ across five European countries (the UK, Germany, Sweden, Italy, and Cyprus). They report good to satisfactory internal consistency for most subscales in most countries, with the lowest for conduct and peer problems. Confirmatory factor analysis (CFA) showed that the three-factor model (internalizing and externalizing difficulties and prosocial behavior) demonstrated best fit in Cyprus whereas the five-factor model showed a better fit in Germany, the UK, and Sweden. The model fit indices for the five-factor model in Sweden and the UK, however, did not reach acceptable levels. A. Goodman, Lamping, and Ploubidis (2010) examined the fit of the three- and five-factor models in a large British sample and concluded that the five-factor model should be maintained for clinical samples whereas the three-factor model may be better suited to assess low-risk community samples.

The reliability and validity of the Norwegian SDQ self, parent, and teacher reports were found to be acceptable (Rønning, Handegaard, Sourander, & Mørch, 2004; Sanne, Torsheim, Heiervang, & Stormark, 2009; van Roy, Groholt, Heyerdahl, & Clench-Aas, 2006; van Roy, Veenstra, & Clench-Aas, 2008). Van Roy et al. (2008) demonstrated acceptable psychometrics of the self-report version for adolescents aged 11 to 19 years although the internal consistency for conduct problems was low for all adolescents ( $\alpha = .44$  to .54).

## The SDQ in DHH Samples

In their meta-analysis, Stevenson et al. (2015) found an elevated rate of emotional and behavioral difficulties in DHH children based on parent and teacher SDQ reports. The most pronounced risk was found for peer problems for informants, whereas hyperactivity-inattention did not show an elevated level for

either of the informants. Stevenson et al. (2015) further argue that the less elevated rates in the SDQ studies in the meta-analysis as compared to the non-SDQ studies may reflect an actual improvement in the provision of services as a number of the non-SDQ studies were published much earlier than the SDQ studies.

The psychometric properties of the written SDQ for DHH children have been examined in Denmark (Niclassen & Dammeyer, 2016) and Germany (Hintermair, 2007). Niclassen and Dammeyer (2016) concluded that the five-factor model could be recommended for DHH children, in a bilingual/bicultural and an oral/mainstream setting, in Denmark, with better model fit demonstrated for the teacher than the parent report. Hintermair (2007) found acceptable internal consistency for most subscales except for conduct problems ( $\alpha = .51$ ) as well as support for the five-factor model for the parent report in Germany.

Studies have reported difficulties in reading in many DHH children (Harris, Terlektsi, & Kyle, 2017; Marschark et al., 2007a; Marschark et al., 2009), which in turn will affect their ability to complete written forms and the validity of the results. Therefore, the SDQ has been translated to British Sign Language (BSL) and Australian Sign Language (Auslan). Cornes, Rohan, Napier, and Rey (2006) found acceptable test-retest reliability (SDQ-Auslan: .75 to .85) and internal consistency (written: .53 to .84; SDQ-Auslan: .42 to .83) for the self-report SDQ. The SDQ-Auslan, however, demonstrated higher internal consistency for all subscales except for peer problems (.42). Peer problems and conduct problems (.55) were found to have the lowest consistency for the Auslan version; construct validity of the SDQ was not assessed. Further, Cornes et al. (2006) found no significant correlations between the written and Auslan versions for emotional problems (.29), conduct problems (.27), and hyperactivity-inattention (.31) subscales. Significant correlations were found for peer problems (.43), prosocial behavior (.44), and total difficulties (.41). Significant correlations were also found for all subscales and total score between the parent report and the written self-report (.34 to .66), whereas only hyperactivity-inattention (.41), peer problems (.35), and total score (.39) were significantly correlated for the SDQ-Auslan and parent report.

Roberts et al. (2015) reported that the BSL versions of the self-, parent, and teacher report demonstrated similar reliability and validity to versions in other studies and recommended their use for future research. Reported internal consistency for the self-report was low for peer problems, hyperactivity-inattention, prosocial behavior, and conduct problems ( $\alpha = .21, .23, .42$  and .48, respectively) and good for emotional problems (.71) and total difficulties (.74). Test-retest reliability was reported as acceptable for total difficulties (.71) and all subscales (.62 to .71) except for peer problems (.45). Significant correlations between parent and self-report were found for all subscales and total score (.20 to .26) except for hyperactivity-inattention (.18). The authors also report lower fit indices on the CFA of the five-factor model for the self-report (comparative fit index, CFI: .718; Tucker-Lewis Index, TLI: .680; and root mean square error of approximation, RMSEA: .071) than the parent and teacher report versions.

## Challenges in Assessing DHH Children

Van Gent, Goedhart, and Treffers (2012) reported that DHH adolescents were significantly older at their first referral than their TH peers and emphasize the need for preventive interventions for early recognition of mental health problems. To ensure early recognition and valid assessment Ohre, Saltnes, von Tetzchner,

and Falkum (2014) and Roberts et al. (2015) emphasize the need for instruments in sign languages. There is, however, a considerable lack of translated and validated versions of instruments such as the SDQ or the Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2001) commonly used for assessing TH children. Bridging such gaps is necessary for understanding the inconsistent findings regarding the prevalence of mental health problems among DHH children. The Youth Self-Report and the SDQ have been translated to Auslan. On both measures, DHH signing adolescents have reported more difficulties on the Auslan than the written versions (Cornes & Brown, 2012; Cornes et al., 2006).

Except for the pilot study by Aanonsen, Heiling, Nøvik, and Jozefiak (2018), there are hardly any studies on Norwegian DHH children's mental health and no studies on the validation of assessment tools in NSL for assessing mental health in DHH children. Norway is unique in offering parents of DHH children 40 weeks (i.e. 2–4 weeks/year) of NSL classes over 16 years with all expenses covered. Therefore, one might expect a higher level of signing skills among Norwegian DHH children and their parents. This, in turn, may have a positive influence on their mental health. As some studies have found that DHH adolescents report more symptoms on assessments based on sign language (Cornes & Brown, 2012; Cornes et al., 2006), validation studies on assessment tools in NSL are necessary. The present study provides psychometric properties for the Norwegian version of the SDQ self-report (SDQ-NOR), which is the first instrument translated to Norwegian Sign Language (NSL) for assessing mental health in children.

## Aims

The main aims of this study were to validate the SDQ self-report in NSL (SDQ-NSL) and to establish the psychometric properties of the SDQ-NOR, as previous studies have shown marked differences in the prevalence of mental health problems based on written versus signed instruments (Brown & Cornes, 2015; Cornes & Brown, 2012; Cornes et al., 2006). The usability of the SDQ-NSL for signing DHH children was assessed from the children's perspective. Finally, rates of emotional and behavioral problems as classified by Norwegian cut-off scores were examined for Norwegian DHH children based on both the written and the NSL versions of the SDQ self-report.

We addressed the following research questions:

1. What are the psychometric properties (internal consistency, test-retest reliability, and construct validity) of the SDQ-NSL and SDQ-NOR for DHH children?
2. What are the correlations between the total score, subscales, and items between the SDQ-NSL and SDQ-NOR?
3. What are the correlations between the total score, subscales, and items between the self-report (SDQ-NSL and SDQ-NOR) and parent report?
4. What do DHH children think about the usability of the SDQ-NSL and SDQ-NOR?
5. What are the rates of emotional and behavioral problems in the clinical range based on the SDQ-NSL and the SDQ-NOR?

## Methods

### Participants

Caluraud et al. (2015) reported that HL of >40 dB affects 1.4 of every 1,000 infants (mild HL in 13%, moderate HL in 50%, severe

HL in 17%, and profound HL in 20%). In Central and Northern Norway, this amounts to an estimate of 205 children with a HL of >40 dB, that is, 35 with severe and 41 with profound HL, based on a population of 146,308 children aged 9 to 18 years. For the whole country, this amounts to an estimate of 151 with a severe and 177 with a profound HL, based on a population of 633,295 children aged 9 to 18 years.

DHH children aged 9 to 17 years who were enrolled part or full time at A.C. Møller School, a school for deaf children of Central and Northern Norway, for the school year of 2016/17 were invited to participate (see Figure 1). DHH adolescents aged 15 to 20 years attending upper secondary school in Central Norway with NSL as their first or second language were also invited. The overall response rate was 86% (49/57). Parents (from the mainstream and the deaf school) also took part in the study.

Two children were excluded based on the assessment of their deaf school teacher because they lacked fluency in NSL as they only recently had started learning NSL. Apart from fluency in both written Norwegian and NSL, we applied no exclusion criteria. Forty-nine DHH children, 35 of them are girls (71.4%), participated in this study. The mean age was 13.5 years (SD = 2.99; range = 9–20), and the mean nonverbal IQ was 108.9 (SD = 18.1; range = 49–143) based on cognitive assessment with Leiter 3. Twenty-nine of 32 (90.6%) mothers had completed 12 years or more of education, whereas 23 of 31 (74.2%) fathers had completed 12 years or more of education. Data were collected between November 1, 2016, and May 9, 2017. The majority of the DHH children (65.6%) mainly attended mainstream schools and spent 2 to 6 weeks at the deaf school per school year.

Hearing- and language-related information for the participants in this study can be found in Tables 1 and 2.

### Measures

**Sociodemographic and hearing related information.** Parents completed a questionnaire about their children's age, sex, and socioeconomic status and their physical and mental health. The parents also completed a questionnaire developed for and used in a pilot study for assessing type and severity of HL, type of schooling, and parents' attendance at sign language classes.

**Language-Related Information.** Parents were asked to respond to questions about their children's preferred mode of communication (spoken Norwegian, NSL, other spoken language, other sign language or bilingual) within and outside the family.

**Spoken language skills.** The participants' auditory performance (speech intelligibility and listening skills) was assessed by parents using the Categories of Auditory Performance (CAP; Archbold, Lutman, & Marshall, 1995) and the Speech Intelligibility Rating (SIR; Allen, Nikolopoulos, Dyar, & O'Donoghue, 2001). CAP and SIR are frequently used in research. The CAP is a single-item scale with a range of 0 to 7. Level 0 is "no awareness of environmental sounds", and Level 7 "uses a telephone with a known speaker." The SIR is also a single-item scale and has a range of 1 to 5. Level 1 is "connected speech is unintelligible," and Level 5 is "connected speech is intelligible to all listeners." Interrater reliability for the Danish version was reported as good (CAP: kappa = .785; SIR: kappa = .848; Dammeyer, 2010b). The sum of CAP and SIR was calculated for each child as the spoken language skills score.

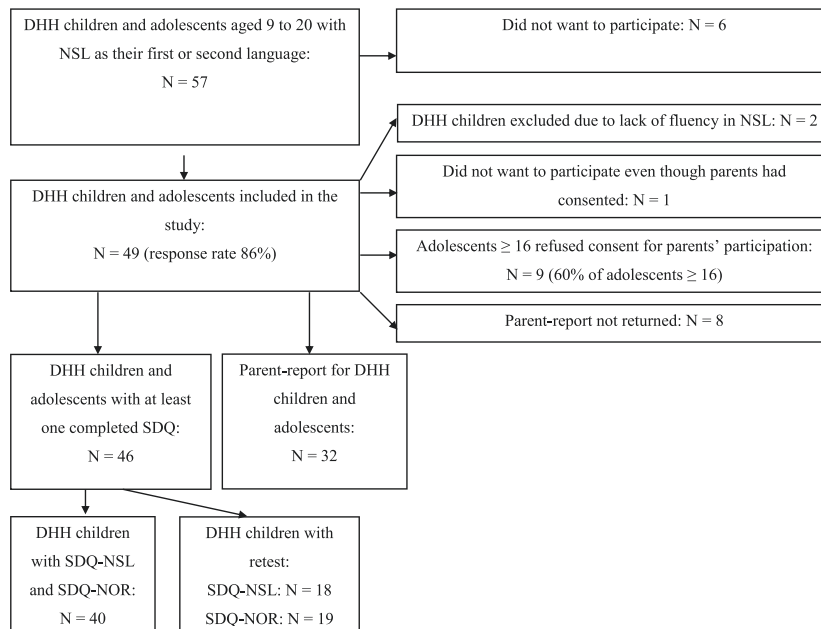


Figure 1 Flow-chart for the inclusion of participants (children and parents).

**Sign language skills.** The participants' sign language skills were assessed with the Norwegian version of the sign language production scale (SPS) and the sign language understanding scale (SUS) developed by Dammeyer (2010b). SPS and SUS were designed by Dammeyer (2010b) as a short screening of sign language skills for research purposes. The structure and range of the SUS and SPS corresponds to that of the CAP and SIR scales. The SPS is a single-item scale with a range of 1 to 5. Level 1 is "the child does not produce real signs," and Level 5 is "the child uses fluent and almost conventional correct sign language." The SUS is a single-item scale with a range of 0 to 7. Level 0 is "does not react to or does not comprehend signs," and Level 7 is "is able to take in long and complex conversations in sign language." The interrater reliability of the Danish version was reported to be good ( $\kappa = .944$  for SUS and  $.921$  for SPS; Dammeyer, 2010b). The validity of the Danish version of the SUS was evaluated by comparing the ratings of 12 children with their scores on the Danish translation (Seiler & Larsen, 2005) of the Assessing British Sign Language Development: Receptive Skills Test (Herman, Holmes, & Woll, 1999). The correlation between the SUS and the Receptive Skill Test reached statistical significance (Spearman rank correlation coefficient =  $.905$ ,  $p < .001$ ; Dammeyer, 2010a). No corresponding test was available for sign language production. The "sign language skills score" was calculated for each child by summing the SPS and SUS scores.

#### Leiter International Performance Scale—Third Edition (Leiter-3)

The nonverbal intelligence of the participants was assessed using the following subtests of figure ground, form completion, classification/analogies and sequential order from the Leiter-3. The composite score for nonverbal intelligence is based on

the sum of the scaled scores for these subtests (Roid, Miller, Pomplun, & Koch, 2013).

#### Emotional and behavioral problems

The SDQ (R. Goodman, 1997) is a multi-informant mental health assessment. For this study, we administered both the parent report and the self-report of the SDQ. Each version of the questionnaire comprises 25 questions, each scored on a three-point Likert scale (0 = "Not true," 1 = "Somewhat true," and 2 = "Certainly true"). These questions can be divided into five subscales measuring emotional problems, conduct problems, hyperactivity-inattention, peer problems, and prosocial behavior, as well as a total difficulties scale of overall psychological adjustment based on the four negative subscales, with higher scores indicating more difficulties.

The SDQ self-report was originally designed for adolescents aged 11 to 16 years (Goodman, 2001). Muris, Meesters, Eijkelboom, and Vincken (2004), however, suggested that the self-report may also be used for children as young as 8 years, whereas van Roy et al. (2006) find evidence that it can be used for adolescents as old as 19 years. Based on this evidence of acceptable psychometric properties for both younger and older children as well as the need for assessment tools of mental health in NSL for children of all ages we have included children aged 9 to 20 years. In our study, children completed both the written and signed self-report versions of the SDQ.

#### The Translation Process

We based the translation process of the SDQ on the guidelines for cross-cultural adaptation of written self-report measures by Beaton, Bombardier, Guillemin, and Ferraz (2000) as well as on adaptations suggested by Roberts et al. (2015) based on differ-

**Table 1** Hearing-related characteristics (parent report)

	N = 32	%
DHH family member(s)		
Yes/no	16/16	50.0/5.0
Time in deaf school		
1–2 days a week <sup>a</sup>	5	15.6
5 days a week	4	12.5
2–6 weeks a year <sup>a</sup>	21	65.6
> 7 weeks a year <sup>a</sup>	6	18.8
Etiology of hearing loss		
Acquired	4	12.5
Hereditary/at birth	26	81.3
Unknown	1	3.1
Missing	1	3.1
Severity of hearing loss		
Moderate: 40–70 dB	7	21.9
Severe: 71–100 dB	10	31.3
Profound: 101+	10	31.3
Unknown	5	15.6
Use of hearing aid		
CI	16	50.0
Hearing aid	24	75.0
Missing	1	3.1
Age at diagnosis		
0–2 years	19	59.4
3–5 years	13	40.6
Preferred Language		
Oral	16	50.0
Sign	7	21.9
Bilingual	9	28.1
Additional impairment		
Vision	12	37.5
Learning	3	9.4
Motor	1	3.1
Other	2	6.3
Missing	2	6.3

Note. DHH = deaf and hard of hearing.

<sup>a</sup>Children attend both mainstream and deaf school.

**Table 2** Language-related information based on parent report

	N	M (SD)
Sign language skills (1–12)	28	9.46 (2.05)
Missing	4	
Spoken language skills (1–12)	30	11.37 (1.35)
Missing	2	

ences in syntax, morphology, and prosody of sign languages and their visual nature. Two independent forward and backward translations of all scales of the SDQ from written Norwegian to NSL were completed. The forward translations were conducted and filmed by two bilingual deaf native NSL users with university degrees in teaching. A panel consisting of the translators, a clinical psychologist, a colleague with a graduate degree in medicine specializing in child and adolescent psychiatry, and a consultant with a master's degree in language and communication and fluent in NSL discussed semantic, conceptual, lexical, and cultural differences and developed a consensus-based forward translation that was filmed. This forward translation was then presented to a focus group consisting of teachers from the local

deaf school. The teachers (deaf, hearing and CODA, i.e., a TH person raised by deaf parents) were asked to evaluate whether DHH children with a mixture of language experiences and levels of fluency would be able to understand the translation. The consensus version was adjusted according to the feedback of the focus group and filmed again. Two independent backward translations of the final consensus version were conducted by two hearing sign language interpreters, one of them with a background as CODA and a master's degree in language and communication. The backward translations were reviewed by the panel and compared to the original written Norwegian version.

To gain approval from YouthInMind (SDQ's copyright holders) the Norwegian back translation was then translated to English. YouthInMind approved items and made suggestions for those not approved. These went back through the translation cycle until final approval was achieved. After the final approval, the SDQ-NSL was filmed professionally and prepared for interactive online administration using Select Survey.

## Procedures

Enrolled children and their parents received verbal and written information about participating in the study during their first attendance at the school after the study was initiated. Written informed consent was obtained from adolescents and parents prior to inclusion. The participating children responded to the web-based SDQ-NSL and SDQ-NOR as well as to a question about the usability of the two versions and completed a nonverbal cognitive assessment. The administration of the SDQ-NSL and SDQ-NOR was conducted on two separate occasions, 2 days apart. The order of these two administrations was randomized. The same procedure was applied for collecting retest data when the children returned for their next stay at the deaf school about 15 weeks after the first data collection. DHH children had access to their teacher and a psychologist, who were both fluent in sign language, during data collection. When children asked for help with the SDQ-NSL they received help in NSL, whereas children responding to the SDQ-NOR were assisted in spoken Norwegian or sign supported speech.

## Statistical Analyses

Seventeen of the 49 parent reports (34%), nine of the 49 SDQ-NSL self-reports (18.4%), and three of the 49 SDQ-NOR reports were not completed. These missing cases were excluded from the analyses. There were no missing items as YouthInMind requires a response to all items on the SDQ in web-based administrations. Five of 14 adolescents aged 16 years or older (35.7%) consented to their parents' participation in the study; two of the five parents (40%) completed the parent report (see Figure 1). On average, adolescents who consented to their parents' participation reported a lower total score on the self-reported SDQ than those who did not consent, but the differences were not statistically significant.

To examine boys' and girls' mean score differences, two-sample t-tests were calculated for the four subscales and for the total score.

Dillon–Goldstein's rho (DG rho) was used to assess internal consistency because of the limitations of Cronbach's  $\alpha$ , such as assumptions of uncorrelated errors, tau-equivalence, and normality (Yanyun & Green, 2011). DG rho was interpreted as acceptable at .6 to .7, and as good when  $>.7$ .

Test-retest reliability based on intraclass correlations (ICCs) was calculated using a two-way random effects model. ICC values of less than .5 were considered poor, .5–.75 was acceptable, .75–.9 was good, and greater than .90 was considered excellent reliability (Koo & Li, 2016).

Spearman's rank correlation coefficient was used to compare total score, subscales, and items between the SDQ-NSL and SDQ-NOR. Significant differences between scores on subscales, and total scores were established based on paired t-tests.

