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Susanna Memmen Bjerke
PSY 2901 – Thesis for the Cand. Psychol. degree
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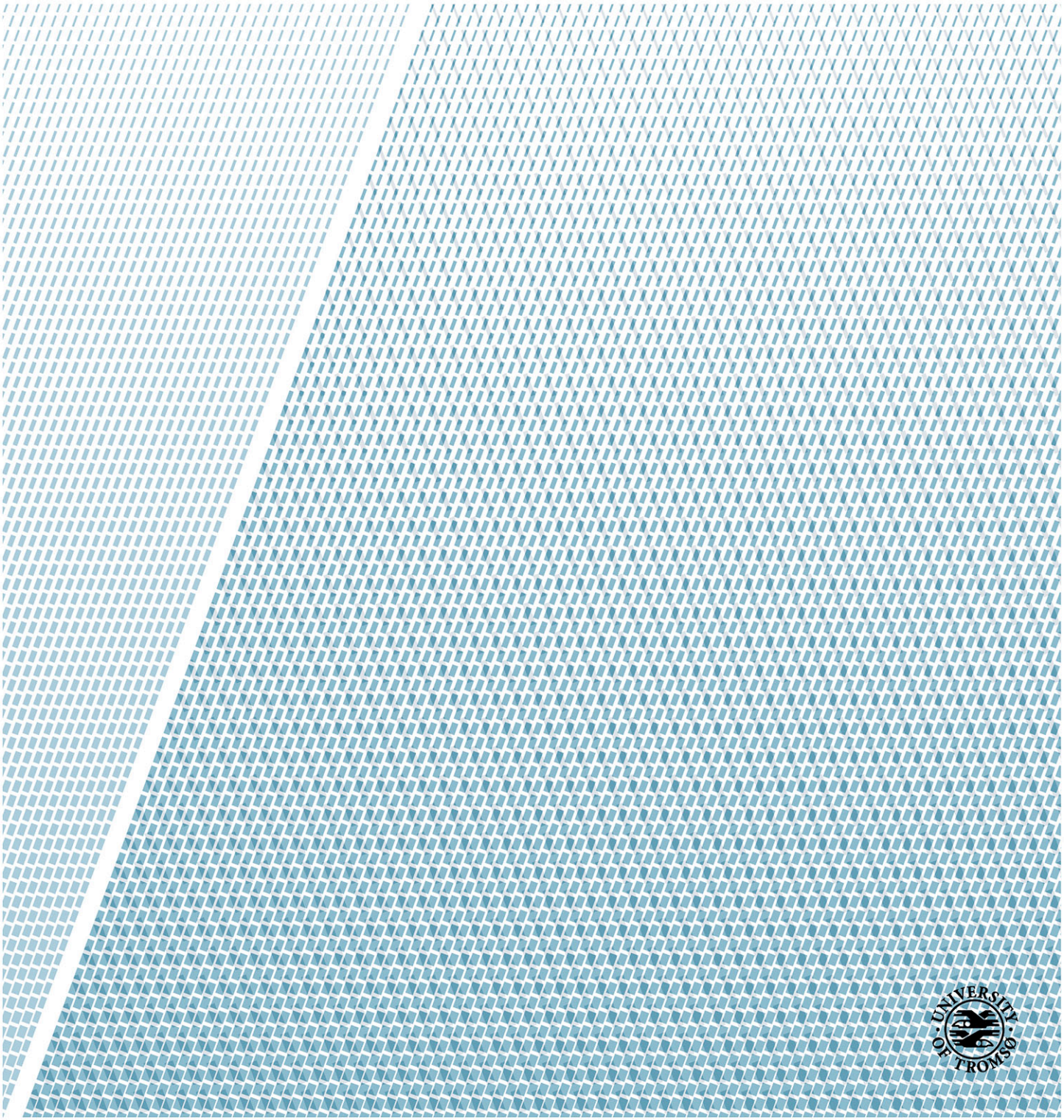

Informant Agreement between Children born with Cleft Lip and/or Palate (CL/P) and their Parents on the Strengths and Difficulties Questionnaire (SDQ)

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Forord

Denne hovedoppgaven ble utformet som en del av profesjonsutdanningen i psykologi ved UiT Norges arktiske universitet. Min interesse for helsepsykologi og egen erfaring på leppe-kjeve-ganespalteteamet ved Statped sørøst i Oslo inspirerte meg til å fordype meg i dette temaet. Hovedoppgaven var en videreføring av semesteroppgaven jeg skrev våren 2014 med tittelen, "The Psychosocial Effects of Being Visibly Different: A Look at Lndividuals with Cleft Lip and/or Palate". Takket være den engasjerte psykologen, Kristin Billaud Feragen, har psykologisk data blitt rutinemessig samlet inn på spalteteamet med formål å kvalitetssikre behandlingen og for å utvide kunnskapen i forskningsfeltet siden 2002. Jeg er takknemlig for å kunne bruke dette datamaterialet til min hovedoppgave.

Underveis i skriveprosessen har jeg hatt to veiledere som har hjulpet meg på ulike arenaer. Min hovedveileder, Svein Bergvik, har bistått med gjennomlesinger og har kommet med gode råd i forhold til oppbygging av teksten og analyser. Min biveileder, Kristin Billaud Feragen, har bidratt med utforming på det faglige planet. Problemstillingen ble foreslått av Feragen, og utvikling av forskningshypoteser og statistisk analyse ble gjort i samarbeid med henne. Jeg fullførte litteratursøket og gjennomgikk dette på egenhånd, men jeg har også fått gode anbefalinger underveis av Feragen. Jeg bidro til inntasting av rådata for ca 80 personer. I tillegg ble jeg godt kjent med denne brukergruppen underveis i min hovedpraksis på spalteteamet ved Statped sørøst fra august 2015 til februar 2016.

Jeg vil takke hovedveilederen min, Svein Bergvik, for konstruktive tilbakemeldinger og støtte. Hans oppmuntring til å utvikle et hovedfokus på oppturer og nedturer av skriveprosessen var svært nyttig. Jeg ønsker også å rette en spesiell takk til Kristin Billaud Feragen. Hennes lidenskap for forskning og bidrag til et psykologisk fokus på spalteteamet er inspirerende.

Abstract

Informant discrepancies can affect the assessment, classification, and treatment of child psychopathology. Scores on the Strengths and Difficulties Questionnaire (SDQ) from different informants have shown to be low to moderately correlated. This study examined agreement between 323 children born with cleft lip and/or palate (CL/P) and their parents to examine whether they follow similar patterns in agreement as the general population. The study investigated whether gender of the child, cleft visibility, and presence of additional difficulty affected informant agreement. Overall, the results suggest that children born with CL/P and their parents follow similar patterns of agreement on the SDQ as the general population. Gender of the child, cleft visibility, and presence of additional condition did not affect the discrepancy between children's and parents' reporting; the scores between children and parents remained low to moderately correlated. Results indicate that children with CL/P and their parents provide different information on the SDQ, and both self- and parent-reports are valuable in the assessment of children's mental health. These results add weight to the notion that children with CL/P and their parents may not be qualitatively different than children and parents in the general population. As with the general population, we should base clinical judgment on a mixture of both informants' reports.

Keywords: cleft lip, cleft palate, informant agreement, informant discrepancy, Strengths and Difficulties Questionnaire.

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The adjective “different” can be defined as being not ordinary, not identical, separate or distinct, not alike in character or quality, differing, or unusual (Dictionary.com, n.d.). In the sense of physical appearance, there are many things that can fall into the category of different. Differences in appearance can have a variety of labels, for example anomaly, impairment, or disfigurement. It is tough to define what it means to be different, and this is largely due to the fact that what is “normal” is not on a set continuum (Rumsey & Harcourt, 2005). It has been argued that a visible difference can be seen as a type of “social disability”; not only does it affect how the persons thinks, behaves and acts, but it can also affect the way others think, feel, and act towards them (Rumsey & Harcourt, 2005). In the field of visible differences, much of what is known has come from research on individuals with the congenital condition cleft lip and/or palate (CL/P). This is largely attributed to the high prevalence and incidence of clefts, and because the condition has the potential to be disfiguring (Rumsey & Harcourt, 2005). Researchers have been interested in what factors and processes may be affected by being different.

To expand on knowledge concerning being different, the current study examined whether children born with CL/P and their parents followed similar patterns in agreement on a well-known questionnaire as those born without a cleft and their parents. By investigating the cross-informant agreement in child/parent reporting of emotional and behavioral problems in this population, we can better determine whether knowledge gained about informant agreement from the general population is applicable to the CL/P population. Before addressing the question of informant agreement in this population, several topics must first be highlighted. Firstly, an introduction to CL/P is essential. One must know what CL/P is, the ways CL/P may potentially affect both functioning and appearance, and take a look at the psychosocial development and functioning of these individuals. By providing a review of the research in this field, we can better understand why we would or would not predict a difference between parents and children within this population compared to the general population. Secondly, the questionnaire used for comparison must be presented. Illustrating how the questionnaire is used and providing information regarding the psychometrics of the questionnaire will lay the groundwork in understanding the basis of using it. Thirdly, it will be important to provide information about informant agreement and discrepancies in general, both in terms of why discrepancies exist and whether higher rates of agreement can be facilitated. Lastly, in order to compare children with CL/P and their parents to the general population, it will be necessary to provide information about how children and parents in the general population score on the questionnaire.

Cleft lip and/or palate (CL/P)

CL/P is one of the most common congenital birth defects, affecting approximately 1 in 500 babies born (e.g. Goodacre & Swan, 2011; IPDTOC Working Group, 2011). The etiology of CL/P is not completely understood; however, it is likely due to an interaction between genes and environmental factors early in the prenatal environment (Mayo Clinic Staff, 2012; Murray, 2002). CL/P occurs when the relevant facial tissue does not fuse together in fetal development during pregnancy (Bernheim, Georges, Malevez, De Mey & Mansbach, 2006). The 5^{th} – 11^{th} week of pregnancy are vital in regards to cell fusion of the face, and any disturbances in this period may result in a cleft (Bernheim et al., 2006). Depending on the timing and severity of disturbance, various degrees of clefts may develop (Bernheim et al., 2006). Cleft lip and palate may occur together or separately, and the cleft may only affect one side (unilateral) or may affect both sides (bilateral) of the mouth (Sosial- og helsedirektoratet, 2007). The condition may potentially affect many areas of the mouth: lip, alveolus (gum), hard and soft palate, and the uvula (Sosial- og helsedirektoratet, 2007). Therefore, the degree to which the child is affected may vary greatly depending on the type of cleft (Figure 1). Clefts may be divided into three main groups (Feragen, 2009; Leppe-ganespalteforeningen, n.d.):

- Cleft palate only (CPO) and submucous cleft palate (SMCP)
- Cleft lip/alveolus (CLA), unilateral or bilateral
- Cleft lip and palate (CLP), unilateral or bilateral

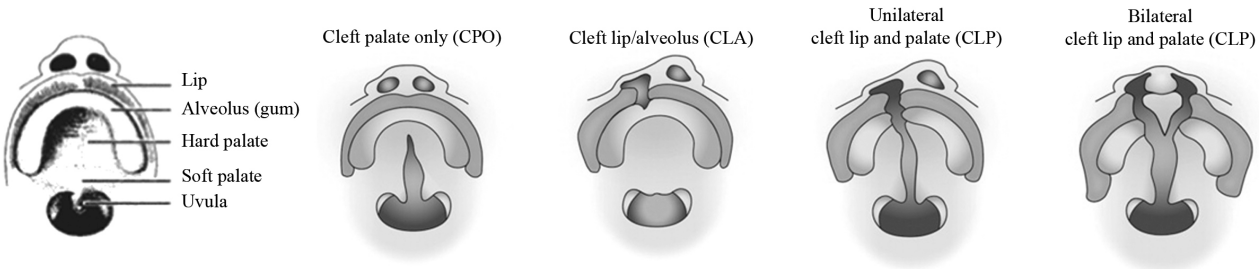

Figure 1. Classification of cleft lip and/or palate. Adapted from "Diagram of Cleft Lip and/or Palate," by Cleft Lip and Palate Association, n.d., and Mossey, Little, Munger, Dixon, & Shaw, 2009, *The Lancet, 374,* p. 1774.

In terms of appearance, a cleft lip/alveolus (CLA) or a cleft lip and palate (CLP) can be categorized as a "visible" difference, while a cleft palate (CPO) or submucous cleft palate (SMCP) can be categorized as a "nonvisible" difference. In Norway approximately 100 – 120 children are born with some form of cleft annually (Leppe-ganespalteforeningen, n.d.). Of these, approximately 50% are born with CLP, 25% with CPO, and the remaining 25% with

CLA (Sosial- og helsedirektoratet, 2007). Boys are more often born with CLA or CLP, while girls are more often born with CPO (Martelli et al., 2012).

Clefts that involve the lip/alveolar affect the person's appearance and teeth/bite, while clefts with palatal involvement may affect the person's speech, resulting in a nasal resonance (Sosial- og helsedirektoratet, 2007). In cases of a submucous cleft, the mucous membrane (lining of soft palate) covers the cleft, making it harder to see (Cleft Palate Foundation, 2007). Like a cleft palate, a submucous cleft may affect speech, and these clefts are typically detected by the presence of abnormal nasal speech (Cleft Palate Foundation, 2007). Other complications that often arise together with a CL/P are feeding difficulties, ear infections, hearing loss, speech and language delay, and dental abnormalities (Stanford Children's Health, 2014).

In order to improve both function and appearance, corrective surgery is performed already during the first year of life (Shaw et al., 2001). The lip is closed when the child is approximately 3 months old, and the palate is closed when the child is approximately 12 months old (Cleft Lip & Palate Association, 2015). These surgeries are a minimum in order to function adequately, and the burden of care extends beyond the closure of the cleft during the first year (Shaw et al., 2001). Later in life other possible surgeries for the child include: alveolar bone graft to close the alveolar cleft, lip and nasal reconstruction in cases where lip is affected, and speech-enhancing surgery in clefts with palatal involvement (Shaw et al., 2001). Children with clefts often have disruptions in dental development in the cleft area, thus making orthodontic treatment typically necessary, as well as corrective orthognathic (i.e. jaw) surgery in some cases (Shaw et al., 2001). Those with clefts with palatal involvement may struggle to make certain sounds, making speech therapy needed (Tørdal & Kjøll, 2010). Treatment is often not completed until the individual reaches early adulthood because of the need for the facial structures to be fully matured prior to some surgeries (Lockhart, 2003).

The great deal of follow-up needed to ensure the proper care of these individuals demonstrates the need for a multidisciplinary approach as a way to reduce the burden of care. Centralizing treatment and having a multidisciplinary team is a way of increasing expertise and ensuring the best possible outcomes for the child born with a cleft (Semb, Åbyholm, Tindlund, & Lie, 2000). In order to provide the best care for the patient, a CL/P ideally consist of: several surgeons (including plastic, oral, and maxillofacial surgeon), orthodontist, speech therapist, ear/nose/throat specialist, social worker, and psychologist (American Cleft Palate – Craniofacial Association, 2010). Norway has adopted a centralized treatment program since the 1950s, and two multidisciplinary teams exist in Oslo and Bergen (Semb et

al., 2000). Data is routinely collected in order to ensure good quality of care and to utilize for research purposes.

One of the most common congenital birth defects, CL/P, has the potential of affecting many areas of the individual's appearance and functioning. It is apparent that individuals born with CL/P face a variety of obstacles and may experience some difficulties as a result of this. A child with CL/P may experience feeling qualitatively different from their peers without a cleft because of their appearance, having abnormalities in speech in terms of articulation and resonance, and having to undergo many surgeries (Feragen, 2009). In a society that emphasizes physical attractiveness and verbal communication, it is conceivable that individuals with clefts may experience difficulties as a result of both cosmetic and communication issues (Lockhart, 2003). Research concerning the psychosocial development of those born with clefts will be covered in the subsequent section in order to highlight how these individuals are potentially affected by their condition.

Psychosocial Issues in Individuals with CL/P

There exists a vast amount of research regarding the psychosocial development and adjustment of individuals affected by CL/P published by an extensive community of psychologists and other professionals. Major areas of investigation include behavioral and emotional adjustment, self-esteem and personality, social functioning, and cognitive development and achievement (Endriga & Kapp-Simon, 1999). As many factors may be affected by having CL/P, these individuals may experience a higher level of distress than individuals without clefts (Feragen, 2009; Hunt, Burden, Hepper, & Johnston, 2005; Mossey et al., 2009; Stock & Feragen, 2016; Thompson & Kent, 2001). Among those with clefts, there has been reported higher rates of: externalizing and internalizing behavioral problems (Endriga & Kapp-Simon, 1999; Hunt, Burden, Hepper, Stevenson, & Johnston, 2006; Ramstad, Ottem, & Shaw, 1995), expressing dissatisfaction with appearance (Thomas, Turner, Rumsey, Dowell, & Sandy, 1997; Versnel, Duivenvoorden, Passchier, & Mathijssen, 2010), difficulties in social interaction and more teasing (Hunt et al., 2006), and experiencing more distress in response to appearance and treatment issues (Hunt et al., 2005). Studies within other populations of children have shown that extensive surgery and medical procedures have the potential to cause post-traumatic stress symptoms (Levenson, 2007; Saxe, Vanderbilt, & Zuckerman, 2003; Tedstone & Tarrier, 2003; Wintgens, Boileau, & Robaey, 1997). To the author's knowledge, this issue not been explicitly studied in the CL/P population. However, given the extent of treatment children with CL/P may have to go

through, it is plausible that some may experience traumatic stress in response to treatment and experience the condition as an underlying stressor.

Research has traditionally taken a somewhat pathologizing approach to the investigation of psychosocial issues in individuals with CL/P. However, more recently, studies have taken a more resilience-focused approach, and looked into the positive aspects of being born with this congenital condition. These studies have focused on whether the cleft may provide a form of emotional resilience. Interestingly, comparative studies of individuals with clefts and control groups have found that in some cases those with clefts report higher levels of self-esteem (Klassen et al., 2012). Many individuals with CL/P also believe that their clefts have been character building and see it as a sign of strength (Stock, Feragen, & Rumsey, 2016). Being born with a difference like CL/P may challenge one's self perception, but it seems that some factors may dampen the feeling of looking and sounding different (Feragen, 2009). Individuals with clefts experience more teasing compared to individuals without clefts, and that this teasing was a significant predictor of poorer psychosocial functioning (Hunt et al., 2006; Turner, Rumsey, & Sandy, 1998). Having been teased was a better predictor of psychosocial functioning, behavioral problems, and dissatisfaction with facial appearance than merely having a cleft lip and/or palate per se (Hunt et al., 2006). Factors associated with positive coping have been investigated, and it appears that positive perceptions of friendships (Feragen, 2012), positive social support from parents (Baker, Owens, Stern, & Willmot, 2009), good social skills (Rumsey & Harcourt, 2005), and absence of teasing (Feragen, Borge, & Rumsey, 2009) may contribute to emotional resilience and better psychosocial adjustment. When controlling for these factors, cleft type and gender did not predict degree of psychosocial resilience (Feragen et al., 2009).

The findings in cleft research have been somewhat mixed, and there are differences in terms of whether the research has taken a pathologizing- or resilience-based approach. Discrepancies in findings likely reflect the many variations and the complex processes involved in adjusting to a difference, in addition to differences in methodologies in the studies (Feragen & Stock, 2014). In an attempt to provide a comprehensive account of the research findings in the field, Hunt et al. (2005) conducted a systematic review to investigate whether individuals with clefts had an increased risk of impaired psychosocial functioning, which types of impairments they develop, and whether an association between cleft type and prevalence and severity exists. Their systematic review, which included 64 articles with studies of longitudinal, cross-sectional, and retrospective design, found support for the notion that overall psychosocial functioning is not greatly affected by being born with CL/P, but

some may have difficulties in some areas (Hunt et al., 2005). Stock and Feragen (2016) recently replicated the systematic review, including research completed in 2005 – 2015, and found similar results. For a full review on psychological adjustment, see Hunt et al., 2005 and Stock & Feragen, 2016.