We conducted a CFA with the weighted least squares means and variances (WLSMV) estimation method for categorical variables to confirm the original factor structure of the SDQ (five-factor model) for DHH children for the SDQ-NOR as well as for the SDQ-NSL. Further CFAs were carried out for the one-factor model, the three-factor model as well as the second-order model. The chi-squared test, the normed chi-square ( $\chi^2/df$ ), RMSEA, CFI, and TLI were used to assess model fit. A nonsignificant chi-square test, CFI and TFI > .9, and RMSEA < .1 were considered indicators of acceptable goodness of fit according to Mehmetoglu and Jakobsen (2017), whereas CFI and TFI > .95 and RMSEA < .05 were considered as indicators of good model fit (Hu & Bentler, 1999). A normed chi-square of <2.0 was considered acceptable for this study although others have reported acceptable ratios as high as 5.0 (Hooper, Coughlan, & Mullen, 2008). Standardized factor loadings greater than .4 were considered acceptable (Mehmetoglu & Jakobsen, 2017).

As Hair, Hult, Ringle, and Sarstedt (2016) point out, small sample size can cause problems with underidentified models and nonconvergence in CFA. The estimator WLSMV has been shown to overestimate interfactor correlations when the sample size is relatively small (Li, 2016). Partial least squares structural equation modeling (PLS-SEM) has been shown to be less prone to these problems as it is nonparametric and makes fewer distributional assumptions. PLS-SEM, however, is mostly used for exploratory purposes as it lacks goodness of fit measures. Because of the small sample size, we also carried out PLS-SEM to establish factor loadings and discriminant validity (average variance extracted, AVE) as suggested by Hair et al. (2016). Factors with AVE scores greater than .5 were regarded as satisfactory for convergent/discriminant validity. Fornell and Larcker (1981), however, argue that AVE > .4 can be treated as acceptable as long as composite reliability is above .6.

We conducted Spearman's rank correlations to assess multi-informant correlations between the parent- and both the self-reported (NSL and NOR) scaled scores of the SDQ. These were compared with multi-informant correlations described in other samples by Achenbach et al. (1987), R. Goodman (2001), and Roberts et al. (2015).

A contingency table was computed for comparing the total score of DHH children within the normal, sub-clinical and clinical ranges for the SDQ-NSL and SDQ-NOR, as well as the concordance between the two self-reports. Based on Fagerland, Lydersen, and Laake's (2017) recommendation we computed a contingency table and used Fisher's exact test to examine the association between the DHH children's preferred mode of communication in everyday life and their preference for the SDQ-NSL or SDQ-NOR. Further contingency tables including Kruskal-Wallis equality-of-populations rank tests were computed for the DHH children's spoken as well as their NSL skills and their preference for the SDQ-NSL or SDQ-NOR.

Descriptive analyses were conducted in IBM SPSS Statistics version 25, the CFA was carried out in MPlus version 8 and ICC, and two-sample and paired sample t-tests, DG rho and Spearman rank correlations were conducted in Stata/SE 14.2 for Windows. PLS-SEM including AVE was conducted in Stata applying the module for PLS-SEM by Venturini and Mehmetoglu (2017). For all analyses, alpha levels of <.05 were considered statistically significant.

## Ethics

Written informed consent was obtained from all parents and from adolescents older than 16 years prior to inclusion. Verbal informed consent was obtained from children under the age of 16 years. Study approval was given by the Regional Committees for Medical and Health Research Ethics (reference number: 2015/1739/REK midt).

## Results

Table 3 presents the means and standard deviations for the DHH participants on the self-report of the SDQ (SDQ-NSL and SDQ-NOR).

**Table 3** Descriptive summary of the self-report SDQ scores (SDQ-NSL and SDQ-NOR): mean and SD

SDQ scale	Emotion	Conduct	Hyperactivity	Peer problems	Prosocial	Total score
SDQ-NSL (N = 40)	4.40 (2.41)	2.35 (1.90)	3.83 (2.40)	2.78 (1.73)	8.18 (1.46)	13.35 (6.28)
SDQ-NOR (N = 46)	4.02 (2.62)	1.61 (1.77)	3.65 (2.28)	2.89 (1.72)	8.02 (1.99)	12.17 (6.59)

Note. SDQ = Strengths and Difficulties Questionnaire possible range of score 0–40 for total score and 0–10 for each subscale. SDQ-NSL = SDQ self-report in Norwegian Sign Language. SDQ-NOR = SDQ self-report in written Norwegian. Norwegian cut-off scores ( $\geq 90$  percentile): emotion = 6, conduct = 5, hyperactivity = 7, peer problems = 5, prosocial = 4, total score = 18

**Table 4** Internal consistency based on Dillon–Goldstein's rho for the five subscales of the SDQ-NSL and SDQ-NOR

SDQ scale	Emotion	Conduct	Hyperactivity	Peer problems	Prosocial
SDQ-NSL (N = 40)	.800 <sup>b</sup>	.736 <sup>b</sup>	.820 <sup>b</sup>	.680 <sup>a</sup>	.641 <sup>a</sup>
SDQ-NOR (N = 46)	.876 <sup>b</sup>	.780 <sup>b</sup>	.798 <sup>b</sup>	.682 <sup>a</sup>	.825 <sup>b</sup>

Note. SDQ = Strengths and Difficulties Questionnaire. SDQ-NSL = SDQ self-report in Norwegian Sign Language. SDQ-NOR = SDQ self-report in written Norwegian.

<sup>a</sup>Acceptable internal consistency

<sup>b</sup>Good internal consistency

A two-sample t-test of the girls' and boys' mean scores on the five subscales and total scores showed no significant difference in gender for either of the self-report versions.

## Reliability

**Internal consistency.** As can be seen in Table 4, internal consistency was found to be acceptable to good for all subscales for both the SDQ-NSL and SDQ-NOR based on DG rho.

**Test-retest reliability.** Test-retest data were collected for 20 participants after they returned to the deaf school. An average of 15.17 weeks ( $SD = 1.01$ ) elapsed between T1 and T2 for the SDQ-NSL and an average of 15.03 weeks ( $SD = 1.05$ ) elapsed for the SDQ-NOR. Test-retest correlations are presented in Table 5.

As can be seen from Table 5, test-retest reliability for SDQ-NSL was found to be acceptable based on ICC for all subscales as well as total difficulties. Test-retest reliability for the SDQ-NOR was established as acceptable for emotional problems, hyperactivity-inattention, and peer problems; as good for emotional problems and total difficulties; and as poor for prosocial behavior.

## Validity

**Construct validity.** The standardized factor loadings, AVE, as well as model fit indices for the subscales of the five-factor model are displayed in Table 6 (SDQ-NSL) and Table 7 (SDQ-NOR).

The goodness of fit indices indicated a better fit for the SDQ-NSL than the SDQ-NOR for the DHH children in this study as the SDQ-NSL showed acceptable model fit on two indices ( $\chi^2/df$  and RMSEA), and the SDQ-NOR showed acceptable fit on one ( $\chi^2/df$ ). Factor loadings based on CFA and PLS-SEM were acceptable for 4–5 items of the emotional problems, conduct problems, and hyperactivity-inattention subscales for both the SDQ-NSL and the SDQ-NOR. For details on the negative factor loading of item 11 of the SDQ-NSL displayed in Table 8, see Appendix A. The subscales of conduct and peer problems showed an interfactor correlation of 1.053 on the SDQ-NOR. None of the modification indices for SDQ-NSL or SDQ-NOR suggested correlated residuals for the five-factor model.

AVE was above the acceptable .5 only for emotional problems on the SDQ-NOR. Fornell and Larcker (1981), however, argue that AVE > .4 can be treated as acceptable as long as composite reliability, in this case DG's rho, is above .6. This was the case for emotional problems and hyperactivity-inattention on the SDQ-

NSL and for conduct problems, hyperactivity-inattention, and prosocial behavior on the SDQ-NOR.

Further comparison of the structure of the SDQ-NSL and SDQ-NOR (see Table 8) showed that the data failed to satisfy the strictest interpretation of goodness of fit measures for the five-factor model as well as the one-factor model (SDQs total score based on the four problem scales). CFA of the proposed three-factor model (A. Goodman et al., 2010) did not converge for either the SDQ-NSL or the SDQ-NOR for DHH children. Overall, the SDQ-NSL showed more acceptable fit than the SDQ-NOR for DHH children in this study for both the five-factor, one-factor, and second-order models. When comparing these different factor models, the SDQ-NSL demonstrated best fit for the five-factor and one-factor model with acceptable fit on two ( $\chi^2/df$  and RMSEA) of the five goodness of fit measures.

**Comparison of SDQ-NSL and SDQ-NOR.** To compare the SDQ-NSL with the SDQ-NOR self-report, Spearman rank correlations were calculated for the five subscales and the total score (Table 9).

All the correlations were highly significant at  $p < .001$ . The correlations for emotional problems, peer problems, and total difficulties were in the good range, and conduct problems, hyperactivity-inattention, and prosocial behavior demonstrated acceptable correlations. DHH children reported significantly more conduct problems on the SDQ-NSL ( $M = 2.35$ ,  $SD = .301$ ) than on the SDQ-NOR ( $M = 1.55$ ,  $SD = .286$ );  $t(39) = 3.439$ ,  $p = .001$ , but other differences were not significant.

All items for emotional, conduct, and peer problems were significantly correlated for the two versions, mostly moderately to strongly (.323 to .736). All items on the hyperactivity-inattention subscale were significantly correlated (weak to moderate correlations; .277 to .535), apart from item 10, "fidgety." The items on the prosocial behavior subscale were not significantly correlated (.102 to .371), apart from item 9, "caring."

## Multi-informant Correlations

Multi-informant correlations between the scores of DHH children and their parents on the self-report SDQ-NSL and SDQ-NOR are presented in Table 10. Correlations between the self- and parent report were significant for emotional problems for both the SDQ-NSL and SDQ-NOR.

## Symptom Levels

The number of DHH children classified as reporting symptoms in the normal, sub-clinical and clinical ranges on the SDQ was calculated based on Norwegian cut-off scores (Rønning et al., 2004) and is shown in Table 11.

Five DHH children (12.5%) were classified as clinical on both the SDQ-NSL and the SDQ-NOR (concordance of 71.4%). Based on both scales, seven of 40 DHH children (17.5%) were identified with symptoms in the clinical range.

## Usability

When asked which version of the SDQ the DHH children preferred, 44.9% (22/40) preferred the SDQ-NOR. The SDQ-NSL or a combination of the signed and written self-report was the preferred choice of 30.6% (15/40), and 6.1% (3/40) did not know.

During administration of the SDQ-NSL and SDQ-NOR, children commented on the fact that they spent more time completing the SDQ-NSL as it took longer to view the video clips

**Table 5** Intraclass correlations and *p* values for test-retest reliability for SDQ-NSL and SDQ-NOR

SDQ-NSL ( <i>N</i> = 18)	ICC <sup>a</sup>	SDQ-NOR ( <i>N</i> = 19)	ICC <sup>a</sup>
Emotional problems	.644	Emotional problems	.796
Conduct problems	.649	Conduct problems	.876
Hyperactivity	.559	Hyperactivity	.748
Peer problems	.660	Peer problems	.687
Prosocial behavior	.505	Prosocial behavior	.433
Total difficulties	.709	Total difficulties	.896

Note. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian. ICC = intraclass correlation.

<sup>a</sup>All intraclass correlations were found to be significant (*p* values between .011 and .001)

**Table 6** Factor loadings, AVE and model fit indices of the SDQ-NSL based on CFA and PLS-SEM of the five-factor model

Subscale and items	$\lambda$ (CFA)	$\lambda$ (PLS)	AVE	$\chi^2(df)$	$p$	$\chi^2/df$	CFI	TLI	RMSEA	90% CI RMSEA
				323.766 (267)	.010	1.213	.801	.776	.073	.038–.100
Emotional			.448							
3. Somatic	.474	.560								
8. Worries	.283	.618								
13. Unhappy	.760	.785								
16. Clingy	.465	.698								
24. Afraid	.911	.664								
Conduct			.383							
5. Tantrum	.831	.707								
7. Obedient	.111	.245								
12. Fights	.635	.797								
18. Lies	.653	.698								
22. Steals	.498	.484								
Hyperactivity			.482							
2. Restless	.728	.755								
10. Fidgety	.836	.734								
15. Distracted	.911	.815								
21. Reflects	.437	.588								
25. Attends	.386	.541								
Peer			.352							
6. Loner	.775	.717								
11. Friend	-.358	.196								
14. Popular	.155	.210								
19. Bullied	.775	.893								
23. Old best	.544	.606								
Prosocial			.318							
1. Considerate	.512	.253								
4. Shares	.082	.105								
9. Caring	.887	.819								
17. Kind	.398	.701								
20. Help out	.512	.593								

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. CFA = confirmatory factor analysis. PLS = partial least squares. PLS-SEM = Partial least squares structural equation modeling. AVE = average variance extracted. CFI = comparative fit index. TLI = Tucker-Lewis Index. RMSEA = root mean square error of approximation.

of the signed items than to read the items. Based on Fisher's exact test no significant association was found between the children's preferred mode of communication in everyday life (based on parent report) and the children's preference for the signed or written versions of the SDQ (see Table 13 in Appendix B). In addition, no significant associations between the parents' assessment of their children's spoken (CAP and SIR) and sign language skills (SUS and SPS) and the children's preference for the NSL or written version were found based on Kruskal Wallis tests (see Tables 14 and 15 Appendix B).

## Discussion

Internal consistency and test-retest reliability were established as acceptable to good. CFA resulted in the best fit for the proposed five-factor model for both versions, although not all fit indices reached acceptable levels. The SDQ-NSL and SDQ-NOR both demonstrated similar psychometric properties to those reported for the SDQ in other studies both for TH (Essau et al., 2012; R. Goodman, 2001; van Roy et al., 2008) and DHH children (Cornes & Brown, 2012; Hintermair, 2007; Niclasen & Dammeyer, 2016; Roberts et al., 2015), except for the subscale of prosocial behavior on the SDQ-NSL.

Both self-report versions demonstrated acceptable levels of internal consistency although the DG coefficients were higher

than Cronbach's  $\alpha$  reported in other studies on both DHH (SDQ-Auslan:  $\alpha = .42$  to  $.83$ ; SDQ-BSL:  $\alpha = .21$  to  $.74$ ) and TH children (Cornes & Brown, 2012; Essau et al., 2012; R. Goodman, 2001; Roberts et al., 2015; Viana, Rabian, & Beidel, 2008). A possible explanation for this may be the known tendency of Cronbach's  $\alpha$  to underestimate internal consistency due to its limitations (assumptions of uncorrelated errors, tau-equivalence, and normality; Yanyun & Green, 2011). Acceptable but relatively lower internal consistency was found for peer problems (DG = .68 compared to .74 to .88 on the other scales) on both the SDQ-NSL and SDQ-NOR. This is in accordance with other studies on DHH with a Cronbach's  $\alpha$  of .42 (peer problems) compared to .55 to .83 for the Auslan version and a Cronbach's  $\alpha$  of .21 (peer problems) compared to .23 to .74 for the BSL (Cornes & Brown, 2012; Roberts et al., 2015). For the SDQ-NSL the lowest, but still acceptable, internal consistency was found for prosocial behavior.

The interval of 15 weeks between test and retest was too long to be regarded as a good measure of test-retest reliability. Score differences may reflect actual changes over time, so correlations here should be seen as a lower bound of test-retest reliability. As data collection was dependent on the participants stay at the deaf school it was not possible to shorten the interval even though this would have been desirable. Cornes and Brown (2012) reported higher test-retest reliability for the SDQ-Auslan (.75 to .85); this, however, was based on an interval of 2 days only. The mean test-retest correlation for the SDQ-NSL (.62) was similar



**Table 7** Factor loadings, AVE and model fit indices for the SDQ-NOR based on CFA and PLS-SEM of the five-factor model

Subscale and items	$\lambda$ (CFA)	$\lambda$ (PLS)	AVE	$\chi^2(df)$	$p$	$\chi^2/df$	CFI	TLI	RMSEA	90% CI RMSEA
				406.420 (266)	.000	1.528	.747	.715	.107	.084–.127
Emotional			.586							
3. Somatic	.755	.648								
8. Worries	.809	.795								
13. Unhappy	.763	.713								
16. Clingy	.843	.826								
24. Afraid	.878	.800								
Conduct			.432							
5. Tantrum	.891	.760								
7. Obedient	.434	.302								
12. Fights	.668	.679								
18. Lies	.747	.710								
22. Steals	.695	.726								
Hyperactivity			.441							
2. Restless	.645	.644								
10. Fidgety	.591	.689								
15. Distracted	.908	.670								
21. Reflects	.606	.648								
25. Attends	.687	.669								
Peer			.337							
6. Loner	.435	.454								
11. Friend	.676	.767								
14. Popular	.426	.524								
19. Bullied	.890	.769								
23. Old best	.141	.153								
Prosocial			.489							
1. Considerate	.937	.730								
4. Shares	.430	.591								
9. Caring	.632	.722								
17. Kind	.937	.806								
20. Help out	.702	.626								

Notes. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian. CFA = confirmatory factor analysis. PLS = partial least squares. PLS-SEM = Partial least squares structural equation modeling. AVE = average variance extracted. CFI = comparative fit index. TLI = Tucker–Lewis Index. RMSEA = root mean square error of approximation.

**Table 8** Comparison of CFA of factor models for the self-report SDQ-NSL and SDQ-NOR with goodness of fit indices

Model	Version	$\chi^2(df)$	$p$	$\chi^2/df$	CFI	TLI	RMSEA	90% CI RMSEA
SDQ 5 factor <sup>a</sup>	NSL	323.766 (267)	.010	1.213	.801	.776	.073	.038–.100
	NOR	406.420 (266)	<.001	1.528	.747	.715	.107	.084–.127
SDQ 1 factor <sup>b</sup>	NSL	218.116 (170)	.008	1.283	.846	.827	.084	.046–.115
	NOR	286.070 (170)	<.001	1.683	.768	.740	.122	.097–.146
SDQ second order <sup>c</sup>	NSL	333.091 (273)	.008	1.220	.789	.769	.074	.041–.101
	NOR	423.994 (271)	<.001	1.565	.724	.695	.111	.090–.131

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian. CFA = confirmatory factor analysis. PLS = partial least squares. PLS-SEM = Partial least squares structural equation modeling. AVE = average variance extracted. CFI = comparative fit index. TLI = Tucker–Lewis Index. RMSEA = root mean square error of approximation.

<sup>a</sup>SDQ-5-factor model based on the five proposed subscales

<sup>b</sup>SDQ-1-factor model based on the four problems subscales included in the total score

<sup>c</sup>SDQ-second-order model based on the five subscales as well as a second-order total score for the four problem subscales

to that found by R. Goodman (2001) for a test–retest interval of 4–6 months (.62), as well as that reported by Roberts et al. (2015) for the SDQ-BSL for an interval of 3 weeks (.61). Overall, test–retest reliability was established as acceptable for both self-report versions.

Correlations between the two self-report versions were all significant except for prosocial behavior and much higher than those reported by Cornes and Brown (2012). This may indicate closer correspondence between the SDQ-NSL and SDQ-

NOR, either due to more equivalent phrasing in both written Norwegian and NSL, greater literacy or the high number of children with a spoken language preference among this DHH sample. Literacy, however, was not assessed in this study; therefore, it is difficult to conclude on this subject. Examination of the interitem correlations for the two versions showed that Items 2 (“I am restless. I cannot stay still for long”) and 10 (“I am constantly fidgeting or squirming”) were not significantly correlated. Rønning et al. (2004) have previously described the

**Table 9** Spearman's rho between subscales and total score of the SDQ-NSL and SDQ-NOR self-report (N = 40)

	SDQ-NSL, M (SD)	SDQ-NOR, M (SD)	Spearman's rho <sup>b</sup>
Emotional problems	4.40 (2.42)	4.15 (2.70)	.660
Conduct problems <sup>a</sup>	2.35 (2.41)	1.55 (2.40)	.509
Hyperactivity	3.82 (1.90)	3.52 (1.81)	.538
Peer problems	2.78 (1.73)	2.85 (1.76)	.599
Prosocial behavior	8.18 (1.47)	8.15 (2.05)	.507
Total difficulties	13.35 (6.28)	12.08 (6.83)	.668

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian.

<sup>a</sup>Significant difference on reported mean for conduct problems between the two self-report forms

<sup>b</sup>All Spearman's rho have  $p < .001$ .

**Table 10** Spearman rank correlations for the self- and parent report of the SDQ-NSL and SDQ-NOR

	SDQ-NSL—parent SDQ-NOR (N = 26)	SDQ-NOR—parent SDQ-NOR (N = 30)
Emotional problems	.521*	.400*
Conduct problems	.043	.170
Hyperactivity	.318	.126
Peer problems	.182	.351
Prosocial behavior	.026	-.029
Total difficulties	.231	.269

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian.

\*Correlations significant at  $p < .05$

**Table 11** Symptoms in the normal, sub-clinical and clinical range based on SDQ self-reports

Classification, N (%)	SDQ-NOR			
	Normal	Sub-clinical	Clinical	Total
SDQ-NSL				
Normal	26 (65.0)	1 (2.5)	0 (.0)	27 (67.5)
Sub-clinical	3 (7.5)	1 (2.5)	2 (5.0)	6 (15.0)
Clinical	2 (5.0)	0 (0.0)	5 (12.5)	7 (17.5)
Total	31 (77.5)	2 (5.0)	7 (17.5)	40 (100)

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian.

semantic similarity between these two items in spoken/written Norwegian based on CFA. In NSL, however, the items are more distinct, which may indicate that the SDQ-NSL is better able to differentiate between the two items. The interitem correlations for four of the five items on prosocial behavior were not significant. The nonsignificant correlations of prosocial behavior at item level may be an indication of an issue with the translation of these items. The items on the SDQ-NSL for prosocial behavior should, therefore, be evaluated by new forward and back translations and reviewed by a new reference group.

Other studies have reported problems with the internal consistency of the conduct and peer problem scales for the SDQ self-report (Cornes & Brown, 2012; Essau et al., 2012; R. Goodman, 2001; van Roy et al., 2008). The same pattern can be seen for both

the SDQ-NSL and SDQ-NOR based on the results for discriminant validity (AVE). A possible explanation for this phenomenon on the self-report may be that children's answers are influenced by their knowledge of the social desirability of positive social behavior and they are therefore less likely to admit negative behavior or problems with peers than their teachers or parents. Another explanation may be that the children's understanding of conduct and peer problems are closely linked, and therefore the factors are also correlated.

In the comparison of several different factor models for the SDQ-NSL and SDQ-NOR (five-factor, one-factor, three-factor, and second-order models) the SDQ-NSL demonstrated the best fit for the five-factor model with an acceptable fit on two ( $\chi^2/df$  and RMSEA) of the five goodness of fit measures. Studies including all three informants have previously shown that the parent and teacher versions of the SDQ show better model fit than the self-report in both TH and DHH children (R. Goodman, 1997; Roberts et al., 2015). The fit indices for the SDQ-NSL (CFI: .747, TLI: .715; and RMSEA: .107) are similar to those reported in the BSL study (CFI: .718; TLI: .680; and RMSEA: .071). It should also be noted that the three-factor model did not converge for either version, which is consistent with Norwegian validation studies (Rønning et al., 2004; van Roy et al., 2006; van Roy et al., 2008) and Essau et al.'s (2012) findings for Sweden, the UK, and Germany. It should be noted, however, that the small sample size might have contributed to non-convergence of the three-factor model. As none of the participants answered "Not true" on Item 11 ("I have one good friend or more") of the SDQ-NSL, the empty cells caused the negative factor loading for that item. A larger sample is likely to have secured an answer for all alternative categories. The interfactor correlation of greater than 1 between conduct and peer problems on the SDQ-NOR can be explained by Li's (2016) findings that the WLSMV estimator demonstrates a tendency to overestimate interfactor correlations in small sample sizes. The nonconvergence of the three-factor model for both self-report versions, the negative factor loading on Item 11 of the SDQ-NSL and the interfactor correlation greater than 1 for conduct and peer problems on the SDQ-NOR do leave some uncertainty regarding the correct identification of the CFA models. As the goodness of fit indices of the CFAs in this study were similar to those in other studies (R. Goodman, 2001; Roberts et al., 2015) it is, however, likely that a larger sample would confirm our present results.

Multi-informant correlations for both self-report versions were close to the mean of .25 reported by Achenbach et al. (1987) in their meta-analysis. Multi-informant correlations (total score and subscales) for the SDQ-NSL (range, .03 to .32) were similar to those found for the SDQ in BSL, (range, .18 to .26) Roberts et al. 2015 although lower than those reported by R. Goodman (2001). The parent-child correlations for emotional problems, however, were significant for both versions and greater than the mean correlation of .25 reported by both Achenbach et al. (1987) and Cornes and Brown (2012) for the Auslan version. A possible explanation for this may be the easy access to early intervention as well as sign language tuition for parents of DHH children in Norway, which may, in turn, lead to better communication skills about emotions between parents and DHH children. Laugen, Jacobsen, Rieffe, and Wichstrom (2017) found that parents of preschool children with HL were more accurate in estimating their child's emotion understanding than parents of TH children. The parents' more accurate estimation of their children's emotion understanding (Laugen et al., 2017) may have contributed to the higher level of agreement on emotional problems found in this study.

The majority of the DHH children reported preferring the SDQ-NOR (44.9%). Analyses showed that language preference in everyday life as well as level of spoken and sign language skills did not influence the participants' preference for the written SDQ or SDQ-NSL. A possible explanation for this is that the children's everyday language preferences are parent reported as the children themselves were not asked to report their language preferences for everyday life. The children's spontaneous feedback during administration indicated that the preference for the written version was related to the more time-consuming nature of the video presentation of the NSL version. It is, however, in contrast to studies reporting reading difficulties in many DHH children (Harris et al., 2017; Marschark, Rhoten, & Fabich, 2007; Marschark et al., 2009). It is possible that the high correlations between the SDQ-NSL and SDQ-NOR in our sample are due to better literacy in this sample than in the one reported by Cornes and Brown (2012). This, in turn, could explain the preference for the SDQ-NOR. As we only assessed spoken and sign language skills but not literacy, this cannot be tested within our study.

The higher level of emotional and behavioral symptoms reported by DHH children on the SDQ-NSL for most subscales is in accordance with Cornes and Brown's (2012) and Cornes et al.'s (2006) findings. The rate of emotional and behavioral symptoms in the clinical range for DHH children (17.5% on both self-report versions) was almost twice as high as that reported in a Norwegian community sample (Rønning et al., 2004). This is in accordance with other studies reporting an elevated prevalence of emotional and behavioral problems in DHH children, but somewhat lower than the 20–50% found in other studies (Fellinger et al., 2012; Stevenson et al., 2015; Theunissen et al., 2014). This is in accordance with Dammeyer's (2010b) study, which found higher rates of emotional and behavioral problems in Danish DHH children as compared to TH children. The same study, however, found no increased risk of mental health problems in DHH children with good communication skills. As previously suggested by Mejstad et al. (2009), the extent of parental support provided in Nordic countries may ensure better mental health in DHH children. Mejstad et al. (2009) also found that boys in their DHH sample reported mental health similar to that of community samples, whereas girls in their sample reported significantly more emotional and behavioral problems. In our study, 71.4% of the participants were girls. No significant differences between the reported mean scores on subscales and total score on either version were found; there was, however, a slight tendency for girls to report more symptoms on emotional and peer problems and to have a higher total score. The small number of boys in this sample may have contributed to a failure to replicate the findings of Mejstad et al. (2009). Girls have been found to report more symptoms on emotional problems in other studies as well (Rønning et al., 2004). A further possible explanation for the higher level of emotional and behavioral problems could be the broad range of cognitive abilities in this sample. A closer examination of the data, however, proved the participant with the lowest nonverbal IQ to be an extreme outlier in the IQ distribution. It is therefore not very likely to have influenced the rate of emotional and behavioral problems in this study. The rates of additional impairment in this study, learning and visual impairment, in particular, are equivalent to those reported in other studies (Armitage, Burke, & Buffin, 1995; Gallaudet Research Institute, 2008) and therefore not likely to have influenced the rate of symptoms in this study either.

The items for prosocial behavior on the SDQ-NSL should, however, be reevaluated using a thorough forward and backward translation process to ensure that the items measure the same

concept in both versions. As prosocial behavior is not part of the total difficulties score, this does not pose a problem for the validity of the total score and the assessment of mental health problems.

### Limitations

A major limitation of this study was the small sample size due to the limited number of signing DHH children in the population. The sample size here was lower than the minimum number of cases recommended for CFA and other multivariate analyses based on covariance. This, in turn, poses a problem for a thorough psychometric evaluation of the SDQ-NSL and SDQ-NOR for DHH children. To compensate for the effects of small sample size on CFA, we used the PLS-SEM as well, which is known to be more robust for such situations (Hair et al., 2016). The combination of analyses used here was chosen as the best practical solution for this study but does still leave room for uncertainty regarding the conclusions.

A further limitation is the absence of a gold standard for establishing criterion validity for mental health problems in DHH children. The use of a written instrument such as the Youth Self-Report (ASEBA) as a gold standard would not have been reliable or valid because there is evidence that many DHH children have difficulties reading (Harris et al., 2017; Marschark et al., 2007b; Marschark et al., 2009). Further, the use of a verbal clinical interview without an interpreter or signed supported speech would not have been possible or valid because of the participants' level of HL. In addition, there are no existing studies on the reliability and validity of the simultaneous translation of a semi-structured diagnostic interview such as the Schedule for Affective Disorders and Schizophrenia—Present Life Version 2009 (Kiddie-SADS-PL 2009; Kaufman et al., 1997) to NSL.

### Conclusion

The evaluation of the psychometric properties of the self-report SDQ-NSL is promising. It primarily suffers from the same weaknesses as found in other studies of the self-report (written and signed). Questions may be raised regarding the quality of the items for prosocial behavior on the SDQ-NSL. The use of the SDQ-NSL for assessing mental health in DHH children may, therefore, be recommended. Based on the participants' feedback, the correspondence between the two self-report versions and their similar psychometric properties, we recommend administering the SDQ self-report with both written and signed items in a combined web-based version. As the validation is based on a small sample, further assessment of its psychometric properties in a larger sample is recommended. Further research on DHH children is needed to ensure early detection and intervention, reliable and valid assessment, and treatment of emotional and behavioral problems. Because of the small number of signing DHH children in the population, cross-cultural studies should be encouraged. This would increase the possibility of conducting research on larger samples as well as allowing examination of cross-cultural similarities and differences.

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## Conflict of Interest

On behalf of all the authors, the corresponding author states that there is no conflict of interest. The first author has been involved in the translation of the SDQ-NSL but has not gained any economic benefits from that or retained any financial interests in the SDQ-NSL.

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## References

- Aanonsen, C. M., Heiling, K., Nøvik, T. S., & Jozefiak, T. (2018). Quality of life, family function and mental health of deaf and hard-of-hearing adolescents in mental health services in Norway—A pilot study. *International Journal on Mental Health and Deafness*, 4, 3–13.
- Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin*, 101, 213–232. doi:10.1037/0033-2909.101.2.2133562706
- Achenbach, T. M., & Rescorla, L. (2001). *Manual for the ASEBA school-age forms and profiles: child behavior checklist for ages 6–18, teacher's report form, youth self-report: an integrated system of multi-informant assessment*. Burlington, VT: ASEBA.
- Allen, C., Nikolopoulos, T. P., Dyar, D., & O'Donoghue, G. M. (2001). Reliability of a rating scale for measuring speech intelligibility after pediatric cochlear implantation. *Otology & Neurotology*, 22, 631–633. doi:10.1097/00129492-200109000-00012
- Archbold, S., Lutman, M. E., & Marshall, D. H. (1995). Categories of auditory performance. *Annals of Otology, Rhinology, and Laryngology. Supplement*, 166, 312–314.
- Armitage, I. M., Burke, J. P., & Buffin, J. T. (1995). Visual impairment in severe and profound sensorineural deafness. *Journal Archives of Disease in Childhood*, 73, 53–56. doi:10.1136/adc.73.1.53
- Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, 25, 3186–3191. doi:10.1097/00007632-200012150-00014
- Brown, P. M., & Cornes, A. (2015). Mental health of deaf and hard-of-hearing adolescents: What the students say. *Journal of Deaf Studies and Deaf Education*, 20, 75–81. doi:10.1093/deaf-ed/enu031
- Caluraud, S., Marcolla-Bouchetembé, A., De Barros, A., Moreau-Lenoir, F., De Sevin, E., Rerolle, S., & Lerosey, Y. (2015). Newborn hearing screening: Analysis and outcomes after 100,000 births in upper-Normandy French region. *International Journal of Pediatric Otorhinolaryngology*, 79, 829–833. doi:10.1016/j.ijporl.2015.03.012
- Cornes, A. J., & Brown, P. M. (2012). Mental health of Australian deaf adolescents: An investigation using an Auslan version of the strengths and difficulties questionnaire. *Deafness & Education International*, 14, 161–175. doi:10.1179/1557069X12Y.0000000009
- Cornes, A. J., Rohan, M. J., Napier, J., & Rey, J. M. (2006). Reading the signs: Impact of signed versus written questionnaires on the prevalence of psychopathology among deaf adolescents. *Australian and New Zealand Journal of Psychiatry*, 40, 665–673. doi:10.1111/j.1440-1614.2006.01866.x.16866762
- Dammeyer, J. (2010a). Congenital rubella syndrome and delayed manifestations. *International Journal of Pediatric Otorhinolaryngology*, 74, 1067–1070. doi:10.1016/j.ijporl.2010.06.007
- Dammeyer, J. (2010b). Psychosocial development in a Danish population of children with cochlear implants and deaf and hard-of-hearing children. *Journal of Deaf Studies and Deaf Education*, 15, 50–58. doi:10.1093/deafed/enp024
- Essau, C. A., Olaya, B., Anastassiou-Hadjicharalambous, X., Pauli, G., Gilvarry, C., Bray, D., O'Callaghan, J., & Ollendick, T. H. (2012). Psychometric properties of the strengths and difficulties questionnaire from five European countries. *International Journal of Methods in Psychiatric Research*, 21, 232–245. doi:10.1002/mpr.1364
- Fagerland, M., Lydersen, S., & Laake, P. (2017). *Statistical analysis of contingency tables (1st Ed.)*. Boca Raton, FL: Chapman & Hall/CRC.
- Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet*, 379, 1037–1044. doi:10.1016/S0140-6736(11)2961143-4
- Fellinger, J., Holzinger, D., Sattel, H., & Laucht, M. (2008). Mental health and quality of life in deaf pupils. *European Child and Adolescent Psychiatry*, 17, 414–423. doi:10.1007/s00787-008-0683-y.18810312
- Fellinger, J., Holzinger, D., Sattel, H., Laucht, M., & Goldberg, D. (2009). Correlates of mental health disorders among children with hearing impairments. *Developmental Medicine and Child Neurology*, 51, 635–341. doi:10.1111/j.1469-8749.2008.03218.x
- Fornell, C., & Larcker, D. F. (1981). Structural equation models with unobservable variables and measurement error: Algebra and statistics. *Journal of Marketing Research (JMR)*, 18, 382–388. doi:10.2307/3150980
- Gallaudet Research Institute (2008). *Regional and national summary report of data from the 2007–08 annual survey of deaf and hard of hearing children and youth*. Washington, DC: GRI, Gallaudet University.
- Goodman, A., Lamping, D. L., & Ploubidis, G. B. (2010). When to use broader internalising and externalising subscales instead of the hypothesised five subscales on the strengths and difficulties questionnaire (SDQ): Data from British parents, teachers, and children. *Journal of Abnormal Child Psychology*, 38, 1179–1191. doi:10.1007/s10802-010-9434-x
- Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Child Psychology & Psychiatry & Allied Disciplines*, 38, 581–586. doi:10.1111/j.1469-7610.1997.tb01545.x.9255702
- Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337–1345. doi:10.1097/00004583-200111000-00015
- Hair, J. F., Hult, G. T. M., Ringle, C. M., & Sarstedt, M. (2016). *A primer on partial least squares structural equation modeling (2nd Ed.)*. Thousand Oaks, CA: Sage.

- Harris, M., Terlektsi, E., & Kyle, F. E. (2017). Concurrent and longitudinal predictors of reading for deaf and hearing children in primary school. *Journal of Deaf Studies and Deaf Education*, 22, 233–242. doi:10.1093/deafed/enw101
- Herman, R., Holmes, S., & Woll, B. (1999). *Assessing British Sign Language development: Receptive skills test*. Coleford, England: Forest Book.
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, 11, 320–330. doi:10.1093/deafed/enl005 16809431
- Hintermair, M. (2007). Prevalence of socioemotional problems in deaf and hard of hearing children in Germany. *American Annals of the Deaf*, 152, 320–330. doi:10.1353/aad.2007.0028 18018674
- Hooper, D., Coughlan, J., & Mullen, M. R. (2008). Evaluating model fit: A synthesis of the structural equation modelling literature. Paper presented at the 7th European Conference on Research Methodology for Business and Management Studies, Regent's College, London, United Kingdom
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling*, 6, 1–55. doi:10.1080/10705519909540118
- Kaufman, J., Birmaher, B., Brent, D., Rao, U., Flynn, C., Moreci, P., Williamson, D., & Ryan, N. (1997). Schedule for affective disorders and schizophrenia for school-age children-present and lifetime version (K-SADS-PL): Initial reliability and validity data. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 980–988. doi:10.1097/00004583-199707000-00021
- Koo, T. K., & Li, M. Y. (2016). A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of Chiropractic Medicine*, 15, 155–163. doi:10.1016/j.jcm.2016.02.012
- Laugen, N. J., Jacobsen, K. H., Rieffe, C., & Wichstrom, L. (2017). Emotion understanding in preschool children with mild-to-severe hearing loss. *Journal of Deaf Studies and Deaf Education*, 22, 155–163. doi:10.1093/deafed/enw069 27881481
- Li, C.-H. (2016). Confirmatory factor analysis with ordinal data: Comparing robust maximum likelihood and diagonally weighted least squares. *Behavior Research Methods*, 48, 936–949. doi:10.3758/s13428-015-0619-7
- Marschark, M., Convertino, C. M., Macias, G., Monikowski, C. M., Sapere, P., & Seewagen, R. (2007a). Understanding communication among deaf students who sign and speak: A trivial pursuit? *American Annals of the Deaf*, 152, 415–424. doi:10.1353/aad.2008.0003
- Marschark, M., Rhoten, C., & Fabich, M. (2007b). Effects of cochlear implants on children's reading and academic achievement. *Journal of Deaf Studies and Deaf Education*, 12, 269–282. doi:10.1093/deafed/enm013
- Marschark, M., Sapere, P., Convertino, C. M., Mayer, C., Wauters, L., & Sarchet, T. (2009). Are deaf students' reading challenges really about reading? *American Annals of the Deaf*, 154, 357–370. doi:10.1353/aad.0.0111
- Mehmetoglu, M., & Jakobsen, T. G. (2017). *Applied statistics using stata*. London, England: Sage Publications Ltd.
- Mejstad, L., Heiling, K., & Svedin, C. G. (2009). Mental health and self-image among deaf and hard of hearing children. *American Annals of the Deaf*, 153, 504–515. doi:10.1353/aad.0.0069
- Muris, P., Meesters, C., Eijkelenboom, A., & Vincken, M. (2004). The self-report version of the strengths and difficulties questionnaire: Its psychometric properties in 8- to 13-year old non-clinical children. *British Journal of Clinical Psychology*, 43, 437–448. doi:10.1348/0144665042388982
- Niclasen, J., & Dammeyer, J. (2016). Psychometric properties of the strengths and difficulties questionnaire and mental health problems among children with hearing loss. *Journal of Deaf Studies and Deaf Education*, 21, 129–140. doi:10.1093/deafed/env067
- Ohre, B., Saltnes, H., Von Tetzchner, S., & Falkum, E. (2014). Psychometric properties of a sign language version of the MINI international neuropsychiatric interview (MINI). *BMC Psychiatry*, 14, 1–10. doi:10.1186/1471-244x-14-148
- Roberts, S., Wright, B., Moore, K., Smith, S., Allgar, V., Tennant, A., & Rogers, K. (2015). Translation into British sign language and validation of the strengths and difficulties questionnaire. *Health Services and Delivery Research*, 3. doi:10.3310/hsdr03020
- Roid, G. H., Miller, L. J., Pomplun, M., & Koch, C. (2013). *Leiter international performance scale manual* (3rd Ed.). Wood Dale, IL: Stoelting.
- Rønning, J. A., Handegaard, B. H., Sourander, A., & Mørch, W. T. (2004). The strengths and difficulties self-report questionnaire as a screening instrument in Norwegian community samples. *European Child and Adolescent Psychiatry*, 13, 73–82. doi:10.1007/s00787-004-0356-4
- Sanne, B., Torsheim, T., Heiervang, E., & Stormark, K. M. (2009). The strengths and difficulties questionnaire in the Bergen child study: A conceptually and methodically motivated structural analysis. *Psychological Assessment*, 21, 352–364. doi:10.1037/a0016317
- Seiler, A. F., & Larsen, T. B. (2005). *Vurdering af børns tilegnelse af dansk tegnsprog*. Forståelsestest. [Assessing Danish Sign Language development]. Aalborg, Denmark: Døveskolernes Materialecenter.
- Sinkkonen, J. (1994). Evaluation of mental health problems among Finnish hearing impaired children. *Psychiatria Fennica*, 25, 52–65.
- Stevenson, J., Kreppner, J., Pimperton, H., Worsfold, S., & Kennedy, C. (2015). Emotional and behavioural difficulties in children and adolescents with hearing impairment: A systematic review and meta-analysis. *European Child and Adolescent Psychiatry*, 24, 477–496. doi:10.1007/s00787-015-0697-1 25758233
- Stevenson, J., Pimperton, H., Kreppner, J., Worsfold, S., Terlektsi, E., Mahon, M., & Kennedy, C. (2017). Language and reading comprehension in middle childhood predicts emotional and behaviour difficulties in adolescence for those with permanent childhood hearing loss. *Journal of Child Psychology and Psychiatry*, 59, 180–190. doi:10.1111/jcpp.12803
- Theunissen, S. C., Rieffe, C., Netten, A. P., Briaire, J. J., Soede, W., Schoones, J. W., & Frijns, J. H. (2014). Psychopathology and its risk and protective factors in hearing-impaired children and adolescents: A systematic review. *Journal of American Medical Association Pediatrics*, 168, 170–177. doi:10.1001/jama-pediatrics.2013.3974
- Van Eldik, T. (2005). Mental health problems of Dutch youth with hearing loss as shown on the youth self report. *American Annals of the Deaf*, 150, 11–16. doi:10.1353/aad.2005.0024
- Van Eldik, T., Treffers, P. D. A., Veerman, J. W., & Verhulst, F. C. (2004). Mental health problems of deaf Dutch children as indicated by parents' responses to the child behavior checklist. *American Annals of the Deaf*, 148, 390–394. doi:10.1353/aad.2004.0002
- Van Gent, T., Goedhart, A. W., Hindley, P. A., & Treffers, P. D. A. (2007). Prevalence and correlates of psychopathology in a sample of deaf adolescents. *Journal of Child Psychology and*