Overall, it appears that being born with CL/P has a low impact on psychosocial adjustment (Hunt et al., 2005; Stock & Feragen, 2016), despite the possible burden in terms of differences in appearance, speech, and experiences with the medical system. Some individuals with clefts show poorer psychosocial functioning, and identifying factors or subgroups in the cleft population with higher risk of psychological maladjustment has been a priority. Both researchers and laypeople have long assumed that the severity of cleft influences psychosocial adjustment. Recently the role of having a condition or difficulty in addition to the cleft has also been investigated. A review of findings concerning these two areas will be covered next in order to understand some possible factors may influence psychosocial adjustment in individuals with CL/P.

Severity of Cleft as a Predictor of Psychosocial Adjustment

Intuitively one may think that someone with a more severe abnormality may experience more distress, and a positive association between severity of deformity and level of distress has previously been proposed (Rumsey & Harcourt, 2005). There are several objective methods of assessment for severity cleft for both in terms of appearance and speech (e.g. Draaijers et al., 2004; Mani et al, 2010; Mars, Plint, Houston, Bergland, & Semb, 1987), so it is possible to rate severity of clefts objectively. One could argue that visible clefts (i.e. clefts where lip is involved) are more severe than nonvisible clefts (i.e. clefts with only palatal involvement) because the aforementioned are objectively visible to the surroundings at all times and can thus affect more areas. One could also argue that having a bilateral cleft is more severe than a unilateral cleft.

Based on these assumptions, one may expect that those with a bilateral cleft lip and palate would show the poorest psychosocial functioning while those with a cleft palate only would show the best psychosocial functioning. However, research does not support this, and it is seems that the rating of objective severity as a way to predict psychosocial functioning is impractical. It is well documented in psychological research that other variables influence psychosocial functioning more than objective severity (Brown, Moss, McGrouther, & Bayat, 2010; Feragen, 2012; Feragen & Stock, 2014; Klassen et al., 2012; Ong, Clarke, White, Johnson, Withey, & Butler, 2007; Rumsey & Harcourt, 2005). It appears that level of

dissatisfaction highly depends on the individual's perceived severity rather than objective severity of the condition (Klassen et al., 2012; Moss, 2005; Ramstad et al., 1995; Thompson & Kent, 2001). This is an important finding because it ultimately means that the concept of objective difference, i.e. how "abnormal" the person looks or sounds, is not a good predictor of psychosocial functioning (Klassen et al., 2012). In terms of appearance it is the person's subjective opinion that matters. It is thus important to adequately assess perceived level of severity for all individuals with clefts if one aims to identify those with adjustment difficulties (Moss, 2005).

The finding that other variables influence psychosocial functioning more than objective severity may be contradictory to what many intuitively assume. This has been demonstrated in many areas of appearance research, but cleft visibility continues to be a factor included in cleft studies because it seems necessary to repeatedly demonstrate this finding. Researchers continue to explore other factors in order to understand what influences psychosocial adjustment.

Presence of Additional Conditions as a Predictor of Psychosocial Adjustment

Another less explored factor that may influence psychosocial functioning is the presence of an additional condition or difficulty. It is well-established knowledge that children born with clefts have heightened risk for associated developmental and cognitive problems (Milerad, Larson, Hagberg, & Ideberg, 1997; Swanenburg de Veye, Beemer, Mellenbergh, Wolters, & Heineman- de Boer, 2003). Though the majority of those with clefts develop normally, in some cases the cleft may be part of a syndrome, like Van der Woude syndrome, velocardiofacial syndrome, and Pierre Robin Sequence (Venkatesh, 2009). The effect of these syndromes can greatly vary (Venkatesh, 2009). It varies whether children with additional conditions are included in cleft samples, thus the results concerning psychosocial functioning may be affected by this potentially mediating or confounding variable.

Recently psychosocial functioning was compared in CL/P children with and without an additional condition (Feragen & Stock, 2014). The range of additional conditions and difficulties included: syndrome with or without other associated conditions, developmental difficulties, ADHD/ADD, specific language impairment, and general learning difficulties (Feragen & Stock, 2014). Children with a cleft and an additional condition reported significantly more psychosocial difficulties than children with a cleft alone as measured by the Strengths and Difficulties Questionnaire (SDQ) and Child Experience Questionnaire (CEQ), while those with a cleft alone scored comparable to their peers without clefts

(Feragen & Stock, 2014). This illustrates that those with an additional condition might be a particularly vulnerable subgroup that report poorer psychological functioning.

In sum, the psychosocial adjustment of an individual with CL/P is dependent on an intricate interaction between many factors that can both provide risk and protection (Endriga & Kapp-Simon, 1999; Feragen, 2009). A number of studies have concluded that the majority of individuals with CL/P have normal development (Endriga & Kapp-Simon, 1999; Pope & Snyder, 2005), and do not experience major psychosocial difficulties or psychopathology (Feragen & Stock, 2016; Hunt et al., 2005). Objective severity of cleft does not seem to be a good predictor of psychosocial functioning; the subjective opinion of the person is more important. The presence of an additional condition may be a confounding variable, and the presence of an additional condition seems to influence psychosocial functioning negatively. For individuals who do experience difficulties, psychological assessment and treatment has been emphasized in terms of providing the best care. Using standardized questionnaires is a way to tap into psychosocial functioning. The following section will highlight the Strengths and Difficulties Questionnaire (SDQ), a questionnaire that is frequently used in clinical settings and research to identify those individuals that are at risk for maladjustment. This questionnaire is systematically used in the psychological assessment at the cleft team in Oslo.

The Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) is a brief screening tool for behavioral and emotional difficulties and positive strengths in children and adolescents (Goodman, 2001), and is widely used in child mental health research (Vostanis, 2006). The SDQ items are divided into five scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. There exists parent, teacher, and self-report versions of the SDQ, with corresponding items and scales (Van Roy, Grøholt, Heyerdahl, & Clench-Aas, 2010). There also exists an extended impact supplement that assesses the degree to which the informant finds the behaviors problematic (Goodman, 1999). The compact one page format and assessment of both problematic and positive behaviors are considered advantageous (Goodman, 1997). The SDQ has been psychometrically validated in several cultural contexts, both in community and clinical populations (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000; Goodman, Renfrew, & Mullick, 2000; Obel et al., 2004; Van Roy, Veenstra, & Clench-Aas, 2008). The SDQ can predict child psychiatric disorders with good specificity and moderate sensitivity when a multi-informant approach is used in community samples, making it a promising tool in

community screening programs (Goodman et al., 2000; Goodman, Renfrew, & Mullick, 2000). Satisfactory convergent and discriminant validity, in addition to support to the five-factor model, have been shown (Van Roy et al., 2008). The distributions of SDQ scores are comparable across the Scandinavian countries (Obel et al., 2004; Rønning, Handegaard, Sourander, & Mørch, 2004). The SDQ has been shown to correlate highly with other well-known questionnaires like the Child Behavior Checklist ([CBCL]; Goodman & Scott, 1999; Klasen et al., 2000; Koskelainen, Sourander, & Kaljonen, 2000; van Widenfelt, Goedhard, Treffers, & Goodman, 2003) and the Rutter questionnaires (Goodman, 1997). The SDQ can be a useful outcome measure to complement the Health of the Nation Outcome Scales for Children and Adolescents ([HoNOSCA]; Mathai, Anderson & Bourne, 2003).

The SDQ has been shown to be a good measure for identifying children who experience psychological distress (Goodman et al., 2000; Goodman, Renfrew, & Mullick, 2000). In addition to the compact format and assessment of both negative and positive behaviors, a main advantage of the SDQ is that it allows health professionals to gather information from several informants. A multi-informant approach has been widely recognized when investigating mental health issues in children and adolescents, and it is common practice to gather collateral source information in clinical settings. However, agreement between informants is typically low to moderate (Achenbach, McConaughy, & Howell, 1987; De Los Reyes & Kazdin, 2005; Duke, Ireland, & Borowsky, 2005; Edelbrock, Costello, Dulcan, Conover, & Kala, 1986; Verhulst & van der Ende, 1992). Parent-child discrepancies on the SDQ have been well documented in the general Norwegian population (Van Roy et al., 2010). In the next section findings concerning informant agreement, the consequences of informant discrepancies, and which factors may influence the agreement and discrepancies will be discussed. Parent-child discrepancies on the SDQ for Norwegian children will also be highlighted.

Informant Agreement and Discrepancies

A multi-informant approach allows diverse informants, like parents, teachers, and mental health workers, to provide valuable information in addition to the youth themselves (Achenbach et al., 1987). Ratings of social, emotional, or behavior problems in children are influenced by whom the informant is (e.g. child, parent, teacher; De Los Reyes & Kazdin, 2005). This is a robust finding, and has been demonstrated in many methods of clinical assessment (e.g. structured interviews, rating scales), in samples of informants from diverse cultural backgrounds, and in both clinical and population samples (Achenbach et al., 1987).

In an attempt to sum up the relations between informant discrepancies and informant characteristics, an array of child characteristics (e.g. age, gender, ethnicity, problem type, social desirability, and perceived distress) as well as parent characteristics (e.g. psychopathology such as depression and anxiety, stress, socioeconomic status, family characteristics) have been investigated (De Los Reyes & Kazdin, 2005). Unfortunately, findings are inconsistent, and correlations are consistently low to moderate. Factors such as gender of parent (i.e. mothers' versus fathers' ratings), gender of child (i.e. boys' versus girls' ratings), type of sample (i.e. clinical versus nonclinical sample) do not influence correlations significantly (Achenbach et al., 1987). Though still in the low to moderate range, correlations are higher for younger children (age 6 – 11) than for adolescents, suggesting that younger children may be easier to observe and act similarly in different settings (Achenbach et al., 1987).

Despite numerous attempts, research falls short in explaining why these discrepancies exist, in addition to how to facilitate improved consistency (De Los Reyes & Kazdin, 2005). Low cross-informant correlations do not necessarily imply that the reports by informants are invalid or unreliable, and rather illustrates that target variables differ from one situation to another (Achenbach et al., 1987). There are many things that will vary based on informants: their opportunities for observation, their effects on the children/adolescents, and their standards of judgment (Achenbach et al., 1987). Theories about why discrepancies exist have been proposed, and rely largely on differences in the contexts observation takes place and differences in the perspectives the informants have (De Los Reyes & Kazdin, 2005).