Psychiatry, 48, 950–958. doi:10.1111/j.1469-7610.2007.01775.x 17714380

Van Gent, T., Goedhart, A. W., & Treffers, P. D. A. (2012). Characteristics of children and adolescents in the Dutch national in- and outpatient mental health service for deaf and hard of hearing youth over a period of 15 years. *Research in Developmental Disabilities*, 33, 1333–1342. doi:10.1016/j.ridd.2012.02.012

Van Roy, B., Groholt, B., Heyerdahl, S., & Clench-Aas, J. (2006). Self-reported strengths and difficulties in a large Norwegian population 10-19 years: Age and gender specific results of the extended SDQ-questionnaire. *European Child and Adolescent Psychiatry*, 15, 189–198. doi:10.1007/s00787-005-0521-4

Van Roy, B., Veenstra, M., & Clench-Aas, J. (2008). Construct validity of the five-factor strengths and difficulties questionnaire (SDQ) in pre-, early, and late adolescence. *Journal of Child Psychology and Psychiatry*, 49, 1304–1312. doi:10.1111/j.1469-7610.2008.01942.x

Venturini, S., & Mehmetoglu, M. (2017). *PLSSEM: Stata module to implement partial least squares structural equation modelling (PLS-SEM)*. <https://EconPapers.repec.org/RePEc:boc:bocode:s458291>.

Viana, A. G., Rabian, B., & Beidel, D. C. (2008). Self-report measures in the study of comorbidity in children and adolescents with social phobia: Research and clinical utility. *Journal of Anxiety Disorders*, 22, 781–792. doi:10.1016/j.janxdis.2007.08.005

Yanyun, Y., & Green, S. B. (2011). Coefficient alpha: A reliability coefficient for the 21st century? *Journal of Psychoeducational Assessment*, 29, 377–392. doi:10.1177/0734282911406668

## Appendix

### A. Detailed information on the CFA of the SDQ-NSL presented in Table 7

As can be seen in Table 7, the factor loading for item 11, “I have one good friend or more,” is negative. We analyzed the bivariate table for items 11 and 18 “I am often accused of lying and cheating.” Results are shown in Table 12.

Table 12 Bivariate table for Items 11 and 18 of the SDQ-NSL

Item 11: I have one good friend or more	Item 18: I am often accused of lying and cheating			Total
	Certainly true	Somewhat true	Not true	
Certainly true	2	11	22	35
Somewhat true	0	0	5	5
Not true	0	0	0	0
Total	27	11	2	40

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language.

The empty cells for Item 11 for “Not true” are due to the small sample size and cause the negative factor loading.

### B.

Table 13 Contingency table for preferred mode of communication in everyday life and preference for the SDQ-NSL or SDQ-NOR

Communication in everyday life	Which version of the SDQ do you prefer?				Total
	NSL	Written	Combined	Don't know	
Spoken Norwegian	2	7	2	1	12
NSL	2	0	2	0	4
Bilingual	1	6	1	2	10
Total	5	13	5	3	26

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian. Fisher's exact test:  $p = .196$ .

Table 14 Contingency table for sign language skills and preference for the SDQ-NSL or SDQ-NOR

Sign language skills	Which version of the SDQ do you prefer?				Total
	NSL	Written	Combined	Don't know	
4	1	0	0	0	1
5	0	1	0	0	1
7	0	1	0	0	1
8	0	2	2	1	5
9	0	2	0	1	3
10	1	2	1	1	5
11	2	2	0	0	4
12	0	3	1	0	4
Total	4	13	4	3	24

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. SDQ-NOR = Strengths and Difficulties Questionnaire self-report in written Norwegian. Sign language skills: Sum score of SUS and SPS, range 0 to 12. Kruskal-Wallis equality-of-populations rank test, chi-squared:  $p = .423$ .

Table 15 Contingency table for spoken language skills and preference for the SDQ-NSL or SDQ-NOR

Spoken language skills	Which version of the SDQ do you prefer?				Total
	NSL	Written	Combined	Don't know	
7	1	0	0	0	1
10	0	2	0	0	2
11	0	1	1	0	2
12	2	10	4	3	2
Total	3	13	5	3	19

Notes. SDQ-NSL = Strengths and Difficulties Questionnaire self-report in Norwegian Sign Language. Spoken language skills: sum score of CAP and SIR, range 0 to 12. Kruskal-Wallis equality-of-populations rank test, chi-squared:  $p = .431$ .

# Paper II





RESEARCH ARTICLE

Open Access



# Psychometric properties of the Inventory of Life Quality in children and adolescents in Norwegian Sign Language

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## Abstract

**Background:** Several studies have assessed the Quality of Life (QoL) in Deaf and hard-of-hearing (DHH) children and adolescents. The findings from these studies, however, vary from DHH children reporting lower QoL than their typically hearing (TH) peers to similar QoL and even higher QoL. These differences have been attributed to contextual and individual factors such as degree of access to communication, the participants' age as well as measurement error. Using written instead of sign language measures has been shown to underestimate mental health symptoms in DHH children and adolescents. It is expected that translating generic QoL measures into sign language will help gain more accurate reports from DHH children and adolescents, thus eliminating one of the sources for the observed differences in research conclusions. Hence, the aim of the current study is to translate the Inventory of Life Quality in Children and Adolescents into Norwegian Sign Language (ILC-NSL) and to evaluate the psychometric properties of the self-report of the ILC-NSL and the written Norwegian version (ILC-NOR) for DHH children and adolescents. The parent report was included for comparison. Associations between child self-report and parent-report are also provided.

**Methods:** Fifty-six DHH children completed the ILC-NSL and ILC-NOR in randomized order while their parents completed the parent-report of the ILC-NOR and a questionnaire on hearing- and language-related information. Internal consistency was examined using Dillon-Goldstein's rho and Cronbach's alpha, ILC-NSL and ILC-NOR were compared using intraclass correlation coefficients. Construct validity was examined by partial least squares structural equation modeling (PLS-SEM).

**Results:** Regarding reliability, the internal consistency was established as acceptable to good, whereas the comparison of the ILC-NSL with the ILC-NOR demonstrated closer correspondence for the adolescent version of the ILC than for the child version. The construct validity, as evaluated by PLS-SEM, resulted in an acceptable fit for the proposed one-factor model for both language versions for adolescents as well as the complete sample.

**Conclusion:** The reliability and validity of the ILC-NSL seem promising, especially for the adolescent version, even though the validation was based on a small sample of DHH children and adolescents.

**Keywords:** Quality of life, DHH children, Psychometric properties, Sign language

## Background

### Quality of life in Deaf and hard-of-hearing children and adolescents

The number of studies on Quality of Life (QoL) in Deaf and hard-of-hearing (DHH) children and adolescents has increased over the past decades, mainly focusing on

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children with cochlear implants. However, as Hintermair [1], points out, several aspects make it difficult to compare these studies. Among these are differences in the definition of QoL, ranging from Health-Related QoL (HRQoL) to social well-being, different types of assessments (generic QoL measures, ad-hoc tools designed for specific studies, and parents' qualitative reports after their children's cochlear implantation), and different informants (parents and children) as well as differences in access to communication and peers. Researchers such as Warner-Czyz et al. [2] have demonstrated the importance of including both parents' and children's perceptions. They found that 4–7-year-old DHH children in their study reported better QoL than their parents. Chmiel et al. [3] support this necessity based on parents reporting better QoL for their 3–20-year-old DHH children and adolescents after cochlear implantation when compared with their children's self-report. Fellingner et al. [4] also report low agreement between parents and their 6–16-year-old DHH children and adolescents on the Inventory of Life Quality in Children and Adolescents (ILC). Parents report the same level of QoL for their DHH children as parents of a typically hearing (TH) normative sample. The DHH children themselves report being less satisfied with play/hobbies when alone, as well as physical health, compared with TH normative data. The same DHH children report better QoL related to school and family. Other researchers such as Pardo-Gijarro et al. [5], on the other hand, find moderate agreement between Spanish DHH children and adolescents and their parents when using a written and a Spanish sign language version of the KIDSCREEN27, with correlations between 0.377 and 0.753. Discrepancies between child- and parent-report have also been reported for TH children and adolescents [6, 7]. Therefore, the multi-informant approach has been emphasized for accessing QoL. Other factors that are likely to have contributed to differences in DHH children and adolescents' QoL are variations in participants' age, their preferred mode of communication and degree of hearing loss. It has previously been found for both TH and DHH children that older adolescents report lower QoL [5, 8–10]. The development of reliable and valid QoL instruments in sign language will help gain more accurate reports from DHH children who use sign language as their preferred language, thus eliminating one of the sources for the observed differences in research conclusions. In the present study, the term "children" is used for those aged 11 and younger, whereas "adolescents" refers to those aged 12 and older.

In their systematic review Roland, Fischer, Tran, et al. [11] report that 11 of 16 studies based on DHH children and adolescents and validated QoL measures find significantly lower QoL when compared with normative scores

or TH controls, whereas five studies do not identify such differences in QoL. Their meta-analysis reveals that DHH children and adolescents report decreased QoL in the social and school domains based on the Pediatric Quality of Life Inventory (PedsQL). Unfortunately, there are some issues with this systematic review [11]. One problem is the lack of information about the informants for the specific studies.

Another issue with Roland, Fischer, Tran, et al.'s [11] systematic review is that Hintermair's [1] and Fellingner, Holzinger, Sattel, et al.'s [4] results are cited wrongly, that is, a maximum of 9 out of 16 studies (not 11 out of 16 as the authors state) find significantly lower QoL when compared with normative scores or TH controls. Hintermair [1] finds that mainstreamed DHH children and adolescents report better QoL based on the total QoL score, as well as in the domains of school, physical health, mental health, and global QoL, on the ILC than a normative TH sample. The effect sizes for the reported differences were small to moderate. Fellingner, Holzinger, Gerich, et al. [12] and Hintermair [1] report QoL being unrelated to the type and degree of hearing loss in DHH adults, children and adolescents respectively, whereas others such as Tsimpida, Kaitelidou, and Galanis [13] find that DHH adults with a higher degree of hearing loss report lower QoL. Kushalnagar, Topolski, Schick et al. [14] demonstrate that adolescents (11–18 years old) report higher QoL when they perceive that they understand most of their parents' expressive communication. This was not dependent on their preferred communication modality or degree of hearing loss. Adolescents with a preference for a combination of sign language and speech, however, reported experiencing less stigma than those with a strong preference for speech only [14].

#### Assessing QoL in DHH children and adolescents

Language and communication are essential for assessing QoL. Sign languages are natural languages that share many linguistic characteristics with spoken languages but also have specific features due to their manual-visual nature [15]. Studies have also shown that cultural context influences the understanding of seemingly identical wordings, especially when translating from written text to sign language [16, 17]. The acknowledgment of sign languages as natural languages has helped lead to a shift from viewing DHH people in a medical and disability perspective to a socio-cultural one, appreciating deaf culture with its language, history, traditions, art and values [18, 19]. For several DHH children and adolescents written language is considered as their second language. Studies have reported reading difficulties for many DHH children and adolescents [20–22], which in turn are likely to affect their ability to complete written forms, compromising

the validity of assessments based on written forms. When assessing symptoms of mental health problems in DHH children and adolescents, it has been confirmed that the use of written self-report measures can lead to underestimating symptoms [23, 24]. Most measures are designed for assessing TH people. A common solution in clinical practice is the use of sign language interpreters, who will provide on-the-spot translations, which will be influenced by their training and experience and therefore vary across settings and children [25]. Pardo-Guijarro, Martínez-Andrés, Notario-Pacheco et al. [5] emphasize the need to translate valid and reliable generic QoL measures into sign language to assess QoL in DHH children and adolescents and compare them to their TH peers' QoL. Assessment tools for QoL exist in some sign languages so far—American [26], Austrian [27], and Spanish Sign Language [5]. To the best of our knowledge, there is a lack of such instruments and a lack of studies on QoL in Norwegian DHH children and adolescents.

#### The Inventory of Life Quality (ILC)

The ILC is a brief measure to assess QoL in children and adolescents. The measure is based on the concept of the individual's perception of their position in life, including their health, functioning, and participation in routines and activities as compared to their peers [6, 7]. It consists of seven items. One item for Global QoL and six items addressing the child's physical and mental health, school and family functioning, social contact with peers as well as play/hobbies when alone. The ILC is a multi-informant assessment and can be completed by children, adolescents, and young adults aged 6–21 and their parents. For children aged 6–11, the self-report is administered as an interview. Achenbach, McConaughy and Howell [28] among others, emphasize the importance of multi-informant assessments for capturing the unique perspectives held by each informant.

The original German validation found acceptable internal consistency ( $\alpha=0.63$  self-report and  $\alpha=0.76$  parent report) and test–retest reliability ( $r=0.72$  self-report and  $r=0.80$  parent report) for the QoL score ( $LQ_{0-28}$ ) for community samples. Convergent validity with the Kinder Lebensqualität Fragebogen (KINDL) was shown to be moderate. Construct validity based on Principal Component Analysis was found to be acceptable for the one-component model in a community sample (self- and parent-report;  $N=9292$  and  $N=1109$ ) and a two-component model in a clinical sample (self- and parent-report;  $N=605$  and  $N=568$ ) [7]. For the two-component model, one component consisted of one item only (play/hobbies when alone) and the other component of the other six items. Based on the low number of items as well as the nature of the clinical sample and the relatively

lower number of participants, the authors concluded that the one-component model fit the theoretical model best [7]. The importance of examining psychometric properties for measures of QoL in both community and clinical samples has been demonstrated by Jozefiak, Mattejat and Remschmidt [6] amongst others when examining the relationship between depression and QoL.

The validation of the Norwegian self and parent report [6] found satisfactory internal consistency for adolescents aged 11 and older (self-report: Cronbach's  $\alpha=0.80$ – $0.82$ , parent report:  $\alpha=0.78$ ). For children aged ten and younger, internal consistency was somewhat lower ( $\alpha=0.64$ ). The two-week test–retest reliability for the self-report was found to be high ( $r=0.86$ ). The one-factor model of the ILC based on confirmatory factor analysis demonstrated good fit in three community samples and acceptable fit in the fourth (clinical) sample. Moderate correlations between the KINDL and ILC self-report were found, supporting convergent validity [6]. A systematic Norwegian review based on five studies of the psychometric properties of the ILC confirmed these findings [29].

To the best of our knowledge, the ILC has only been used to study QoL in DHH in Germany, Austria, and Norway. Construct validity for DHH children and adolescents has only been studied in Germany [1]. In this sample, the DHH children and adolescents were all mainstreamed, indicated a preference for spoken language, and were assessed with the original written version. Hintermair [1] finds satisfactory internal consistency ( $\alpha=0.71$ ) for the ILC in this German DHH sample with 212 participants; interitem correlations showed the same pattern as for TH children and adolescents with the items “Mental Health” and “Global QoL”, demonstrating the highest correlations with the QoL score ( $LQ_{0-28}$ ). A principal component analysis with subsequent varimax rotation resulted in the best fit for the two-component solution, “Family” and “Alone (play/hobbies),” constituting one component, while the other five items constituted the other component. Hintermair [1] concludes that these results support the use of the ILC for DHH mainstreamed children and adolescents with a preference for spoken language.

Except for the pilot study by Aanondsen et al. [8], there are hardly any studies on Norwegian DHH children and adolescents' QoL, and no studies validating assessment tools in NSL for assessing QoL in DHH children and adolescents. Norway is unique in offering the parents of DHH children and adolescents 40 weeks (i.e., 2–4 weeks/year) of NSL classes over the course of 16 years, with all expenses covered. Therefore, one might expect a higher level of sign language skills among Norwegian DHH children and adolescents and their parents. This, in turn, may have a positive influence on their QoL. The

inconsistencies in previous studies regarding DHH children and adolescents' QoL necessitate valid tools, both written and in sign language, to bridge the gap. The present study contributes to this by both translating the ILC to NSL as well as providing psychometric properties for the Norwegian version of the ILC self-report (ILC-NOR) and the NSL version (ILC NSL). The ILC NSL is the first instrument translated to NSL for assessing QoL in Norwegian DHH children and adolescents.

**Methods**

**Aims**

The main aims of the present study were to translate and validate the ILC self-report in NSL (ILC-NSL) and compare it with the ILC-NOR in Norwegian DHH children and adolescents. Both self-reports of the ILC were compared with the parent report. Finally, the usability of the ILC-NSL for signing DHH children and adolescents was assessed from the children and adolescents' perspective.

We addressed the following research questions.

1. What is the internal consistency of the ILC-NSL and ILC-NOR for DHH children and adolescents?
2. What are the correlations between the total scores and items between the self-report ILC-NSL and ILC-NOR?
3. What is the construct validity of the ILC-NSL and ILC-NOR for DHH children and adolescents?

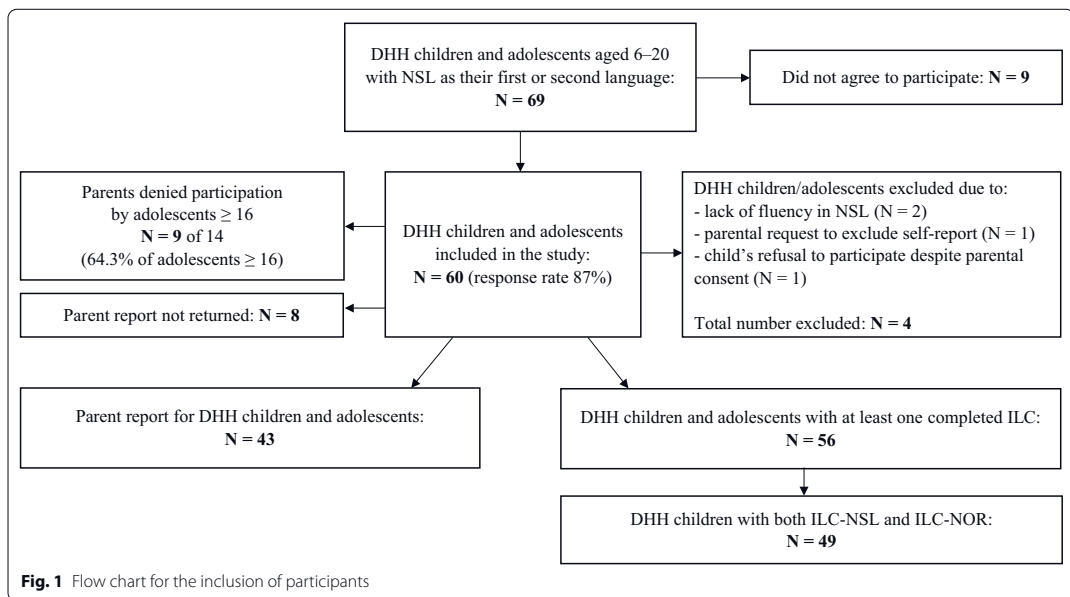
4. What are the correlations between the QoL score (LQ<sub>0-28</sub>) and items between the self-reports (ILC-NSL and ILC-NOR) and parent report?
5. What do DHH children and adolescents think about the usability of the ILC-NSL and ILC-NOR?