Informant discrepancies can have several consequences in both clinical and non-clinical settings. The assessment, classification, and treatment of child psychopathology may be influenced by informant discrepancies; the child in question may meet different diagnostic criteria depending on which informant one chooses to base assessment and classification on (De Los Reyes & Kazdin, 2005). Treatment may be delayed due to disagreement in defining the problem and the need for treatment (De Los Reyes & Kazdin, 2005). A particular conundrum is the decision of whom to listen to in instances where only one informant identifies a problem or there is disagreement in defining the problem. Despite informant discrepancies it is common to obtain collateral source information in clinical settings in order to provide a comprehensive assessment because it is believed that both views provide valuable albeit different information (Van Roy et al., 2010). Commonly, the information from different informants has been combined in order to arrive at a classification of the child's difficulty (Offord et al., 1996).

Parent-child discrepancies on the SDQ have been previously been investigated (Goodman, 2001; van der Meer, Dixon, & Rose, 2008; Van Roy et al., 2010). Discrepancies in the general Norwegian population was investigated as part of a large epidemiological study by comparing differences in the prevalence and means of SDQ symptom and impacts scores from 8154 children aged between 10 and 13 years and their parents (Van Roy et al., 2010). Scores were low to moderately correlated, suggesting that Norwegian children and parents provide different information on the SDQ and that both self- and parent-reports were valuable in the assessment of children's mental health (Van Roy et al., 2010).

Discrepancies between informants exist in ratings on clinical assessments (Achenbach et al., 1987), and these discrepancies can influence the assessment, classification, and treatment of child psychopathology (De Los Reyes & Kazdin, 2005). When working with various populations of clients/patients, it is important to be able to base decisions on sound research and not only on clinical judgment or assumptions. Generally, children with CL/P develop in a typical manner and the majority does not experience more psychosocial difficulties than their peers without a cleft (Hunt et al., 2005; Stock & Feragen, 2016). However, they may experience feeling different in terms of appearance, speech, and because of medical follow-up (Feragen, 2009). The SDQ has been shown to be a good measure for identifying children who experience psychological distress (Goodman et al., 2000; Goodman, Renfrew, & Mullick, 2000), and discrepancies between informants have been demonstrated in a large population study (Van Roy et al., 2010). The SDQ is used in the psychological assessment of children with CL/P, but whether discrepancies exist between children with CL/P and their parents has yet to be determined. The aim of this study is to examine informant discrepancies between children born with CL/P and their parents, and to explore if this population show comparable patterns of agreement as those found between children and parents in the general Norwegian population.

Current Study

By investigating the cross-informant agreement in child/parent reporting of emotional and behavioral problems in this population, one can better determine whether knowledge concerning informant discrepancies gained from the general population is applicable to the CL/P population. Parent reports on the SDQ have not previously been investigated; therefore knowledge about informant agreement between children and parents is missing for this population. The study investigated whether gender of the child, cleft visibility, and presence of additional condition affected informant agreement between children and their parents.

As results concerning which parent/child characteristics affect informant agreement in reporting have been inconclusive (De Los Reyes & Kazdin, 2005), it was uncertain whether there might exist particular factors in the relationship between children and parents that would affect agreement. Treatment for CL/P starts from a very young age, and the family is very much involved in the whole process, thus making it an interesting area to explore. Both higher and lower rates of agreement between children with CL/P and their parents are plausible. One could imagine that parents of children with clefts become more attuned to their child and aware of potential problems that may arise due to the frequent visits to the CL/P team. This may lead to a more open relationship where discussions around topics concerning areas of psychosocial functioning may be facilitated. On the contrary, it may be possible that the close follow-up by the team may make it so the parents worry more and attribute more trouble to the clefts, thus heightening their report of symptom. Studies on parents perceptions of their child's cleft have been limited, so it is uncertain whether parents may have preconceived notions about cleft visibility and presence of additional condition that may influence their ratings.

Based on previous studies on child-parent agreement, several hypotheses were formed. The first hypothesis stated that agreement on the SDQ between children with CL/P and their parents would be low to moderate, and this would be true for both genders. The second hypothesis stated that cleft visibility (visible vs. nonvisible cleft) would not influence agreement, and agreement between children and parents would be low to moderate regardless of having a visible or nonvisible cleft. The third hypothesis stated that children with additional conditions would report more symptoms than the children with a cleft alone. However, whether the nature of the discrepancies between children and parents would be affected by the presence of an additional condition was uncertain. The scope of this study was limited to investigating the nature of discrepancies in this population to see if they were similar to the general population. Explanations for informant discrepancies and how to increase agreement has been previously investigated, and findings have been inconclusive (De Los Reyes & Kazdin, 2005), therefore the study did not attempt to explain why discrepancies exist or investigate which factors in the relationship between children with CL/P and their parents could explain the agreement patterns.

Method

Treatment Setting and Data Acquisition

Treatment for CL/P is centralized to two multidisciplinary teams in Norway: one at Oslo University Hospital and the other at Haukeland University Hospital in Bergen. These two teams work closely together, and use similar treatment protocols (Semb et al., 2000). The team in Oslo is responsible for 2/3 of the Norwegian cleft population, while the team in Bergen is responsible for the remaining 1/3 (Semb et al., 2000). The centralized team in Oslo provides a standardized treatment protocol (Appendix A), which includes meetings with a psychologist at various points in time. All children born with a cleft and their parents are called in for a check-up with a psychologist prior to the first surgery, at age 2, 10, and 16.

Data was collected as part of the Oslo CL/P team's routine psychological assessment procedure, and assessments were conducted at Statped sørøst, the Norwegian National Resource Center for Special Education.

Participants

The current study was based on cross-sectional clinical data from children born with CL/P and their parents. Children were 10 years of age at the time of psychological assessment. All children born with clefts are called in around their 10th birthday, and attendance rate is typically high (approx. 96 – 98%; Feragen, 2009). The current study included seven consecutive birth cohorts of children born between 1997 and 2005, and data was registered at their assessment in the period between 2007 and 2015. Only pairs where both the child and parent had completed the SDQ were eligible for inclusion. To ensure a representative sample and to be able to compare with the general population, all children were included, regardless of additional conditions.

Procedure for Assessment at Age 10

The assessment at age 10 was coordinated between several groups of professionals: a clinical psychologist, an orthodontist, and a speech therapist. All children met with the psychologist and orthodontist, while only children with clefts with palatal involvement met with speech therapists.

The psychological assessment involved a semi-structured interview completed by the team's psychologist, the child completed self-report questionnaires, and the parents completed parent-rated questionnaires. The psychologist and child were in the assessment room while the parents filled out the questionnaire in a different room. At the end of

assessment, the parents were invited back to the assessment room to briefly sum up the conversation with the child. Based on reporting, follow-up meetings were scheduled in cases where the psychologist deemed it necessary.

Measures and Instruments

Strengths and Difficulties Questionnaire (SDQ). The Norwegian version of the SDQ was introduced as part of the routine psychological assessment at age 10 in mid-2007. The one page version without impact supplement was used. The children filled out the self-report SDQ (Appendix B), while parents/caregivers filled out the parent version of SDQ (Appendix C). The SDQ consists of 25 items that are divided into five scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. Each item is answered on a 3-point scale: "not true", "somewhat true", or "certainly true", and rated 0 -1– 2 respectively for items that are negatively worded and reversed 2 -1– 0 for items that are positively worded (Van Roy et al., 2010). Sum scores are calculated for each subscale by adding the items that are part of the subscale, and can range from 0 – 10. All subscales except the prosocial behavior subscale are added to obtain a total difficulties score, and this can range from 0 – 40 (Van Roy et al., 2010). A high score indicates a higher risk for psychological and emotional problems, and warrants further attention (Achenbach et al., 2008; Feragen & Stock, 2014).

Cleft visibility. Visibility of cleft was determined based on whether a cleft lip was present or not; "visible" clefts included cleft lip and palate (CLP) and cleft lip alveolus (CLA) and "nonvisible" clefts included cleft palate only (CPO) and submucous cleft palate (SMPO). Information regarding type of cleft was obtained from the child's health records. This was only a categorization of cleft type, rather than objective rating of cleft visibility.

Additional conditions and difficulties. Information regarding the presence of an additional condition and other difficulties was obtained from the child's records and/or from information provided by the parents at the time of assessment. The wide range of additional conditions included developmental difficulties/delays affecting the child's cognitive capacities and learning, syndromes, attention and/or hyperactivity disorders, specific language impairment, and dyslexia and general learning difficulties. Additional conditions were collapsed into one group due to the scope of this study. All children were included in the sample regardless of additional condition, but this variable was controlled for in the statistical analyses.

Other collected items/measures. A semi-structured interview conducted by the psychologist (Appendix D) assessed knowledge of cleft/condition, psychosocial wellbeing, presence of friendships, and occurrence of teasing, staring, questions, and avoidance behaviors. In addition to the SDQ, the child also completed an abbreviated version of the Cleft Hearing, Appearance and Speech Questionnaire (CHASQ) and the Child Experience Checklist (CEQ).

The parents completed a parent-rated questionnaire (Appendix E), which in addition to the SDQ included questions regarding occurrence of teasing, staring, questions, and avoidance behaviors, and whether the parent had any concerns. Information concerning who had filled out the SDQ (mother, father, or both) was available, but these data were not included in the present study; the sample size was too small to run analyses based on both gender of the child and gender of parent.

The questionnaires used are based on questionnaires that were originally developed by the Special Interest Group - Psychology of the Craniofacial Society of Great Britain and Ireland.

Statistical Methods

All statistical analyses were conducted in SPSS version 22.0. The statistical level was set at $p < 0.05$. All analyses were performed separately for both genders. The variables (gender of child, visibility of cleft, presence of additional difficulty) were used as categorical/nominal variables, while the SDQ score was considered an ordinal variable.

Descriptive statistics were used to analyze the frequency of the included variables and response rate. Raw scores on SDQ were utilized in the analyses as these appeared to provide the most accurate measure of discrepancy. Paired sample t-tests were used to compare outcome measures between child-parent pairs. Cohen's *d* effect sizes were calculated in cases of significant differences between means. To control for dependence among means the correlation was entered when calculating effect sizes (Morris & Deshon, 2002). Cross-informant agreement (i.e. child versus parent) was determined by using Pearson's correlation coefficient *r*.

In order to determine whether children with CL/P and their parents follow the same trends in informant discrepancies, agreement was examined by comparing means, correlations, and effect sizes to the large national reference study (Van Roy et al., 2010).

Ethical Considerations

Participation was voluntary, and informed consent was obtained from the child's parents. For children who were born before 2001, parents received a letter in the mail with information about the research project, and had to actively consent by mailing back a form. Parents of children born in 2001 or later are routinely asked for consent in being registered in the National Quality Registry for CL/P. All parents who had given their active consent for their child to be included in the registry were informed about ongoing research. Data for those who had not provided consent or where consent was missing was deleted from the file prior to completing analyses. The study adhered to guidelines provided by the regional ethics committee (Regional Committee for Medical Research Ethics, Region Oslo-East). However, the study was considered to be quality assurance, and was therefore not subject to approval from this entity.

Results

Only pairs where both the child and parent had filled out the SDQ were eligible for inclusion; in the seven consecutive birth cohorts of children born between 1997 and 2005 a total of 363 child-parent pairs were identified as complete. Of these, 89% consented to participate in the study (n = 323). Information regarding consent was missing for 8,8% (n = 32), and 2,2% did not consent to participate in the study (n = 8).

The sample consisted of 181 boys (56%) and 142 girls (44%). A total of 206 children (63,8%) had a visible cleft, and a total of 115 children (35,6%) had one or several additional conditions in addition to the cleft. Figure 2 and Figure 3 show a visual presentation of the sample based on gender.

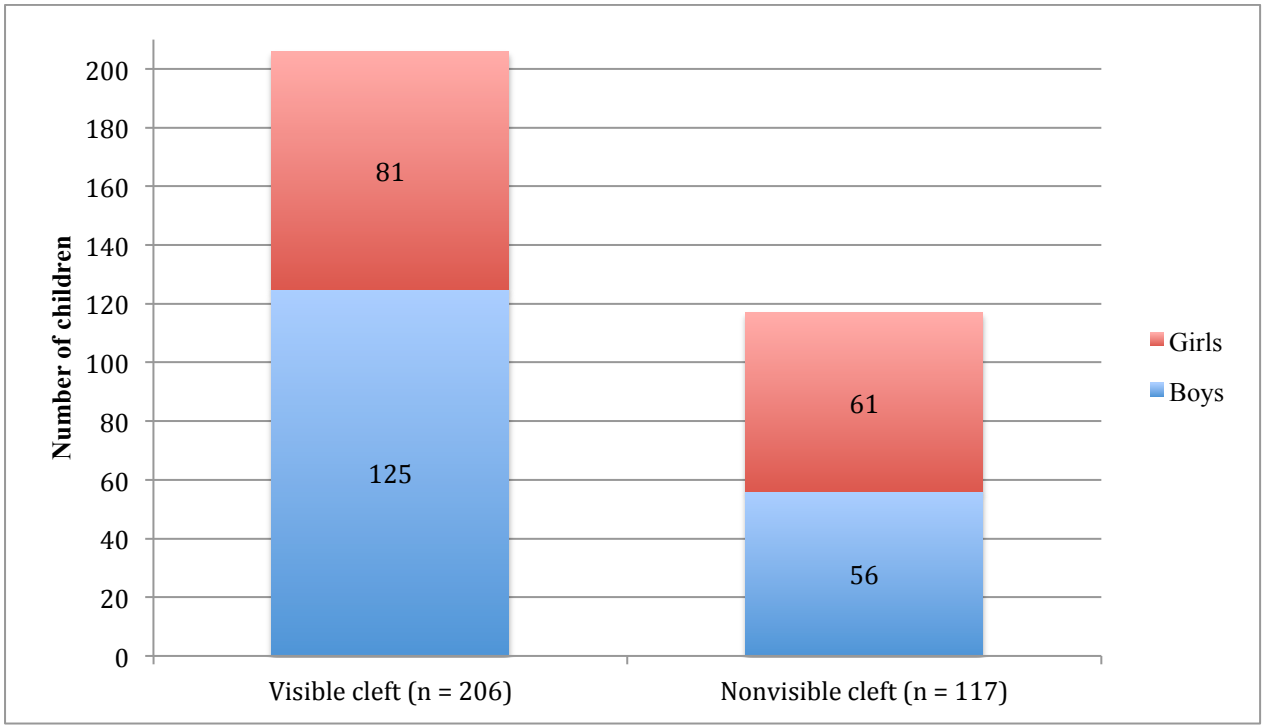

Figure 2. Sample based on cleft visibility and gender.

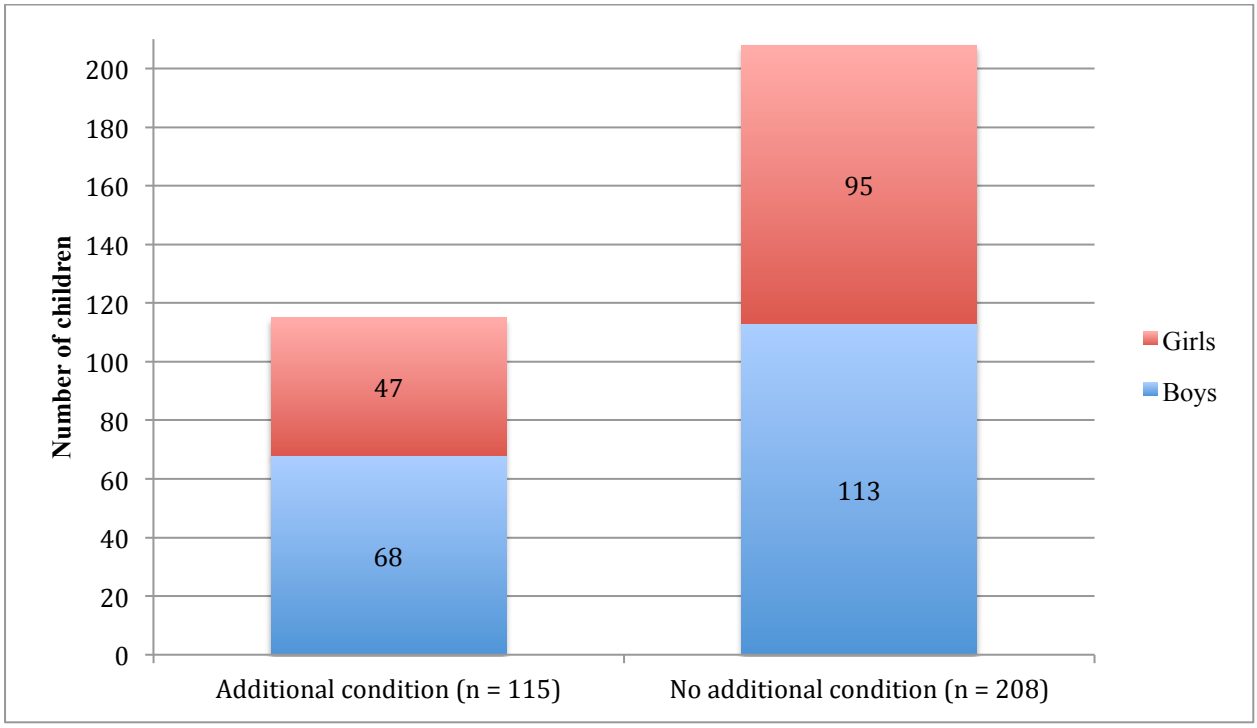

Figure 3. Sample based on presence of additional condition and gender.

SDQ Reports by Children and Parents

Table 1 presents the means (SD) of the children's and parents SDQ scores, differences in means, and correlations between child-parent scores. Children were categorized by gender, and all cleft types were included in these categories.

Table 1

SDQ Ratings from 10-year olds' Self-Report and their Parents´ Report

		Parent-report	**Self-report**	**Parent-/self-report**			
SCALES ON SDQ		***M (SD)***		Paired samples t-test	t-value	Effect size	*r*
Total difficulties	Boys	8.2 (6.3)	11.0 (5.8)	***	5.90	-0.44	.43 ***
	Girls	7.0 (5.7)	10.5 (5.0)	***	7.60	-0.64	.49 ***
Emotional	Boys	1.9 (2.1)	2.8 (2.4)	***	4.52	-0.15	.24 ***
	Girls	2.0 (2.0)	3.1 (2.3)	***	5.58	-0.47	.36 ***
Conduct	Boys	1.4 (1.5)	1.9 (1.6)	**	3.15	-0.24	.31 ***
	Girls	1.0 (1.3)	1.5 (1.3)	***	3.76	-0.31	.37 ***
Hyperactivity	Boys	3.6 (2.8)	4.4 (2.3)	***	3.84	-0.29	.44 ***
	Girls	2.7 (2.6)	3.9 (2.0)	***	5.84	-0.50	.42 ***
Peer problems	Boys	1.4 (1.8)	2.1 (1.7)	***	5.30	-0.40	.42 ***
	Girls	1.4 (1.8)	2.0 (1.7)	***	4.06	-0.34	.46 ***
Prosocial	Boys	8.5 (1.7)	7.9 (1.8)	***	-4.03	0.30	.19 *
	Girls	8.8 (1.8)	8.6 (1.6)	n.s.	-0.69		.24 **

Note. M = mean, *SD* = standard deviation, *r* = Pearson's correlation coefficient *r*.

Boys: n = 181, girls: n = 142

* $p < .05$, ** $p < .01$, *** $p < .001$; n.s. = non-significant

Symptom reports based on gender. Children of both genders reported higher scores than parents on all subscales, with the exception of the prosocial subscale where parents' scores were higher (Table 1). Boys reported significantly more symptoms than girls on all scales except on emotional problems, and this pattern was also observed in parents' report. Means for children and parents were comparable to those found in the reference study with large national sample of Norwegian children (Van Roy et al., 2010) (Table 2).