**Participants**

Caluraud, Marcolla-Bouchetemplé, de Barros et al. [30] report that hearing loss (HL) of >40 dB affects 1.4 per 1000 infants (mild HL in 13%, moderate HL in 50%, severe HL in 17%, and profound HL in 20%). In central and northern Norway, this amounts to 266 children and adolescents with a HL of >40 dB, that is, 45 with severe and 53 with profound HL based on a population of 189,737 children and adolescents aged 6–18.

DHH children and adolescents aged 6–17 were recruited from the part- and full-time students at A.C. Møller school, a Deaf school for central and northern Norway during the school year of 2016/17. DHH adolescents aged 15–20 attending Tiller upper secondary school in central Norway with NSL as their first or second language were also invited. The overall response rate for the combined subsamples was 87% (60/69) (see Fig. 1).

Two children were excluded because of a lack of fluency in Norwegian sign language. Apart from fluency in both written and signed Norwegian (NSL), we applied



**Fig. 1** Flow chart for the inclusion of participants

no exclusion criteria. In total, 56 DHH children and adolescents (67.9% girls) participated in the current study, with a mean age of 12.4 years ( $SD=3.65$ ; range = 6–20) and a mean nonverbal IQ of 106.91 ( $SD=17.74$ ; range = 49–143). The participant with the lowest nonverbal IQ was included in further analysis despite being an extreme outlier in the IQ distribution (range excluding outlier = 74–143). Thirty-seven of the 42 (88.1%) mothers had completed 12 years or more of education, whereas 28 of the 41 (68.3%) fathers had completed 12 years or more of education. Data were collected between November 1, 2016 and May 9, 2017. The majority of the DHH children and adolescents (69%) mainly attended mainstream schools while spending two to six weeks at the deaf school per school year.

Hearing- and language-related information for the participants in the current study can be found in Tables 1 and 2.

## Measures

### *Sociodemographic and hearing-related information*

A questionnaire completed by the parents was used to assess the participants' age, sex, type and severity of HL, type of education, and parents' attendance of sign language classes. The same questionnaire was also used in a previous study by the same authors [31].

### *Language-related information*

**Spoken language skills** Categories of Auditory Performance (CAP; Archbold, Lutman and Marshall [32]) and Speech Intelligibility Rating (SIR, Allen, Nikolopoulos, Dyar et al. [33]) were used to assess participants' speech intelligibility and listening skills. The CAP is a single-item scale with a range of 0–7. Level 0 is “no awareness of environmental sounds”, and Level 7 “uses a telephone with a known speaker.” The SIR is also a single-item scale with a range of 1–5. Level 1 is “connected speech is unintelligible”, and 5 “connected speech is intelligible to all listeners.” The interrater reliability of the Danish version is based on the reports of two teachers and was reported as good (CAP:  $\kappa=0.785$ ; SIR:  $\kappa=0.848$ ; Dammeyer [34]). The Norwegian versions of the CAP and SIR were recently used in a study by Aanondsen, Jozefiak, Heiling et al. [31] for a similar group of participants. The scores of CAP and SIR were combined to form the Spoken Language Skills Score.

**Sign language skills** The Norwegian versions of the Sign Language Production Scale (SPS) and the Sign Language Understanding Scale (SUS) were used to assess Sign Language Skills [34]. The SPS and SUS were designed as a short screening of sign language skills for research purposes and have previously been used in Norway [31]. SUS

**Table 1** Hearing-related characteristics (parent report)

Variable	N = 42	%
DHH family member(s)		
Yes/no	22/20	52.4/47.6
Time in deaf school <sup>a</sup>		
1–2 days a week <sup>b</sup>	8	19.0
5 days a week	4	9.5
2–6 weeks a year	29	69.0
> 7 weeks a year	8	19.0
Etiology of hearing loss		
Acquired	4	9.5
Hereditary/at birth	36	85.7
Unknown	1	2.4
Missing	1	2.4
Severity of hearing loss		
Moderate: 40–70 dB	10	23.8
Severe: 71–100 dB	14	33.3
Profound: 101+	12	28.6
Unknown	5	11.9
Missing	1	2.4
Use of hearing aid (yes/no) <sup>c</sup>		
CI	20/21	47.6/50.0
Hearing aid	33/ 8	78.6/19.0
Missing	1	2.4
Age at diagnosis		
0–2 years	27	64.3
3–5 years	15	35.7
Preferred language		
Oral	21	50.0
Sign	6	14.3
Bilingual	15	35.7
Other impairment		
Vision	14	32.6
Motor	1	2.3
Learning	4	9.3
Other	8	18.7
Missing	3	7.0

<sup>a</sup> All children attend both mainstream and deaf school

<sup>b</sup> Children attending the deaf school for 1–2 days a week combine this with two or more week-long stays during the school year; that is, total number of answers is greater than the number of participants

<sup>c</sup> Based on reports of ever having used a hearing aid

and SPS are based on the structure and range of CAP and SIR. The SPS is a single-item scale with a range of 1–5. Level 1 is “the child does not produce real signs” and Level 5 “the child uses fluent and almost conventional correct sign language.” The SUS is a single-item scale with a range of 0–7. Level 0 is “does not react to or does not comprehend signs” and Level 7 “is able to participate in long and complex conversations in sign language.” The interrater

**Table 2** Language-related information based on parent report

Language skills	N	M (SD)
Sign language skills (1–12; CA)	38	9.05 (2.09)
Ages 6–11 (ILC Child) <sup>1</sup>	23	8.87 (1.82)
Ages 12–20 (ILC Adol.)	15	9.33 (2.50)
Spoken language skills (1–12; CA)	40	11.20 (1.70)
Ages 6–11 (ILC Child) <sup>1,2</sup>	25	11.28 (1.70)
Ages 12–20 (ILC Adol.)	15	11.07 (1.75)

Sign Language Skills based on the sum scores of the sign language production scale (SPS) and the sign language understanding scale (SUS); range 0–12. Higher scores indicate better communication skills

Spoken Languages Skills based on the sum scores of Categories of Auditory Performance (CAP) and Speech Intelligibility Rating (SIR); range 0–12. Higher scores indicate better communication skills

CA children and adolescents—complete sample

<sup>1</sup> Significant difference between scores for Sign Language Skills (M = 8.87, SD = 1.82) and Spoken Language Skills (M = 11.28, SD = 1.70) for ages 6–11;  $t(22) = -5.53$ ,  $p < .001$

<sup>2</sup> One extreme outlier with a sum score of 4 (> 3 SD) was found for ages 6 to 11 for spoken language skills

reliability of the Danish version based on the reports of two teachers was reported as good ( $\kappa = 0.944$  for SUS and  $\kappa = 0.921$  for SPS; Dammeyer [34]). The Danish version [35] of Assessing British Sign Language Development: Receptive Skills Test [36] was used to assess the validity of the SUS. The SUS and the sign language receptive skills test correlated significantly (Spearman rank correlation coefficient = 0.905,  $p < 0.000$ ; [37]). The validity of the SPS could not be evaluated due to the lack of a comparable assessment. The scores of SPS and SUS were combined to form the “Sign Language Skills Score”.

### Cognitive abilities

The Leiter International Performance Scale – Third Edition (Leiter-3) was used to assess nonverbal intelligence. It includes the following subtests: Figure Ground, Form Completion, Classification/Analogies, and Sequential Order. The sum of the scaled scores for these subtests constitutes the composite score of nonverbal IQ and is converted to the standard score [38].

### Quality of life (QoL)

The Inventory of Life Quality in Children and Adolescents—ILC [6, 7] is a multi-informant assessment for QoL based on seven items. One item assesses overall QoL, and six items address the child’s physical and mental health, school and family functioning, social contact with peers, play/hobbies when alone. Items are rated on a 5-point Likert scale from 1 = “Very Good” to 5 = “Very Bad.” The QoL score ( $LQ_{0-28}$ ) is calculated by multiplying the mean of the seven items by seven and subtracting

35, thus obtaining absolute values with a range of 0 to 28; higher scores representing better QoL ( $LQ_{0-28}$ ) and lower QoL scores reflecting poorer overall QoL [6, 7].

In the current study, we administered the written parent report (ILC-NOR) and the self-report versions for children (6–11) and adolescents (12 and older) in both written and signed Norwegian (ILC-NOR and ILC-NSL), according to the manual [6]. Because of the differences reported [6] in internal consistency between the adolescent (Cronbach’s  $\alpha = 0.81$ ) and the child version (Cronbach’s  $\alpha = 0.64$ ), psychometric properties will be reported separately for the child and the adolescent versions, as well as for the complete sample (CA).

### The translation process

The translation of the ILC was conducted based on the guidelines for cross-cultural adaptation of written self-report measures by Beaton, Bombardier, Guillemin et al. [39] with adaptations suggested by Roberts, Wright, Moore et al. [25]. Suggestions were based on the differences in syntax, morphology and prosody of sign languages and their visual nature. The same translation process was applied and described in this study by Aanondsen, Jozefiak, Heiling et al. [31]. The ILC-NOR went through two independent forward and backward translations from written Norwegian to NSL. Two bilingual deaf native NSL users with university degrees in teaching conducted and recorded these. The semantic, conceptual, lexical, and cultural differences were discussed by a panel. Members of the panel were the translators, a clinical psychologist, a colleague with a graduate degree in medicine specializing in child and adolescent psychiatry, and a consultant with a master’s degree in language and communication and fluency in NSL. Based on these discussions, the panel developed a consensus-based forward translation that was filmed. Teachers from the local deaf school were used as a focus group. Best practice recommends including DHH children and adolescents in these focus groups. Due to constraints related to time and access to children of the right ages, teachers, who meet DHH children and adolescents with varying degrees of NSL and ages were recruited instead. The teachers (Deaf, hearing, and CODA, that is, a TH person raised by deaf parents) were asked to evaluate whether DHH children and adolescents with a mixture of language experiences and levels of fluency would be able to understand the translation. Based on the feedback of the focus group, the consensus version was adjusted and filmed again. Two hearing sign language interpreters, one with a background as a CODA and a master’s degree in language and communication conducted the backward translations of the final consensus version. These were

reviewed by the panel and compared with the original written Norwegian version.

The author of the Norwegian version of the ILC, Thomas Jozefiak, approved the items and made suggestions for those not approved on behalf of the copyright holders (Hogrefe). These items went back through the translation cycle until final approval was achieved. After the final approval, the ILC-NSL was filmed professionally and prepared for interactive online administration using Select Survey.

### Procedures

The enrolled children and adolescents and their parents received oral/signed and written information about participating in the study during their first attendance at the school after the survey had been initiated. Written informed consent was obtained from the adolescents and parents prior to inclusion, according to the study's survey procedures. The participating children and adolescents responded to the web-based ILC-NSL and ILC-NOR as well as a question about the usability of the two language versions and completed a nonverbal cognitive assessment. The nonverbal cognitive assessment was administered by a psychologist experienced in working with DHH children in mental health services and fluent in NSL. The administration of the ILC-NSL and ILC-NOR were conducted on two separate occasions with an interval of two to three days. The order of these two administrations was randomized. Parents also responded to a questionnaire on socioeconomic status, as well as questionnaires assessing their children's mental health, communication skills in spoken and signed Norwegian, and hearing status. DHH children and adolescents had access to their teacher and a psychologist, both of whom were fluent in NSL, during data collection. When the children and adolescents asked for help with the ILC-NSL, they received support in NSL, whereas the children and adolescents replying to the ILC-NOR were assisted in spoken Norwegian or sign-supported speech.

### Statistical analyses

Missing values on five cases with  $\leq 3$  missing item values were substituted using expectation maximization (EM; [40]). Gender differences in item and scale mean scores were analyzed using independent samples t-tests. Mean differences were calculated. Bootstrapped confidence intervals were calculated using the bias corrected and accelerated method (BCa) and  $B=1000$  bootstrap samples. Differences between spoken and sign language skills were analyzed using paired sample t-tests for both age groups.

Dillon–Goldstein's rho (DG rho) was used to assess internal consistency because of the limitations of

Cronbach's  $\alpha$ , such as assumptions of uncorrelated errors, tau-equivalence and normality [41]. As most authors, however, report internal consistency based on Cronbach's  $\alpha$ , we also calculated Cronbach's  $\alpha$ , including bootstrapped confidence intervals for comparison. DG rho and Cronbach's  $\alpha$  were interpreted as acceptable internal consistency at 0.6–0.7, and as good internal consistency when  $> 0.7$ . Intraclass correlation coefficients (ICC) based on a two-way mixed effects model with absolute agreement were used to evaluate associations between the scale and item scores of the two self-reports (ILC-NSL and ILC-NOR). Intraclass correlation coefficients (ICC) were calculated for each of the seven items and the QoL score  $LQ_{0-28}$  to compare the two language versions of the self-report. We calculated Spearman's rank correlations to assess multi-informant correlations between the QoL scores on the parent and self-reported versions (NSL and NOR).

Partial least squares structural equation modeling (PLS-SEM) is a robust method when dealing with small sample sizes because it is nonparametric and makes fewer distributional assumptions. PLS-SEM, however, is mostly used for exploratory purposes because it lacks goodness of fit measures. Because of the small sample size, we primarily used PLS-SEM to establish factor loadings and discriminant validity (average variance extracted (AVE)) as suggested by Hair, Hult, Ringle et al. [42]. Standardized factor loadings greater than 0.4 were considered acceptable [43]. Factors with AVE scores greater than 0.5 were regarded as satisfactory for convergent/discriminant validity. Fornell and Larcker [44], however, argue that  $AVE > 0.4$  can be treated as acceptable if composite reliability is above 0.6.

As a supplementary analysis of the confirmed ILC factor structure, we used confirmatory factor analysis (CFA) with the weighted least squares means and variances adjusted (WLSMV) estimation method for categorical variables. The chi-square test, the normed chi-square ( $\chi^2/df$ ), the root mean square error of approximation (RMSEA), comparative fit index (CFI) and Tucker-Lewis Index (TLI) were used to assess model fit. A non-significant chi-square test, CFI and TFI  $> 0.9$ , RMSEA  $< 0.1$  were considered indicators of acceptable goodness of fit according to Mehmetoglu and Jakobsen [43], whereas CFI and TFI  $> 0.95$  and RMSEA  $< 0.05$  were considered as indicators of good model fit [45]. A normed chi-square of  $< 2.0$  was considered as good for this study, and ratios of  $< 5.0$  as acceptable [46]. Standardized factor loadings greater than 0.4 were considered acceptable [43]. Hair, Hult, Ringle et al. [42] point out that a small sample size can cause problems with unidentified models and nonconvergence in CFA. The estimator WLSMV has been shown to overestimate interfactor correlations

when the sample size is relatively small [47]. Due to these problems, the CFA was used as a supplementary analysis only and can be found in Additional file 1: Appendix C. All analyses were conducted separately for the child and the adolescent versions, as well as for the complete age sample, that is, both the child and adolescent versions combined (CA).

The CFA was conducted in MPlus version 8. All other-analyses were conducted in Stata/SE 14.2 for Windows. PLS-SEM, including AVE, was conducted in Stata by applying the module for PLS-SEM [48]. For all analyses, two-sided p-values < 0.05 were considered statistically significant.

**Ethics**

Written informed consent was obtained from the parents and adolescents older than 16 prior to inclusion, as well as oral/signed informed consent from the children and adolescents under the age of 16. Study approval was given by the Regional Committees for Medical and Health Research Ethics (reference number: 2015/1739/REK midt).

**Results**

Table 3 presents the means and standard deviations for the DHH participants on the self-report of the ILC (ILC-NSL and ILC-NOR). A table with mean differences for all items and bootstrapped confidence intervals can be found in Additional file 1: Appendix A. The full distribution of all items and QoL score for both self-reports is reported in Additional file 1: Appendix B.

Independent sample t-tests for the complete sample showed a significant gender difference for the QoL score LQ<sub>0-28</sub> (girls: M = 20.916, SD = 0.780; boys: M = 24.239, SD = 0.651); t(54) = - 2.720, p = 0.009 for the ILC-NOR and none for the ILC-NSL.

**Reliability**

**Internal consistency**

As can be seen in Table 4, internal consistency based on DG rho and Cronbach's alpha was found to be good for all scales and age versions, except for the ILC-NSL child version, which demonstrated acceptable internal consistency based on Cronbach's alpha and good internal consistency based on DG rho.

**Comparison of the ILC-NSL and ILC-NOR**

To compare the ILC-NSL with the ILC-NOR self-report, intraclass correlation coefficients (ICC) were calculated for each of the seven items and the QoL score (Table 5).

The ICCs between the LQ<sub>0-28</sub> of the ILC-NSL and ILC-NOR were highly significant at p < 0.001 for the complete sample, as well as for the adolescent version, but not for the child version.. The items on the adolescent versions were all significantly correlated, moderately to strongly (0.441–0.867), while none of the items on the child versions correlated significantly.

**Table 4** Internal consistency for the ILC

ILC LQ <sub>0-28</sub>	DG	Cronbach's alpha	[95% CI] <sup>2</sup>	
ILC-NSL CA <sup>1</sup> (N = 49)	.827	.747	.569	.842
ILC-NSL child (N = 22)	.815	.698	.379	.874
ILC-NSL adol. (N = 27)	.861	.805	.618	.949
ILC-NOR CA <sup>1</sup> (N = 56)	.874	.824	.704	.903
ILC-NOR child (N = 25)	.856	.785	.491	.880
ILC-NOR adol. (N = 31)	.885	.842	.680	.923

The Inventory of Life Quality in Children and Adolescents (ILC); QoL score (LQ<sub>0-28</sub>)

<sup>1</sup> CA children and adolescents—complete sample

<sup>2</sup> CI: bootstrapped confidence intervals

**Table 3** Mean and SD for ILC-NSL and ILC-NOR self-report item scores and QoL Score (LQ<sub>0-28</sub>)

ILC	School	Family	Other children	Alone (play/hobbies)	Physical Health	Mental Health	Global QoL	LQ <sub>0-28</sub>
ILC-NSL CA <sup>1</sup> (N = 49)	1.86 (0.95)	1.71 (0.86)	2.05 (1.05)	2.33 (1.07)	1.92 (0.86)	2.02 (1.05)	1.97 (0.81)	21.15 (4.23)
ILC-NSL child (N = 22)	1.59 (0.78)	1.76 (0.87)	1.94 (1.10)	2.64 (1.05)	1.95 (1.09)	1.81 (1.01)	1.75 (.81)	21.56 (3.99)
ILC-NSL adol. (N = 27)	2.07 (1.04)	1.67 (0.88)	2.15 (1.03)	2.07 (1.04)	1.89 (0.70)	2.19 (1.08)	2.15 (0.77)	20.81 (4.47)
ILC-NOR CA <sup>1</sup> (N = 56)	1.89 (0.93)	1.45 (0.74)	1.79 (0.75)	2.11 (1.06)	1.95 (1.02)	1.96 (0.93)	1.88 (0.99)	21.98 (4.51)
ILC-NOR child (N = 25)	1.48 (0.71)	1.32 (0.69)	1.61 (0.69)	2.28 (1.10)	1.76 (0.93)	1.47 (0.82)	1.52 (1.05)	23.56 (4.02)
ILC-NOR adol. (N = 31)	2.23 (0.96)	1.55 (0.77)	1.94 (0.77)	1.97 (1.02)	2.10 (1.08)	2.35 (0.84)	2.16 (0.86)	20.71 (4.54)

The Inventory of Life Quality in Children and Adolescents (ILC); Range of item scores 1–5, 1 = high QoL; QoL score (LQ<sub>0-28</sub>); range 0–28, 28 = high QoL

<sup>1</sup> CA: children and adolescents—complete sample



**Table 5** ICCs<sup>1</sup> between ILC-NSL and ILC-NOR self-report

	M (SD) ILC-NSL	M (SD) ILC-NOR	ICC	[95% CI]		P
LQ <sub>0-28</sub> CA (N = 49)	21.15 (4.23)	21.86 (4.52)	.508	.269	.688	<.001
School	1.86 (0.95)	1.92 (0.93)	.598	.382	.751	<.001
Family	1.71 (0.86)	1.51 (0.77)	.470	.225	.660	<.001
Other children	2.05 (1.05)	1.88 (0.75)	.288	.013	.524	.021
Alone	2.33 (1.07)	2.10 (1.00)	.409	.152	.616	<.001
Physical Health	1.92 (0.86)	1.92 (0.95)	.392	.123	.606	.003
Mental Health	2.02 (1.05)	1.93 (0.90)	.554	.326	.722	<.001
Global QoL	1.97 (0.81)	1.88 (0.99)	.217	-.069	.469	.068
LQ <sub>0-28</sub> child (N = 22)	21.56 (3.99)	23.23 (4.14)	.012	-.381	.414	.478
School	1.59 (0.78)	1.55 (0.74)	-.019	-.457	.409	.532
Family	1.76 (0.87)	1.36 (0.73)	-.003	-.377	.393	.507
Other children	1.94 (1.10)	1.70 (0.70)	.104	-.324	.496	.319
Alone	2.64 (1.05)	2.23 (0.97)	.081	-.318	.469	.350
Physical Health	1.95 (1.09)	1.82 (0.96)	.363	-.067	.677	.048
Mental Health	1.82 (1.01)	1.53 (0.85)	.290	-.125	.624	.086
Global QoL	1.75 (.81)	1.59 (1.10)	-.143	-.551	.300	.734
LQ <sub>0-28</sub> adol. (N = 27)	20.81 (4.47)	20.74 (4.57)	.836	.671	.922	<.001
School	2.07 (1.04)	2.23 (0.97)	.817	.642	.912	<.001
Family	1.67 (0.88)	1.63 (0.76)	.867	.729	.937	<.001
Other children	2.15 (1.03)	2.04 (0.76)	.424	.055	.689	.013
Alone	2.07 (1.04)	2.00 (1.04)	.651	.365	.825	<.001
Physical Health	1.89 (0.70)	2.00 (0.96)	.441	.079	.701	.010
Mental Health	2.19 (1.08)	2.26 (0.81)	.712	.461	.858	<.001
Global QoL	2.15 (0.77)	2.11 (0.85)	.511	.163	.744	.003

The Inventory of Life Quality in Children and Adolescents (ILC); QoL score (LQ<sub>0-28</sub>); CA: children and adolescents—complete sample

<sup>1</sup> ICC intraclass correlation coefficients based on a two-way mixed effects model with absolute agreement

**Validity**

**Construct validity**

The standardized factor loadings and AVE of the one-factor model are displayed in Table 6 for the ILC-NSL and ILC-NOR.

All factor loadings were above the recommended 0.4 for both adolescent versions and the complete sample. The factor loading for “Family” on the ILC-NOR child

as well as those for “Alone” and “Physical Health” on the ILC-NSL child were lower than recommended. AVE was above the acceptable 0.5 for the ILC-NOR CA and ILC-NOR child. Fornell and Larcker [44], however, argue that AVE > 0.4 can be treated as acceptable if composite reliability, in this case, DG’s rho, is above 0.6. This was the case for the complete sample as well as the child and adolescent versions of both the ILC-NSL and the ILC-NOR.

**Table 6** Factor loadings and AVE of the ILC-NSL and ILC-NOR based on PLS-SEM CA: (children, adolescents, complete sample)

	λ (PLS)							AVE
	School	Family	Other children	Alone	Physical Health	Mental Health	Global QoL	
ILC-NSL CA (N = 49)	.784	.814	.698	.430	.269	.665	.722	.427
ILC-NSL child (N = 22)	.889	.856	.791	.306	-.041	.525	.790	.449
ILC-NSL adol. (N = 27)	.719	.829	.564	.690	.622	.731	.625	.473
ILC-NOR CA (N = 56)	.802	.613	.707	.531	.594	.822	.836	.504
ILC-NOR child (N = 25)	.788	.348	.857	.553	.460	.809	.842	.480
ILC-NOR adol. (N = 31)	.769	.762	.546	.702	.641	.797	.822	.526

The Inventory of Life Quality in Children and Adolescents (ILC); AVE: average variance extracted

**Table 7** Spearman rank correlations for the LQ<sub>0-28</sub> of the ILC-NSL self- and parent report

	M (SD) ILC-NSL	M (SD) parent ILC	Spearman's rho	[95% CI] <sup>2</sup>	P
LQ <sub>0-28</sub> CA <sup>1</sup> (N = 35)	21.55 (3.89)	22.17 (4.00)	.057	-.363 .359	.746
LQ <sub>0-28</sub> child (N = 22)	21.56 (3.99)	22.45 (3.56)	-.245	-.629 .213	.271
LQ <sub>0-28</sub> adol. (N = 13)	21.54 (3.89)	21.69 (4.79)	.511	-.411 .911	.075

The Inventory of Life Quality in Children and Adolescents (ILC); QoL score (LQ<sub>0-28</sub>)

<sup>1</sup> CA children and adolescents—complete sample

<sup>2</sup> CI bootstrapped confidence intervals

**Table 8** Spearman rank correlations for the LQ<sub>0-28</sub> of the ILC-NOR self- and parent report

	M (SD) ILC-NOR	M (SD) parent ILC	Spearman's rho	[95% CI] <sup>2</sup>	P
LQ <sub>0-28</sub> CA <sup>1</sup> (N = 39)	22.57 (4.04)	22.03 (3.98)	-.038	-.577 .323	.819
LQ <sub>0-28</sub> child (N = 24)	23.46 (4.08)	22.54 (3.41)	-.281	-.652 .190	.184
LQ <sub>0-28</sub> adol. (N = 15)	21.13 (3.66)	21.20 (4.75)	.319	-.371 .757	.247

The Inventory of Life Quality in Children and Adolescents (ILC) QoL score (LQ<sub>0-28</sub>)

<sup>1</sup> CA children and adolescents—complete sample

<sup>2</sup> CI bootstrapped confidence intervals

Supplementary analyses based on CFA support these findings and can be found in Additional file 1: Appendix C.

**Multi-informant correlations**

Multi-informant correlations between the LQ<sub>0-28</sub> scores of DHH children and adolescents and their parents on the self-report ILC-NSL and ILC-NOR are presented in Tables 7 and 8. Correlations between the self- and parent-reported QoL score (LQ<sub>0-28</sub>) were not significant for any of the versions. There was a moderate correlation for LQ<sub>0-28</sub> of the adolescent ILC-NSL and the parent ILC. Analysis of the multi-informant correlations at the item level did not demonstrate significant correlations for any of the versions.

**Usability**

The DHH children and adolescents' preferences for the presentation of the ILC are presented in Table 9.

During administration of the ILC-NSL and ILC-NOR, some of the children and adolescents commented that they spent more time completing the ILC-NSL because it took longer to view the video clips of the signed items than to read the items.

**Discussion**

Internal consistency was established as good for both language and age versions. A comparison of the two language versions showed that the adolescent version corresponded closely for both item and total scores, whereas the child version did not correspond well between the languages. Construct validity based on PLS-SEM was

**Table 9** The DHH children and adolescents' preferences for presentation of the ILC

	Frequency	Percent
ILC-NSL/comb. <sup>1</sup> CA <sup>2</sup>	19	39.9
ILC-NOR CA	26	54.2
Do not know CA	3	6.3
Total	48	100.0
ILC-NSL/comb. <sup>1</sup> child	10	47.6
ILC-NOR child	8	38.1
Do not know child	3	14.3
Total	21	100
ILC-NSL/comb. <sup>1</sup> adol	9	33.3
ILC-NOR adol	18	66.7
Do not know adol	4	14.8
Total	27	100

The Inventory of Life Quality in Children and Adolescents (ILC)

<sup>1</sup> comb.: A potential combination of the written and signed versions

<sup>2</sup> CA children and adolescents—complete sample

found to be acceptable for the proposed one-factor model for both language versions and all ages.. This is also in line with the previously confirmed one-factor model based on the original theoretical concept of QoL that the ILC is based on [6, 7].

The ILC-NSL and ILC-NOR demonstrated similar psychometric properties to those reported for the ILC in other studies both for TH [6, 7] and DHH children and adolescents [1]. The ILC-NSL demonstrated the same pattern as the original Norwegian validation (ILC-NOR) with lower internal consistency based on Cronbach's  $\alpha$

for the child version than the adolescent version [6]. The relative cognitive immaturity in younger children or the significantly lower NSL skills may be a possible explanation for this.

Associations between the two language versions of the self-report were high for both item and scale scores for the ILC adolescent version. They were higher than we expected based on other studies comparing written and sign language versions of mental health assessments [23, 24]. This may indicate a close correspondence between the ILC-NSL and ILC-NOR because of equivalent phrasing in written Norwegian and NSL. Other reasons for the close correspondence may have been the high number of children and adolescents with a spoken language preference among this DHH sample or possibly good literacy, which was not assessed. The associations between the two language versions of the child self-report, however, were much weaker, indicating problems with the translation, literacy, or Norwegian sign language skills. As no DHH children or adolescents were included in the focus groups during the translation process, it is possible that the translation was not clear or not at an appropriate level for DHH children with varying NSL skills. Including them in the focus group, however, would have decreased the number of potential participants for this study. Literacy was not assessed in the current study; therefore, it is difficult to conclude on this matter. Other possible reasons for this finding might be that the child version is constructed for individual administration but was administered in groups in the current study. The individual administration is designed as a conversation with the child and contains longer sentences and explanations than the adolescent version. As the younger participants have attended deaf school less than the adolescents and their parents have received fewer sign language lessons, the children's sign language skills might not enable them to cope with the longer sentences. Therefore, they might have benefitted from the adolescent version with its shorter and simpler sentences. Consequently, we suggest that a validation study be carried out for younger DHH children using the adolescent version of the ILC-NSL after having included DHH children in focus groups on this NSL version and making adjustments if necessary.

There was a moderate, but not significant, correlation between adolescent self-reports (ILC-NSL and ILC-NOR) and parent reports for QoL scores  $LQ_{0-28}$  whereas the two language versions of the child self-report showed no associations with the parent reports. This is somewhat in contrast to the significant, but low informant agreement reported previously [6] for TH children and adolescents, whereas other researchers on DHH child and adolescent QoL report similar low agreement with parent reports [2, 3, 49] as seen in

our study. Pardo-Guijarro, Martínez-Andrés, Notario-Pacheco et al. [5], reason that hearing parents experience the impact of their children's deafness on QoL to a larger degree than their children. Warner-Czyz, Loy, Roland et al. [2] argue that several aspects of QoL are less observable for parents, such as self-esteem, family, and friends. Others [4, 50] have suggested that DHH children and adolescents not sharing the same mode of communication with their parents might lessen the parents' insight into their children's subjective world, including QoL. Aanondsen, Jozefiak, Heiling et al. [31] find parent–DHH child correlations for the Strengths and Difficulties Questionnaire (SDQ) assessing mental health, close to those reported in another study [51] for TH children and adolescents. The difference in parent–child agreement between the SDQ and ILC might be related to the different nature of the items describing QoL compared with mental health symptoms (SDQ), which are more easily observed by others. This illustrates the definition of QoL as a subjective concept. The low agreement between parents and DHH, as well as TH children and adolescents, emphasizes the need to consider the self-report as the authentic QoL report, whereas the parent report should be used as supplemental information from a more remote informant [52]. This conclusion enhances the importance of developing sign language versions of generic QoL instruments for capturing DHH children and adolescents' own views. This does not, however, lessen the importance of assessing parents' perspective on their children's QoL as is also emphasized by the authors of the ILC [6, 7].

Most of the DHH children and adolescents reported preferring the written instrument (ILC-NOR), and this preference was more pronounced for the adolescents than the children, possibly reflecting the lower NSL competence among children and their parent-reported preference for spoken Norwegian. There may have been subsamples based on spoken or sign language proficiency that could have influenced these results. These were not examined, however, due to the small sample size. Spontaneous feedback during administration indicated that the preference for the written version (ILC-NOR) was related to the less time-consuming nature of this version. Greater mastery of literacy in DHH adolescents could explain their preference for the written version of the ILC. The preference of the written version, however, is somewhat surprising given that other studies report reading difficulties to be frequent in many DHH children and adolescents [20, 22, 53] and their preference for sign language. As we only assessed spoken and sign language skills but not literacy, we could not test this.

### Strengths and limitations

A major strength of the current study is the use of a generic assessment tool for QoL that was translated into NSL, and that also examined psychometric properties for both written and sign language for DHH children and adolescents. A further strength of the choice of the ILC is the multi-informant perspective. Both these factors have been found necessary to solve some of the current inconsistencies in findings on the QoL of DHH children and adolescents.

A major limitation of the present study is the small sample size due to the limited number of signing DHH children and adolescents in the population. The sample size here was smaller than the minimum number of cases recommended for multivariate analyses based on covariance, especially when analyzing the child and the adolescent versions separately. This, in turn, poses a problem for a thorough psychometric evaluation of the ILC-NSL and ILC-NOR for DHH children and adolescents. Alternatively, the hypotheses could have been framed more precisely and tailored to the expected small sample size, in turn choosing statistical procedures more in line with these. By reporting the confidence intervals for the results, we have attempted to partly compensate for this. To offset the effects of small sample size, we have also used the PLS-SEM, which is known to be robust for such situations [42]. The combination of analyses used here was chosen as the best practical solution for the small sample size but leaves room for uncertainty regarding the conclusions.

A further limitation is the short interval of two to three days between the administration of the two language versions. This may have led to participants remembering their former answers and creating a bias. The randomized order of administration of the two versions was conducted to counteract this.

The lack of including the target population for the ILC-NSL in the focus group for the translation is a further limitation as well as the use of single-item measures to assess spoken and sign language skills which cannot be regarded as a complete assessment of the participants' communication skills. A minor limitation is the absence of a gold standard for establishing convergent validity for QoL in DHH children and adolescents. The use of a written instrument, such as the KIDSCREEN, as a gold standard, however, would not have been reliable or valid because of the evidence showing that many DHH children and adolescents have reading difficulties [20, 22, 53] even though this did not seem prominent in our sample. Another translation cycle into NSL and validation of this translation would have been necessary and too time-consuming for the scope of the current study. A further limitation is the lack of test–retest reliability.

### Conclusion

The evaluation of the psychometric properties of the self-report ILC-NSL is promising. The use of the self-report ILC-NSL for assessing QoL in DHH children and adolescents is essential given its subjective nature. For children younger than the age of 11, the use of the ILC-NSL is more questionable, possibly because of their lower sign language skills. Until better alternatives are developed, we suggest that the psychometric properties of the written and NSL adolescent versions are studied for DHH children after focus groups are conducted, including representatives for the target population. Alternatively, that it is investigated whether individual rather than group administration may result in better usability and validity of the child ILC-NSL and ILC-NOR. Based on the children and adolescents' feedback, we recommend presenting both the written and NSL versions in combination to evaluate QoL among DHH children and adolescents rather than using only one language. Further research on DHH children and adolescents is needed to solve the current inconsistencies in the findings related to QoL. Because of the small number of signing DHH children and adolescents in the population, cross-cultural studies should be encouraged; this would increase the possibility of conducting research on larger samples, as well as allowing for an examination of cross-cultural similarities and differences.

### Abbreviations

QoL: Quality of life; DHH: Deaf and hard-of-hearing; TH: ILC; PedsQL: Pediatric Quality of Life Inventory; NSL: Norwegian Sign Language; KINDL: Kinder Lebensqualität Fragebogen; ILC: The Inventory of Life Quality; CAP: Categories of Auditory Performance; SIR: Speech Intelligibility Rating; SPS: Sign Language Production Scale; SUS: Sign Language Understanding Scale; CA: Children and adolescents—complete sample; CODA: Children of deaf adults; DG rho: Dillon–Goldstein's rho; CI: Confidence interval; ICC: Intraclass correlation coefficients; CFA: Confirmatory factor analysis; WLSMV: Weighted least squares means and variances adjusted; RMSEA: Root mean square error of approximation; CFI: Comparative fit index; TLI: Tucker–Lewis index; PLS-SEM: Partial least squares structural equation modeling; AVE: Average variance extracted.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40359-021-00590-x>.

**Additional file 1.** Appendix A and B.

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### Authors' contributions

CAA contributed to the study design, data collection, statistical analysis, interpretation of the data, and drafting of the manuscript. TJ, KH, and TR contributed to the study design, interpretation of the data, and revision of the manuscript. SL contributed to statistical analysis, interpretation of data and revision of the manuscript. All authors read and approved the final manuscript.

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### Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available because of the sensitivity of the information, as well as the small sample size. They are available from the local research committee or the corresponding author upon reasonable request.

### Declarations

#### Ethics approval and consent to participate

Study approval was given by the Regional Committees for Medical and Health Research Ethics (reference number: 2015/1739/REK midt). Written informed consent was obtained from all participants.

#### Consent for Publication

Not applicable.

#### Competing interests

On behalf of the authors, the corresponding author states that there are no competing interests. CAA was involved in the translation of the ILC-NSL but has not gained any economic benefits from it or retained any financial interests in the ILC-NSL. TJ receives royalties from publisher Hogrefe/Psychologiförlag Stockholm for authorship of the "Norwegian Manual—ILC QoL measure, 2012" (ILC-NOR) which is used in this study.

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### References

- Hintermair M. Health-related quality of life and classroom participation of deaf and hard-of-hearing students in general schools. *J Deaf Stud Deaf Educ*. 2011;16(2):254–71.
- Warner-Czyz AD, Loy B, Roland PS, Tong L, Tobey EA. Parent versus child assessment of quality of life in children using cochlear implants. *Int J Pediatr Otorhinolaryngol*. 2009;73(10):1423–9.
- Chmiel R, Sutton L, Jenkins H. Quality of life in children with cochlear implants. *Ann Otol Rhinol Laryngol*. 2000;109:103–5.
- Fellinger J, Holzinger D, Sattel H, Laucht M. Mental health and quality of life in deaf pupils. *Eur Child Adolesc Psychiatry*. 2008;17(7):414–23.
- Pardo-Guijarro MJ, Martínez-Andrés M, Notario-Pacheco B, Solera-Martínez M, Sánchez-López M, Martínez-Vizcaíno V. Self-reports versus parental perceptions of health-related quality of life among deaf children and adolescents. *J Deaf Stud Deaf Educ*. 2015;20(3):275–82.
- Jozefiak T, Matthejat F, Remschmidt H. Inventory of Life Quality in children and adolescents manual, Norwegian Version. Stockholm: Hogrefe; 2012.
- Matthejat F, Remschmidt H. Das Inventar zur Erfassung der Lebensqualität bei Kindern und Jugendlichen (ILK) [The inventory of quality of life in children and adolescents ILC]. Bern: Verlag Hans Huber; 2006.
- Aanondsen CM, Heiling K, Nøvik TS, Jozefiak T. Quality of Life, family function and mental health of deaf and hard-of-hearing adolescents in mental health services in Norway—a pilot study. *Int J Ment Health Deaf*. 2018;4(1):3–13.
- Jozefiak T, Larsson B, Wichstrom L. Changes in quality of life among Norwegian school children: a six-month follow-up study. *Health Qual Life Outcomes*. 2009;7:7.
- Warner-Czyz AD, Loy B, Tobey EA, Nakonezny P, Roland PS. Health-related quality of life in children and adolescents who use cochlear implants. *Int J Pediatr Otorhinolaryngol*. 2011;75(1):95–105.
- Roland L, Fischer C, Tran K, Rachakonda T, Kallogjeri D, Lieu JE. Quality of life in children with hearing impairment: systematic review and meta-analysis. *Otolaryngol Head Neck Surg*. 2016;155(2):208–19.
- Fellinger J, Holzinger D, Gerich J, Goldberg D. Mental distress and quality of life in the hard of hearing. *Acta Psychiatr Scand*. 2007;115(3):243–5.
- Tsimpida D, Kaitelidou D, Galanis P. Determinants of health-related quality of life (HRQoL) among deaf and hard of hearing adults in Greece: a cross-sectional study. *Arch Public Health*. 2018;76:55.
- Kushalnagar P, Topolski TD, Schick B, Edwards TC, Skalicky AM, Patrick DL. Mode of communication, perceived level of understanding, and perceived quality of life in youth who are deaf or hard of hearing. *J Deaf Stud Deaf Educ*. 2011;16(4):512–23.
- Stokoe WCJ. Sign language structure: an outline of the visual communication system for the deaf. *Stud Linguist*. 1960;8:1–78.
- Jones EG, Mallinson RK, Phillips L, Kang Y. Challenges in language, culture, and modality: translating English measures into American sign language. *Nurs Res*. 2006;55(2):75–81.
- Mason TC. Cross-cultural instrument translation: assessment, translation, and statistical applications. *Am Ann Deaf*. 2005;150(1):67–72.
- Maxwell-McCaw D, Zea MC. The Deaf Acculturation Scale (DAS): development and validation of a 58-item measure. *J Deaf Stud Deaf Educ*. 2011;16(3):325–42.
- Meadow-Orlans K, Erting C. Deaf people in society. In: Hindley P, Kitson N, editors. *Mental health and deafness*. London: Whurr Publishers; 2000. p. 3–24.
- Harris M, Terlektsi E, Kyle FE. Concurrent and longitudinal predictors of reading for deaf and hearing children in primary school. *J Deaf Stud Deaf Educ*. 2017;22(2):233–42.
- Marschark M, Rhoten C, Fabich M. Effects of cochlear implants on children's reading and academic achievement. *J Deaf Stud Deaf Educ*. 2007;12(3):269–82.
- Marschark M, Sapere P, Convertino CM, Mayer C, Wauters L, Sarchet T. Are deaf students' reading challenges really about reading? *Am Ann Deaf*. 2009;154(4):357–70.
- Cornes AJ, Rohan MJ, Napier J, Rey JM. Reading the signs: Impact of signed versus written questionnaires on the prevalence of psychopathology among deaf adolescents. *Aust NZ J Psychiatry*. 2006;40(8):665–73.
- Cornes AJ, Brown PM. Mental health of Australian deaf adolescents: an investigation using an Auslan version of the Strengths and Difficulties Questionnaire. *Deaf Educ Int*. 2012;14(3):161–75.
- Roberts S, Wright B, Moore K, Smith S, Allgar V, Tennant A, et al. Translation into British Sign Language and validation of the Strengths and Difficulties Questionnaire. *Health Serv Del Res*. 2015;3(2):66.
- Patrick DL, Edwards TC, Skalicky AM, Schick B, Topolski TD, Kushalnagar P, et al. Validation of a quality-of-life measure for deaf or hard of hearing youth. *Otolaryngol Head Neck Surg*. 2011;145(1):137–45.
- Fellinger J, Holzinger D, Dobner U, Gerich J, Lehner R, Lenz G, et al. An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community. *Soc Psychiatry Psychiatr Epidemiol*. 2005;40(3):245–50.
- Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioral and emotional problems: implications of cross-informant correlations for situational specificity. *Psychol Bull*. 1987;101(2):56.
- Kristensen H, Hove P. Måleegenskaper ved den norske versjonen av Inventory of Life Quality in Children and Adolescents. *PsykTestBarn*. 2013;1(5):56.