Table 2.

SDQ Ratings from 10-year olds' Self-report with CL/P and their Parents´ Report Compared to Reference Study (Van Roy et al., 2010).

	Girls		Boys	
	CL/P[a]	Ref. study[b]	CL/P[c]	Ref. study[d]
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
Self-report				
Total difficulties	10.5 (5.0)	10.5 (5.1)	11.0 (5.8)	10.1 (5.2)
Emotional	3.1 (2.3)	3.0 (2.2)	2.8 (2.4)	2.2 (1.9)
Conduct	1.5 (1.3)	1.7 (1.4)	1.9 (1.6)	2.1 (1.7)
Hyperactivity	3.9 (2.0)	3.5 (2.0)	4.4 (2.3)	3.8 (2.1)
Peer problems	2.0 (1.7)	1.9 (1.7)	2.1 (1.7)	2.1 (1.8)
Prosocial	8.6 (1.6)	8.2 (1.6)	7.9 (1.8)	7.4 (1.8)
Parent-report				
Total difficulties	7.0 (5.7)	5.7 (4.8)	8.2 (6.3)	6.6 (5.2)
Emotional	2.0 (2.0)	1.4 (1.8)	1.9 (2.1)	1.2 (1.7)
Conduct	1.0 (1.3)	1.0 (1.2)	1.4 (1.5)	1.1 (1.4)
Hyperactivity	2.7 (2.6)	2.2 (2.0)	3.6 (2.8)	3.0 (2.4)
Peer problems	1.4 (1.8)	1.1 (1.6)	1.4 (1.8)	1.3 (1.7)
Prosocial	8.8 (1.8)	8.5 (1.5)	8.5 (1.7)	8.0 (1.7)

Note. M = mean, *SD* = standard deviation.

[a] n = 142. [b] n = 4061. [c] n = 181. [d] n = 4076.

Symptom reports based on visibility of cleft. There were no significant differences in mean scores for total difficulties or on other subscales between those with a visible cleft and those with a nonvisible cleft on self-report or parent reports (Table 3). This applied to both boys and girls.

Table 3.

SDQ Ratings from 10-year olds' Self-report with CL/P and their Parents´ based on Cleft Visibility.

	Girls		Boys	
	Visible[a]	Nonvisible[b]	Visible[c]	Nonvisible[d]
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
Self-report				
Total difficulties	9.8 (4.9)	11.4 (5.0)	11.1 (5.5)	10.7 (6.4)
Emotional	2.8 (2.0)	3.5 (2.6)	2.9 (2.3)	2.5 (2.6)
Conduct	1.4 (1.4)	1.6 (1.2)	2.0 (1.7)	1.6 (1.5)
Hyperactivity	3.7 (2.0)	4.2 (2.1)	4.3 (2.1)	4.5 (2.6)
Peer problems	1.9 (1.7)	2.1 (1.7)	2.1 (1.8)	2.1 (1.7)
Prosocial	8.4 (1.8)	8.4 (1.8)	7.8 (1.7)	8.0 (1.7)
Parent-report				
Total difficulties	6.7 (5.4)	7.4 (6.1)	8.3 (6.3)	8.0 (6.3)
Emotional	1.6 (1.7)	2.4 (2.4)	1.9 (2.1)	1.8 (2.0)
Conduct	1.1 (1.3)	0.9 (1.3)	1.4 (1.5)	1.4 (1.5)
Hyperactivity	2.6 (2.6)	2.7 (2.7)	3.6 (2.7)	3.6 (3.0)
Peer problems	1.4 1.7)	1.4 (1.9)	1.5 (1.9)	1.3 (1.7)
Prosocial	8.7 (1.6)	8.8 (1.7)	8.7 (1.6)	8.2 (2.0)

Note. M = mean, *SD* = standard deviation.

[a] n = 81. [b] n = 61. [c] n = 125. [d] n = 56.

Symptom reports based on presence of additional difficulty. Children with an additional difficulty and their parents had higher mean scores for symptoms than those with a cleft alone and their parents, whose reported means were comparable to those reported in the reference study (Table 4).

Table 4.

SDQ Ratings from 10-year olds' Self-report with CL/P and their Parents´ based on Presence of Additional Condition.

	Girls		Boys	
	Cleft only[a]	Add. cond.[b]	Cleft only[c]	Add. cond.[d]
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
Self-report				
Total difficulties	9.5 (4.9)	12.5 (4.7)	9.4 (5.0)	13.7 (6.1)
Emotional	2.7 (2.0)	3.9 (2.6)	2.3 (2.1)	3.6 (2.6)
Conduct	1.4 (1.3)	1.7 (1.3)	1.6 (1.5)	2.2 (1.7)
Hyperactivity	3.5 (2.0)	4.7 (1.9)	3.9 (2.1)	5.2 (2.3)
Peer problems	1.9 (1.6)	2.1 (1.8)	1.8 (1.6)	2.7 (1.8)
Prosocial	8.8 (1.3)	8.4 (1.9)	7.8 (1.8)	7.9 (1.9)
Parent-report				
Total difficulties	5.7 (4.7)	9.7 (6.6)	5.7 (4.8)	12.2 (6.4)
Emotional	1.7 (1.8)	2.6 (2.4)	1.3 (1.5)	2.8 (2.5)
Conduct	0.9 (1.2)	1.3 (1.4)	1.2 (1.4)	1.9 (1.6)
Hyperactivity	2.1 (2.3)	3.7 (2.9)	2.6 (2.1)	5.2 (3.0)
Peer problems	1.1 (1.6)	2.0 (2.0)	0.8 (1.3)	2.4 (2.0)
Prosocial	8.8 (1.8)	8.7 (1.8)	8.5 (1.7)	8.5 (1.8)

Note. Add. cond. = child has additional condition, *M* = mean, *SD* = standard deviation.
[a] n = 95. [b] n = 47. [c] n = 113. [d] n = 68.

Agreement Between Children and Parents

Agreement between children and parents was examined by differences in means as measured by paired samples t-test and cross-informant agreement as measured by Pearson's correlation coefficient *r* (Table 1).

Agreement based on gender. The paired samples t-test showed significant differences between means for children and parents ($p < .001$) for both genders with small to moderate effect sizes (0.15 – 0.64). The correlation coefficient between parents' and self-report SDQ was 0.43 ($p < .001$) for boys and 0.49 ($p < .001$) for girls. On the subscales the correlations ranged from 0.19 (prosocial behavior) to 0.44 (hyperactivity) for boys, and from 0.24 (prosocial behavior) to 0.46 (peer problems) for girls. All correlations were significant for both genders ($p < .05$). These results are consistent with those reported in the reference study, indicating that correlations are low to moderate. As can be seen in Figure 4 and Figure 5, agreement between children and parents were comparable to those found in the reference study (Van Roy et al., 2010).

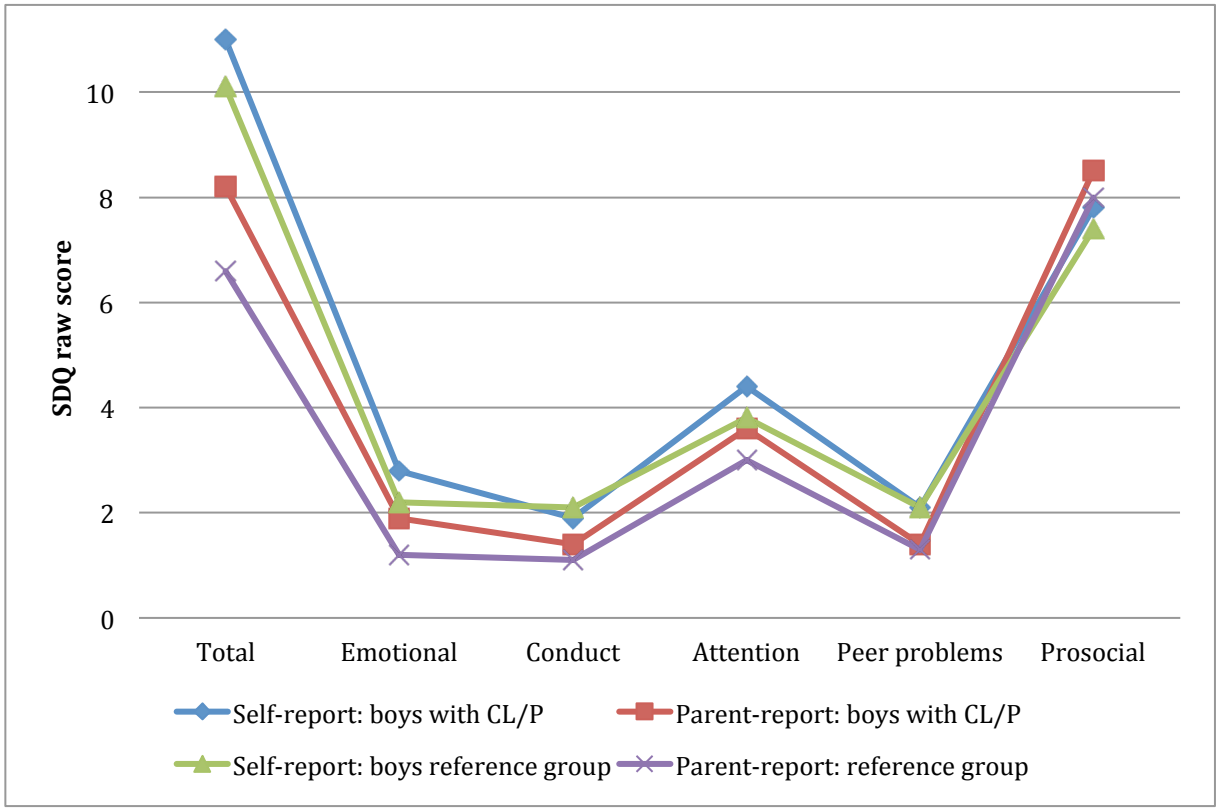

Figure 4. Agreement between boys with CL/P and their parents compared with reference study.