30. Caluraud S, Marcolla-Bouchetemblé A, de Barros A, Moreau-Lenoir F, de Sevin E, Rerolle S, et al. Newborn hearing screening: analysis and outcomes after 100,000 births in Upper-Normandy French region. *Int J Pediatr Otorhinolaryngol*. 2015;79(6):829–33.
31. Aanondsen CM, Jozefiak T, Heiling K, Rimehaug T. Validation of the strengths and difficulties self-report in Norwegian Sign Language. *J Deaf Stud Deaf Educ*. 2020;25(1):91–104.
32. Archbold S, Lutman ME, Marshall DH. Categories of auditory performance. *Ann Otol Rhinol Laryngol Suppl*. 1995;166:312–4.
33. Allen C, Nikolopoulos TP, Dyar D, O'Donoghue GM. Reliability of a rating scale for measuring speech intelligibility after pediatric cochlear implantation. *Otol Neurotol*. 2001;22(5):631–3.
34. Dammeyer J. Psychosocial development in a Danish population of children with cochlear implants and deaf and hard-of-hearing children. *J Deaf Stud Deaf Educ*. 2010;15(1):50–8.
35. Seiler AF, Larsen TB. Vurdering af børns tilegnelse af dansk tegnsprog. Forståelsestest [Assessing Danish Sign Language development]. Aalborg: Døveskolernes Materialecenter; 2005.
36. Herman R, Holmes S, Woll B. Assessing British Sign Language development: receptive skills test. Coleford: Forest Book; 1999.
37. Dammeyer J. Congenital rubella syndrome and delayed manifestations. *Int J Pediatr Otorhinolaryngol*. 2010;74(9):1067–70.
38. Roid GH, Miller LJ, Pomplun M, Koch C. Leiter International Performance Scale manual. 3rd ed. Wood Dale: Stoelting; 2013.
39. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*. 2000;25(24):3186–91.
40. Dempster AP, Laird NM, Rubin DB. Maximum likelihood from incomplete data via the EM Algorithm. *J Roy Stat Soc Ser B (Methodol)*. 1977;39(1):1–38.
41. Yanyun Y, Green SB. Coefficient alpha: a reliability coefficient for the 21st century? *J Psychoeduc Assess*. 2011;29(4):377–92.
42. Hair JF, Hult GTM, Ringle CM, Sarstedt M. A primer on partial least squares structural equation modeling. 2nd ed. Thousand Oaks: Sage; 2016.
43. Mehmetoglu M, Jakobsen TG. Applied statistics using stata. London: Sage; 2017.
44. Fornell C, Larcker DF. Structural equation models with unobservable variables and measurement error: algebra and statistics. *J Mark Res*. 1981;18(3):382–8.
45. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Model*. 1999;6(1):1–55.
46. Hooper D, Coughlan J, Mullen MR, editors. Evaluating model fit: a synthesis of the structural equation modelling literature. In: 7th European conference on research methodology for business and management studies; 2008; Regent's College, London.
47. Li C-H. Confirmatory factor analysis with ordinal data: comparing robust maximum likelihood and diagonally weighted least squares. *Behav Res Methods*. 2016;48(3):936–49.
48. Venturini S, Mehmetoglu M. PLSEM: Stata module to implement partial least squares structural equation modelling (PLS-SEM). 2017. <https://econpapers.repec.org/software/bocbocode/s458291.htm>.
49. Fellingner J, Holzinger D, Dobner U, Gerich J, Lehner R, Lenz G, et al. Mental distress and quality of life in a deaf population. *Soc Psychiatry Psychiatr Epidemiol*. 2005;40(9):737–42.
50. Barnett S, Klein JD, Pollard RQ, Samar V, Schlehofer D, Starr M, et al. Community participatory research with deaf sign language users to identify health inequities. *Am J Public Health*. 2011;101(12):2235–8.
51. Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioral and emotional problems: implications of cross-informant correlations for situational specificity. *Psychol Bull*. 1987;101(2):213–32.
52. Holte A, Barry MM, Bekkhus M, Borge AIH, Bowes L, Casas F, et al. Psychology of child well-being. In: Ben-Arieh A, Casas F, Frønes I, Korbin JE, editors. *Handbook of child well-being: theories, methods and policies in global perspective*. Dordrecht: Springer; 2014. p. 555–631.
53. Marschark M, Convertino CM, Macias G, Monikowski CM, Sapere P, Seewagen R. Understanding communication among deaf students who sign and speak: a trivial pursuit? *Am Ann Deaf*. 2007;152(4):415–24.

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## Appendix A

**Table A** Mean gender differences (MD) with CIs for item scores for both ILC-NSL and ILC-NOR

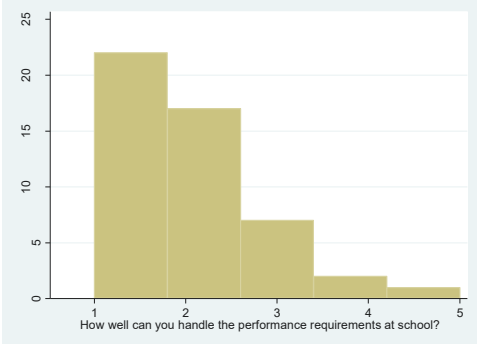
	MD ILC-NSL	[95% CI]		MD ILC-NOR	[95% CI]	
LQ <sub>0-28</sub> CA	.760	-1.491	4.163	-3.323	-5.923	-1.638
School	-.102	-.937	.436	.415	.070	.868
Family	-.210	-.912	.231	.330	.009	.567
Other children	-.123	-.909	.414	.446	.035	.848
Alone	.057	-.922	.532	.895	.517	1.263
Physical Health	.386	-.040	.980	.497	.088	.977
Mental Health	-.171	-.961	.405	.269	-.194	.833
Global QoL	-.595	-1.019	.121	.471	.018	.901

*Notes.* CA: Complete sample MD: mean difference between boys and girls, CI: bootstrapped

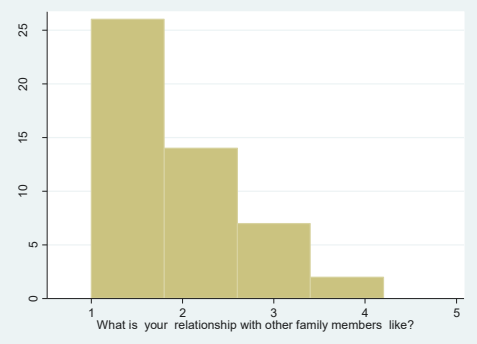
# Appendix B

ILC-NSL complete sample (CA; N=49)

**Fig. B1 School**

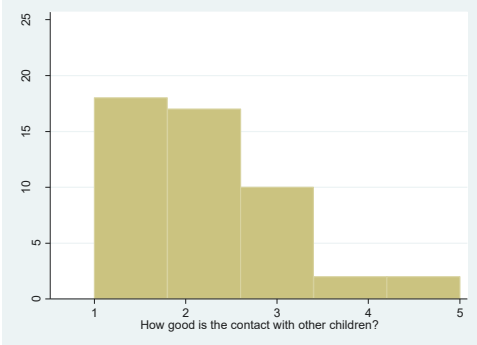


**Fig. B2 Family**

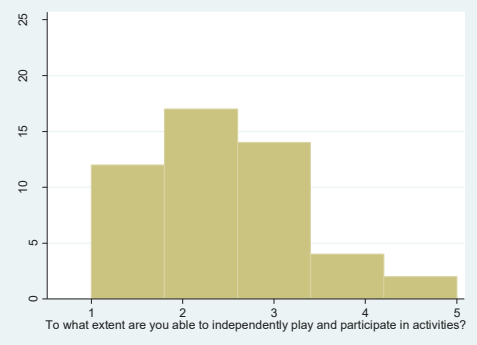


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B3 Other children**



**Fig. B4 Alone**

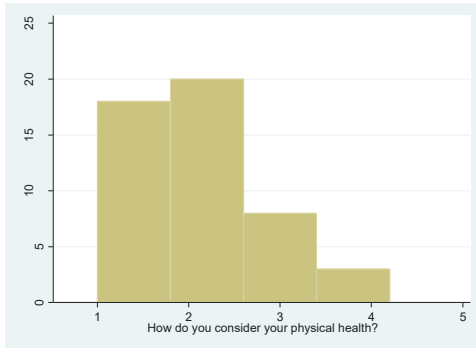


*Note.* Range of item scores 1–5, 1=high QoL

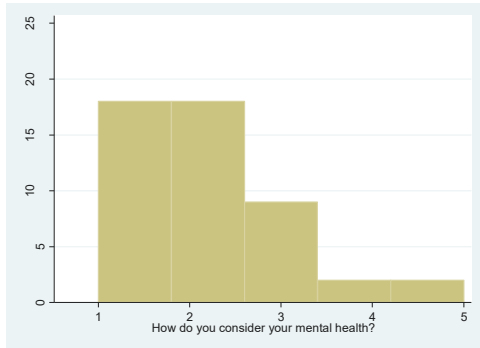


ILC-NSL CA (N=49)

**Fig. B5** Physical Health

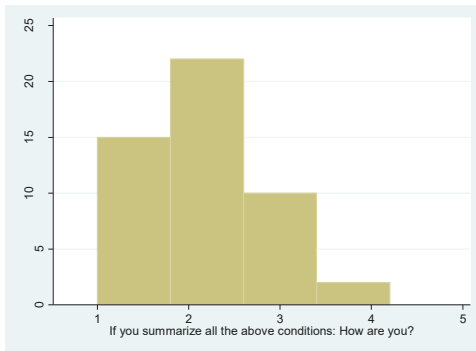


**Fig. B6** Mental Health

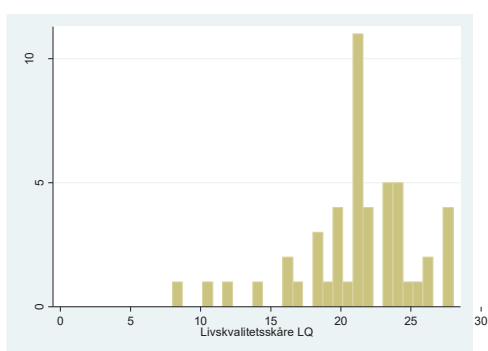


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B7** Global QoL



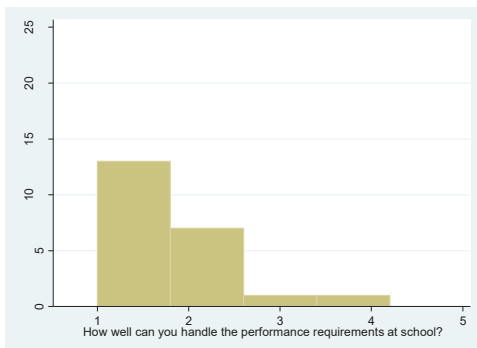
**Fig. B8** LQ0-28



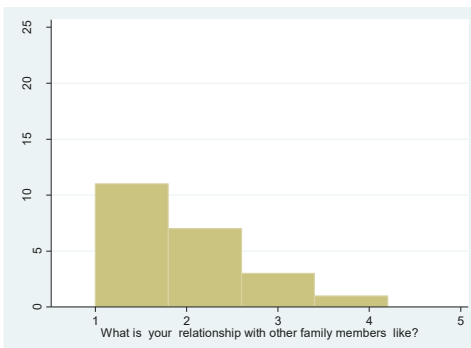
*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ0-28): range 0–28, 28=high QoL

ILC-NSL child (N=22)

**Fig. B9** School

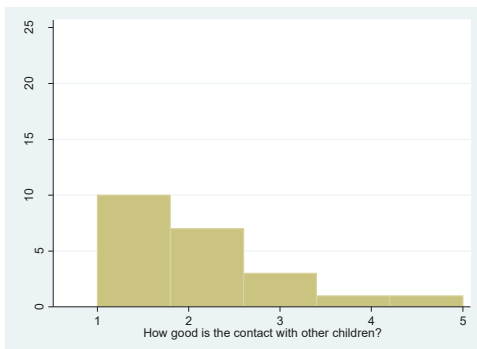


**Fig. B10** Family

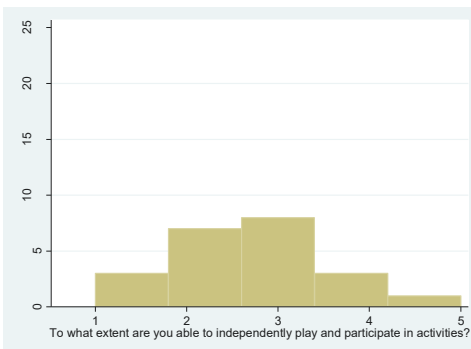


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B11** Other children



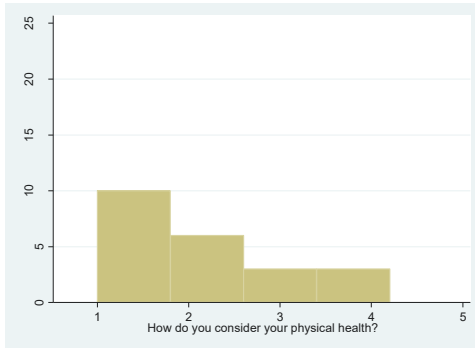
**Fig. B12** Alone



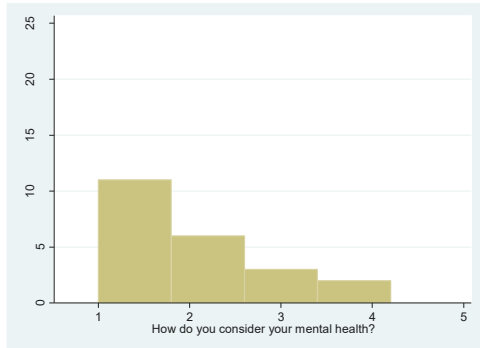
*Note.* Range of item scores 1–5, 1=high QoL

ILC-NSL child (N=22)

**Fig. B13 Physical Health**

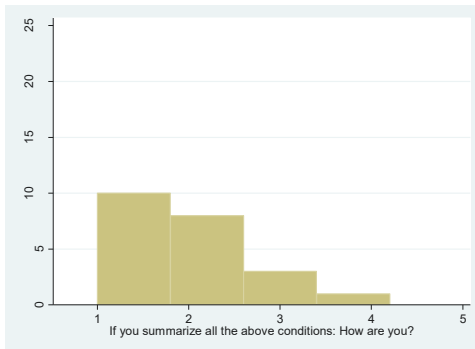


**Fig. B14 Mental Health**

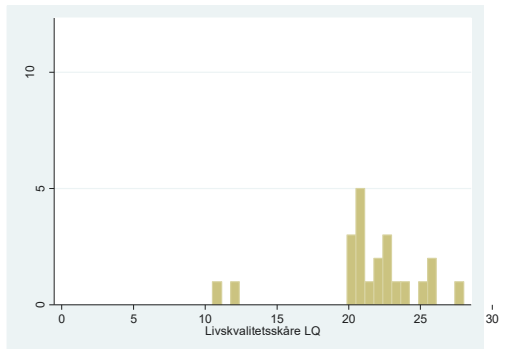


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B15 Global QoL**



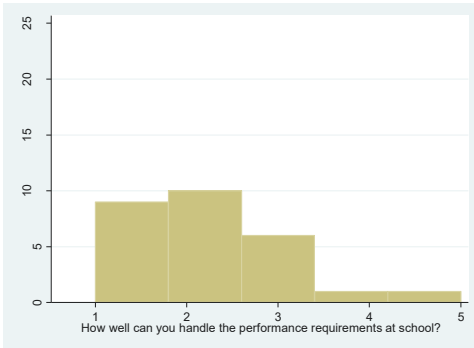
**Fig. B16 LQ0-28**



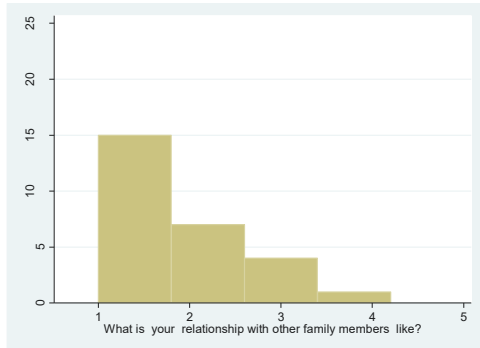
*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ<sub>0-28</sub>): range 0–28, 28=high QoL

ILC-NSL adolescent (N=27)

**Fig. B17** School

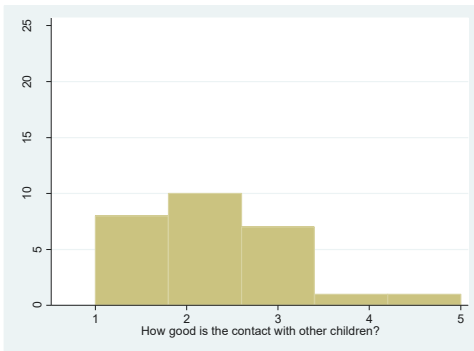


**Fig. B18** Family

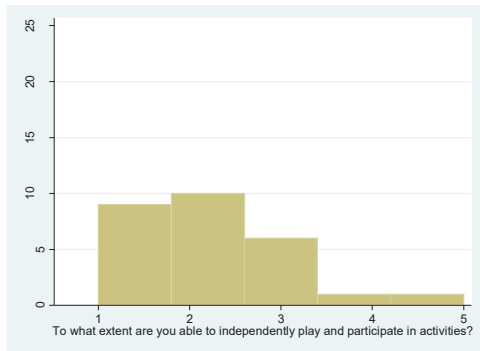


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B19** Other children



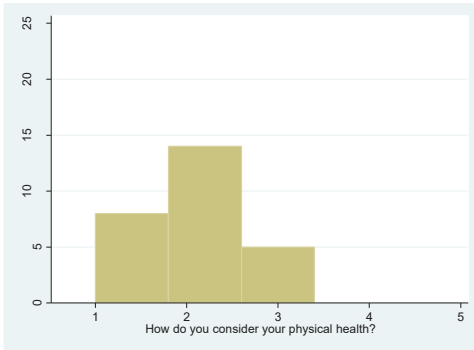
**Fig. B20** Alone



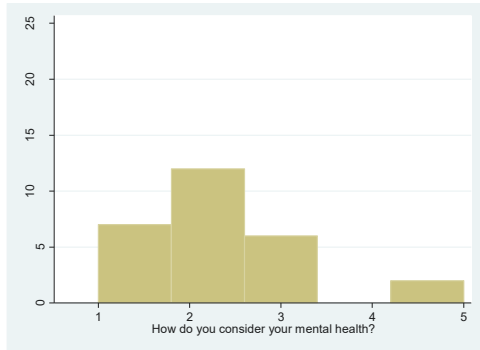
*Note.* Range of item scores 1–5, 1=high QoL

ILC-NSL adolescent (N=27)

**Fig. B21 Physical Health**

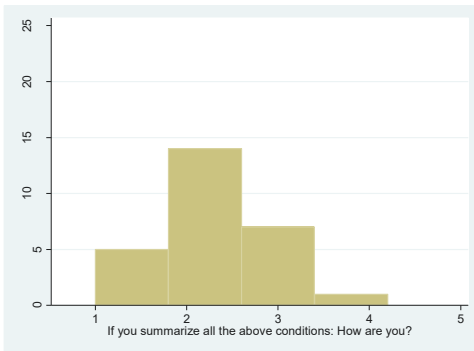


**Fig. B22 Mental Health**

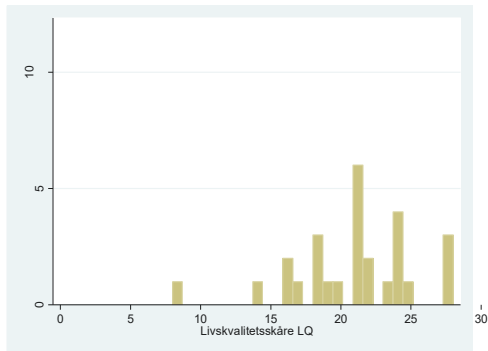


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B23 Global QoL**



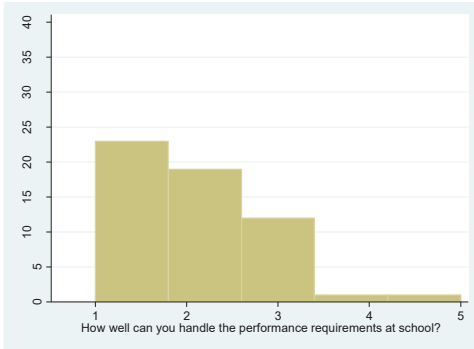
**Fig. B24 LQ0-28**



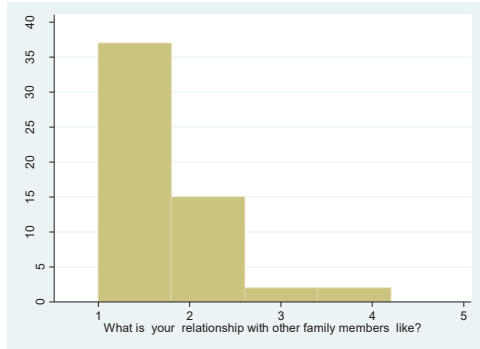
*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ<sub>0-28</sub>): range 0–28, 28=high QoL

ILC-NOR CA (N=56)

**Fig. B25 School**

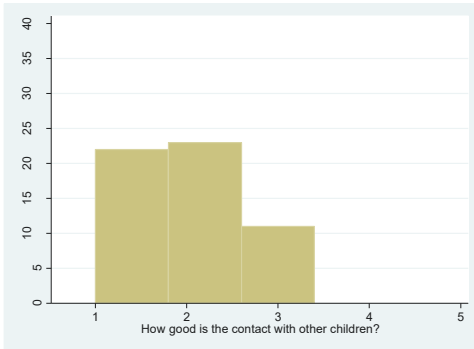


**Fig. B26 Family**

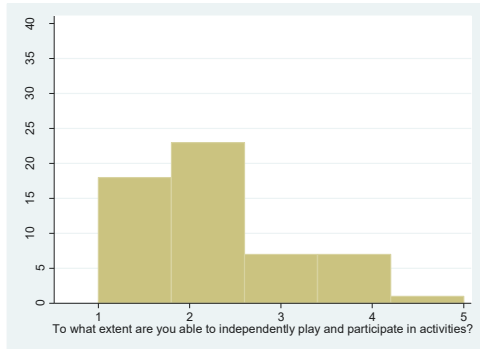


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B27 Other children**



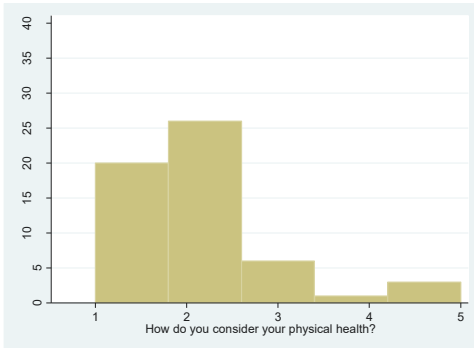
**Fig. B28 Alone**



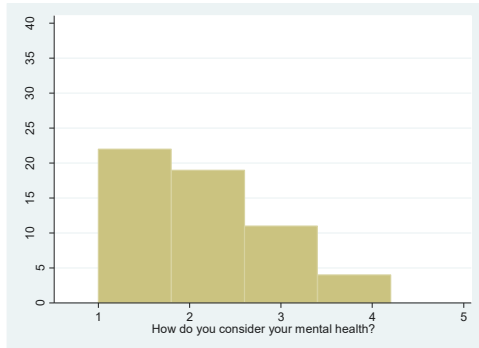
*Note.* Range of item scores 1–5, 1=high QoL

ILC-NOR CA (N=56)

**Fig. B29 Physical Health**

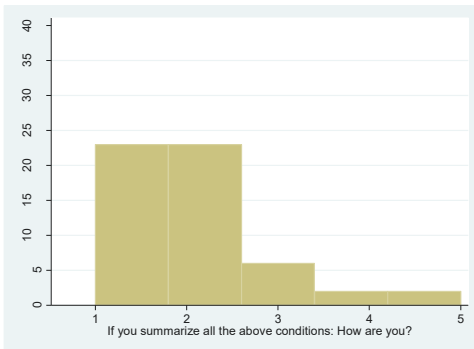


**Fig. B30 Mental Health**

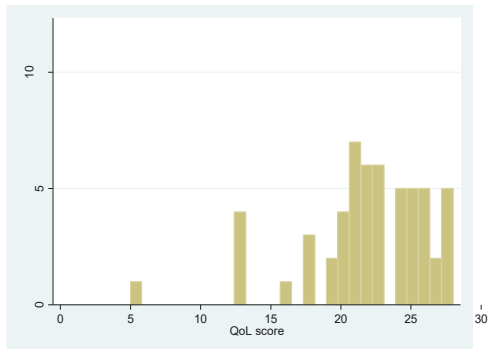


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B31 Global QoL**



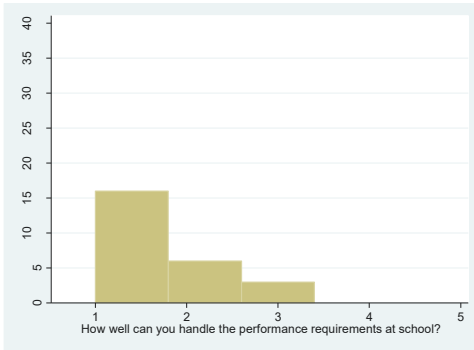
**Fig. B32 LQ0-28**



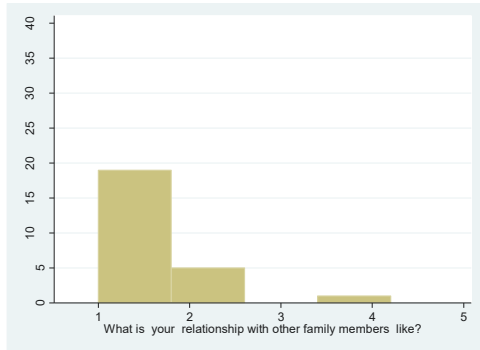
*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ0-28): range 0–28, 28=high QoL

ILC-NOR child (N=25)

**Fig. B33** School

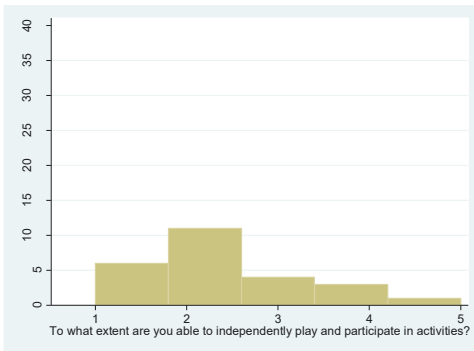


**Fig. B34** Family

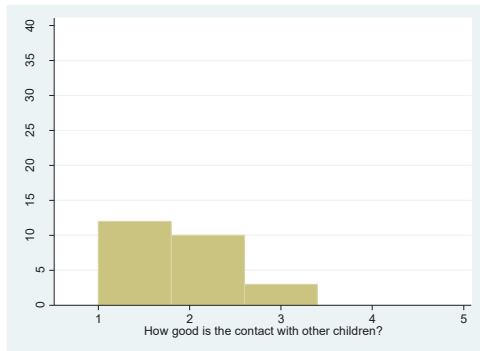


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B35** Other children



**Fig. B36** Alone

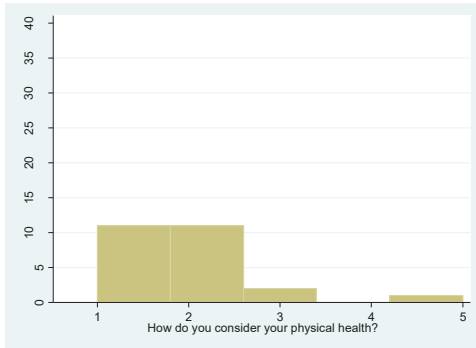


*Note.* Range of item scores 1–5, 1=high QoL

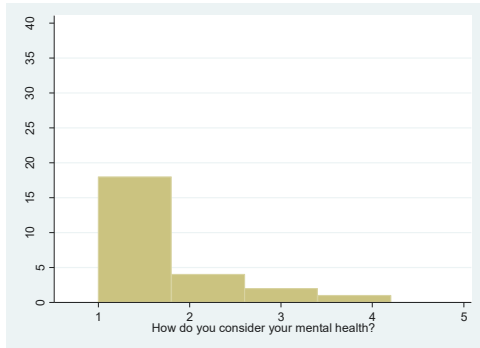


ILC-NOR child (N=25)

**Fig. B37 Physical Health**

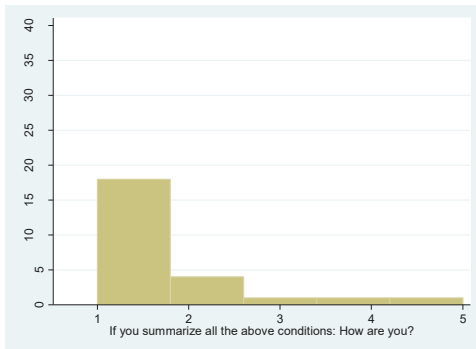


**Fig. B38 Mental Health**

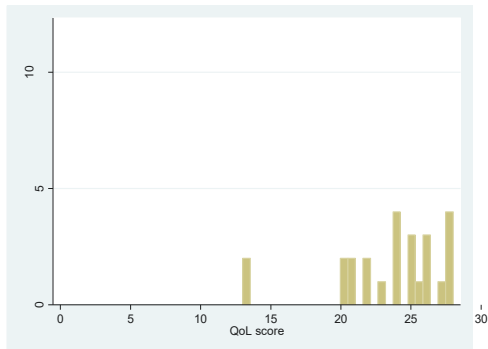


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B39 Global QoL**



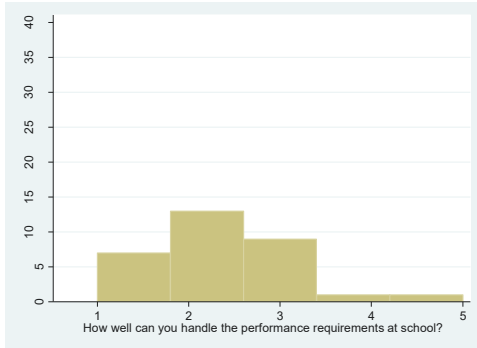
**Fig. B40 LQ0-28**



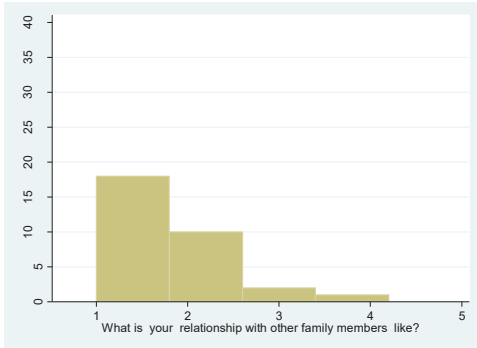
*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ0-28): range 0–28, 28=high QoL

ILC-NOR adol. (N=31)

**Fig. B41** School

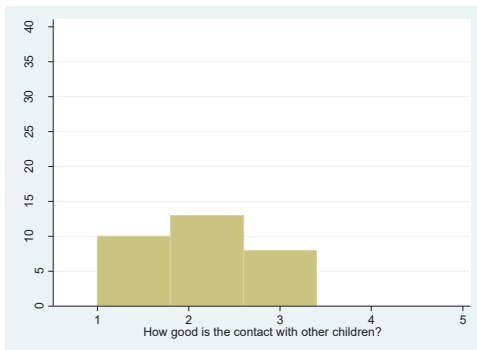


**Fig. B42** Family

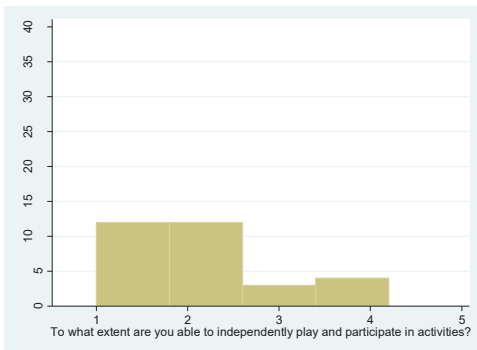


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B43** Other children



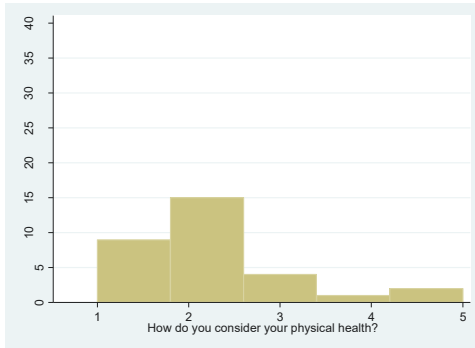
**Fig. B44** Alone



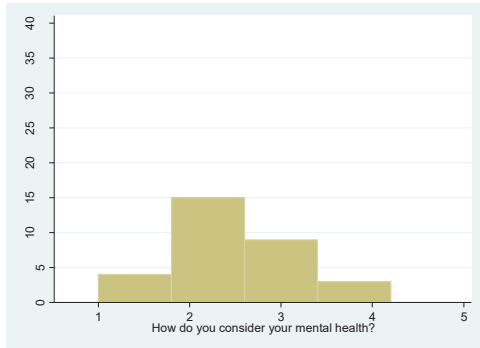
*Note.* Range of item scores 1–5, 1=high QoL

ILC-NOR adol. (N=31)

**Fig. B45 Physical Health**

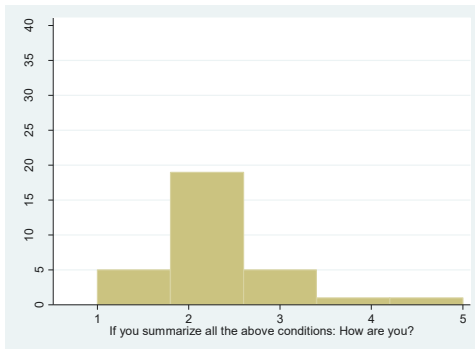


**Fig. B46 Mental Health**

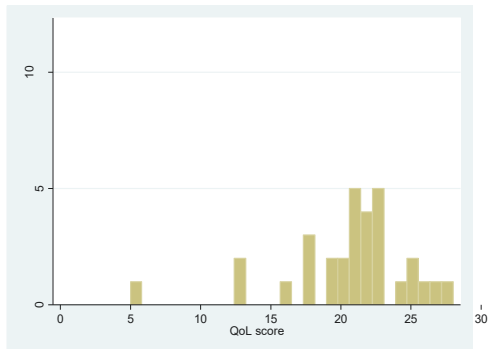


*Note.* Range of item scores 1–5, 1=high QoL

**Fig. B47 Global QoL**



**Fig. B48 LQ0-28**



*Note.* Range of item scores 1–5, 1=high QoL; QoL score (LQ0-28): range 0–28, 28=high QoL

## Appendix C

### Construct validity – supplementary results

The ILC-NSL CA showed good model fit for  $\chi^2/df$  and acceptable model fit for two indices (CFI and TLI). The ILC-NOR CA showed acceptable fit for  $\chi^2/df$  and CFI. Factor loadings based on CFA were acceptable for all seven items of the ILC-NSL for adolescents. None of the modification indices for ILC-NSL or ILC-NOR suggested correlated residuals for the one-factor model. The results support the results of the PLS-SEM.

< Table C1 and C2 here >

**Table C1** Factor loadings, and model fit indices of the ILC-NSL based on CFA

Items	$\lambda$ (CFA)	$\chi^2(df)$	<i>p</i>	$\chi^2/df$	CFI	TLI	RMSEA	90% CIRMSEA
ILC CA (N=49)		23.283 (14)	.056	1.663	.947	.920	.116	.000-.197
School	.735							
Family	.815							
Other children	.680							
Alone (play/hobbies)	.388							
Physical Health	.260							
Mental Health	.609							
Global QoL	.725							
ILC child (N=22)		17.543 (14)	.228	1.253	.966	.949	.107	.000-.245
School	.914							
Family	.834							
Other children	.767							

Items	$\lambda$ (CFA)	$\chi^2$ (df)	<i>p</i>	$\chi^2/df$	CFI	TLI	RMSEA	90% CIRMSEA
Alone	.279							
Physical Health	-.031							
Mental Health	.386							
Global QoL	.803							
ILC adol. (N=27)		26.818 (14)	.020	1.916	.903	.854	.184	.071-.289
School	.672							
Family	.912							
Other children	.534							
Alone	.664							
Physical Health	.616							
Mental Health	.692							
Global QoL	.618							

*Notes.* The Inventory of Life Quality in Children and Adolescents (ILC); QoL score (LQ<sub>0-28</sub>); CA: children and adolescents—complete sample

**Table C2** Factor loadings, and model fit indices for the ILC-NOR based on CFA

Items	$\lambda$ (CFA)	$\chi^2$ (df)	<i>p</i>	$\chi^2/df$	CFI	TLI	RMSEA	90% CI	RMSEA
ILC CA (N=56)		48.086 (14)	.001	3.435	.928	.892	.209		.146-.275
School	.805								
Family	.632								
Other children	.714								
Alone (play/hobbies)	.448								
Physical Health	.446								
Mental Health	.940								
Global QoL	.862								
ILC child (N=25)		15.658 (14)	.335	1.118	.990	.986	.069		.000-.0211
School	.832								
Family	.506								
Other children	.863								

Items	$\lambda$ (CFA)	$\chi^2(df)$	<i>p</i>	$\chi^2/df$	CFI	TLI	RMSEA	90% CI	RMSEA
Alone (play/hobbies)	.547								
Physical Health	.369								
Mental Health	.837								
Global QoL	.887								
ILC adol. (N=31)		37.153 (14)	.007	2.654	.919	.878	.231		.142-.323
School	.718								
Family	.803								
Other children	.543								
Alone (play/hobbies)	.617								
Physical Health	.390								
Mental Health	.952								
Global QoL	.875								

*Notes.* The Inventory of Life Quality in Children and Adolescents (ILC); QoL score (LQ<sub>0-28</sub>); CA: children and adolescents—complete sample



# Paper III

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