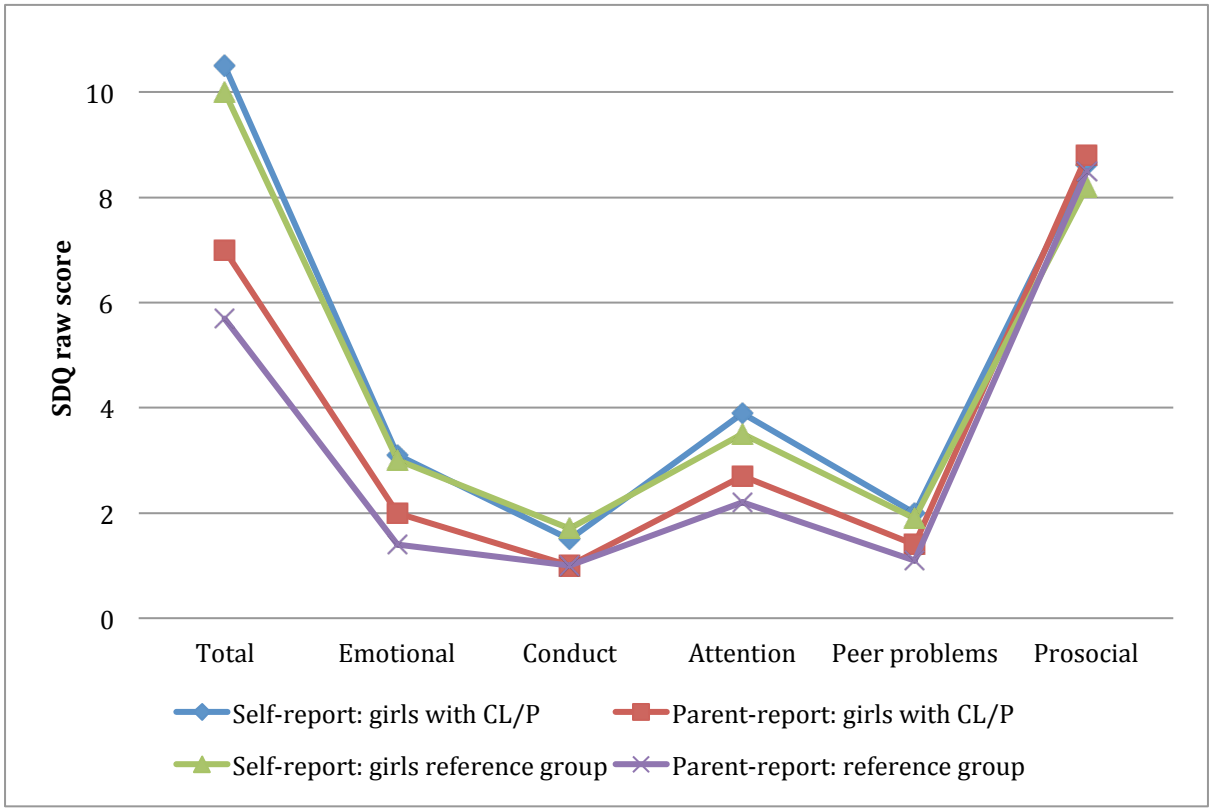

Figure 5. Agreement between girls with CL/P and their parents compared with reference study.

Agreement based on cleft visibility. Similar patterns of agreement were found for both boys and girls regardless of cleft visibility (Figure 6 and Figure 7). For boys, differences in means were significant for all subscales ($p < .01$), with the exception of the prosocial subscale for boys with nonvisible clefts. For girls, differences in means were significant for all subscales ($p < .01$), with the exception of the conduct subscale for girls with nonvisible clefts.

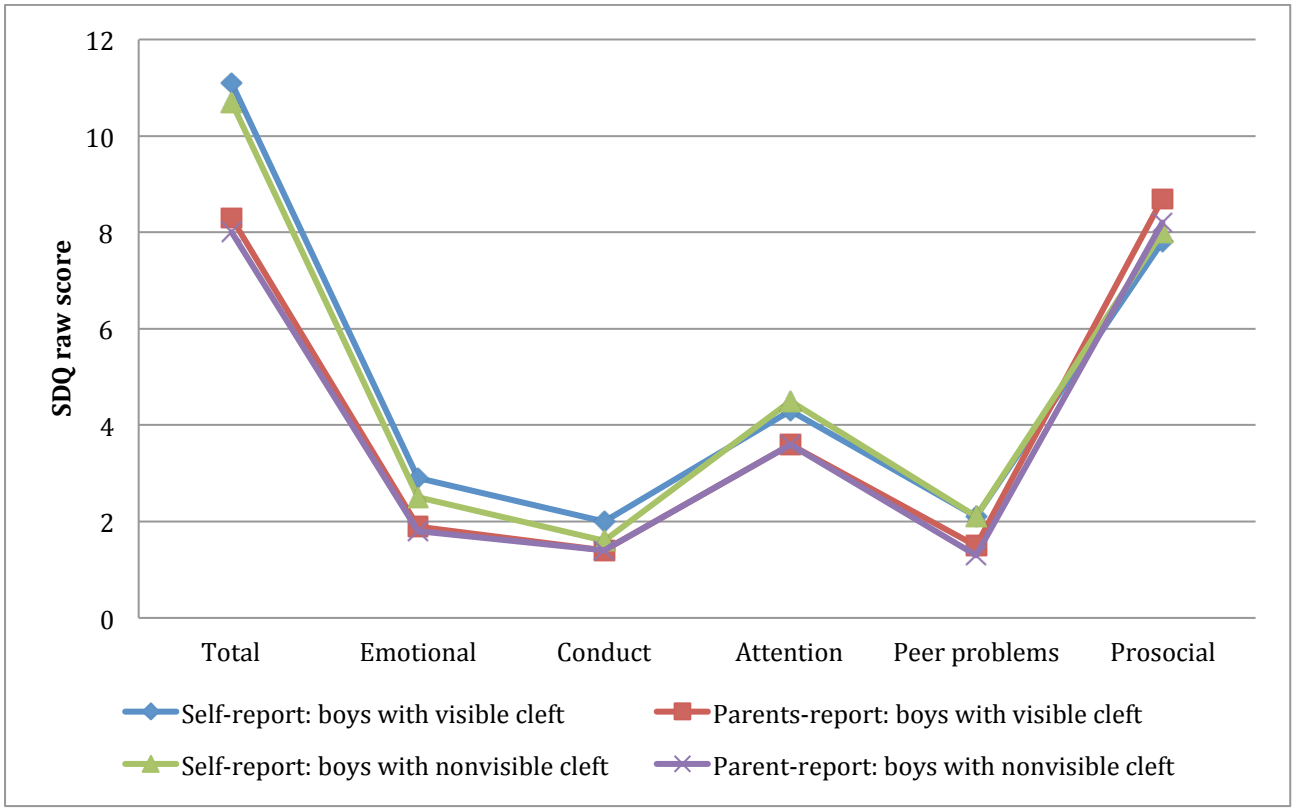

Figure 6. Agreement between children and parents on the SDQ for boys based on cleft visibility.

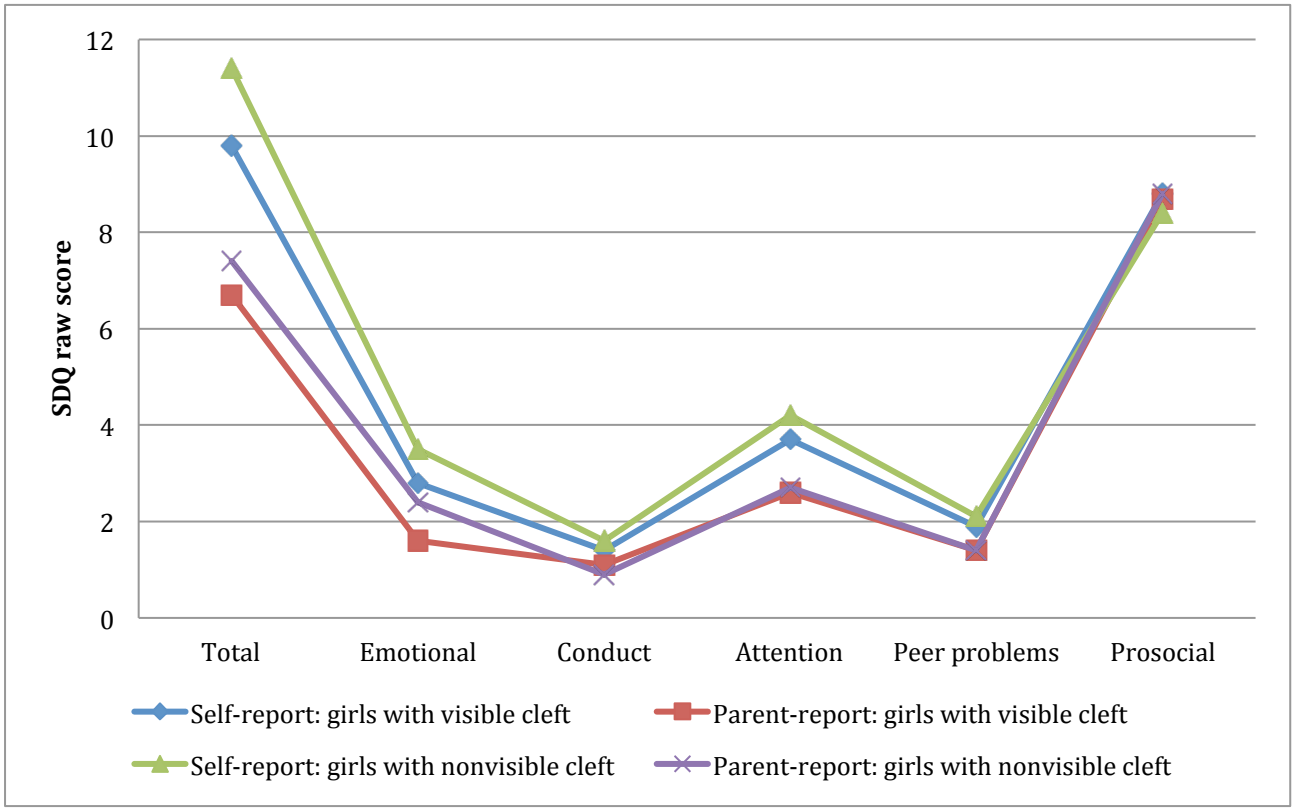

Figure 7. Agreement between children and parents on the SDQ for girls based on cleft visibility.

Agreement based on presence of an additional condition. The presence of additional condition did not appear to considerably influence agreement between children and parents. Similar patterns of agreement were found for both genders irrespective of cleft visibility (Figure 8 and Figure 9). For boys, differences in means were significant for all subscales ($p < .01$), with the exception of the prosocial subscale for boys with nonvisible clefts. For girls, differences in means were significant for all subscales ($p < .01$), with the exception of the conduct subscale for girls with nonvisible clefts.

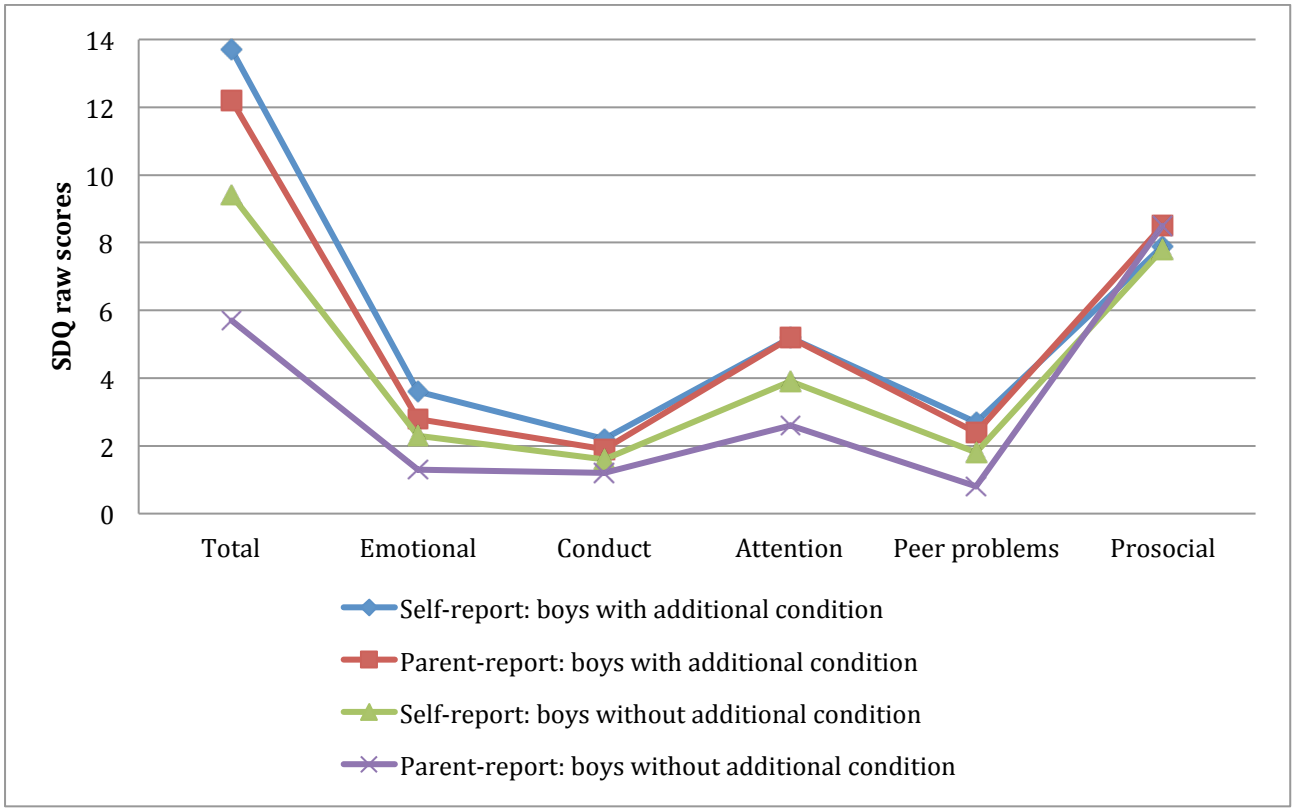

Figure 8. Agreement between children and parents on the SDQ for boys based on presence of an additional condition.

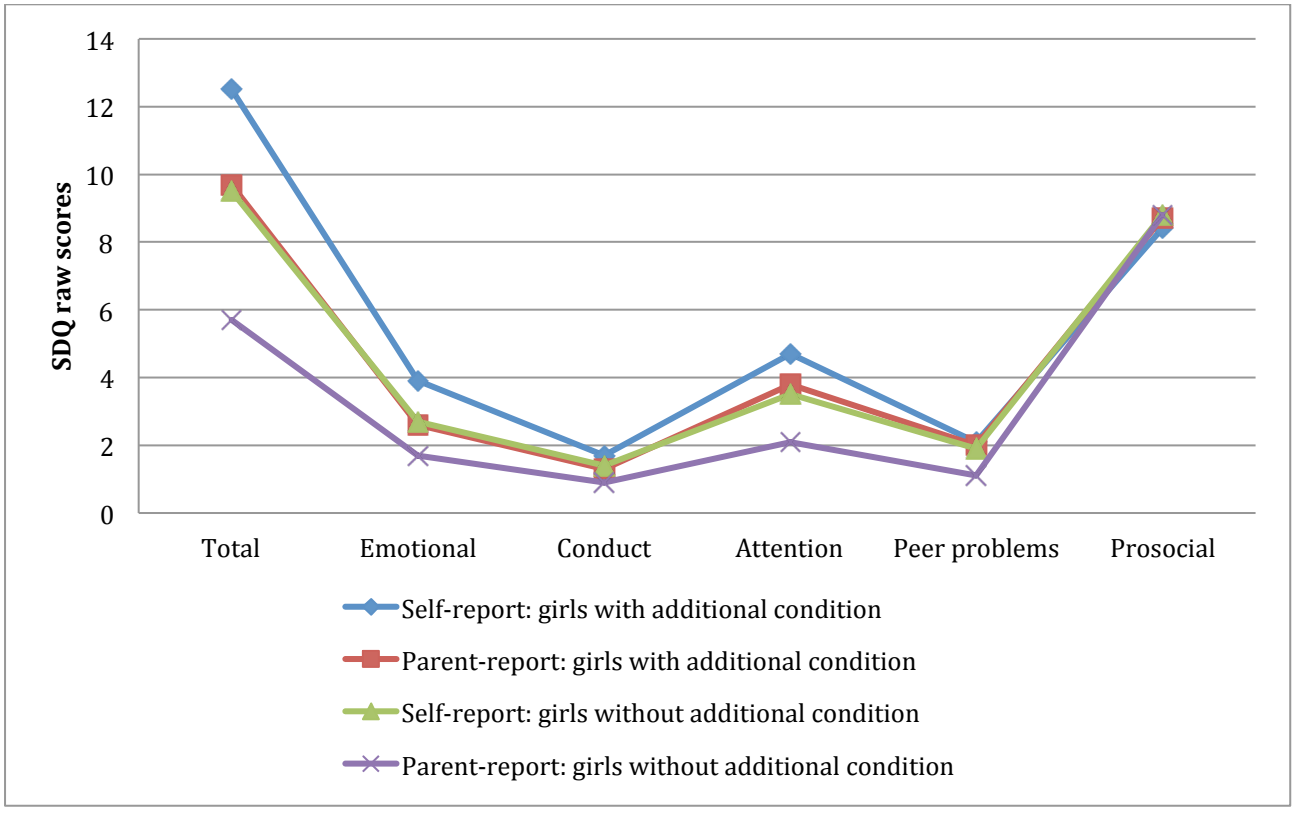

Figure 9. Agreement between children and parents on the SDQ for girls based on presence of an additional condition.

Discussion

This study examined informant agreement between 10-year-old children born with CL/P and their parents on the SDQ. The goal of the study was to determine whether this population follows the same pattern of agreement as those found in the general Norwegian population. In doing so, one can better determine whether knowledge gained from the general population concerning informant discrepancies is applicable to the CL/P population. The study investigated whether gender of the child, visibility of cleft, and presence of additional condition affected informant discrepancies between children and their parents. Symptom reports for children and parents based on the three factors investigated (i.e. gender of the child, cleft visibility, presence of additional condition) will first be discussed, followed by a discussion concerning informant agreement between children and parents based on these factors. Possible implications of the findings will also be reviewed. Strengths and limitations of the study, in addition to directions of future research, will be covered last.

The current findings on symptom levels are consistent with findings from previous studies on children with CL/P and SDQ. Investigations concerning parent-reports on the SDQ have not previously been completed, so new knowledge has been added in this area. As a whole, children with CL/P and their parents report similar symptoms as the general population despite the child's potential differences in appearance and speech, and having to go through extensive treatment. Children of both genders reported more symptoms than parents on all subscales, with the exception of the prosocial subscale where parents reported higher scores than children. This may illustrate that children have a heightened sensitivity to problems and report these while parents do not recognize them as problems (Van Roy et al., 2010). This may also be a sign that parents underreport problems, or have a higher threshold for describing behaviors as challenging. The reference study found that though children report more symptoms than parents, they also report less impact of perceived difficulties than parents (Van Roy et al., 2010). The study also showed that parents were more consistent in their ratings on symptom and impact evaluation (Van Roy et al., 2010). Children and parents in the current study did not complete the extended impact supplement, thus the perceived impact of these symptoms and consistency between symptoms and impact cannot be determined.

The finding that parents report more prosocial behavior than the child themselves is noteworthy. Results are similar to those found in the general population. Reasonable explanations for this may be that the children do not recognize their behaviors as prosocial, or

their parents' may overreport these behaviors. The social desirability bias, that is the tendency to respond in a manner that presents oneself in a favorable manner, may help describe both these possible explanations. If children recognized their behavior as helpful or altruistic, they would likely report the prosocial behavior if they deemed as such in order to present themselves in a favorable light. Parents, wanting to present their children in a good manner, may overreport behaviors that are considered desirable.

Intuitively one may assume that someone with a more severe abnormality (i.e. bilateral cleft lip and palate) may experience more distress than someone with a less severe abnormality (i.e. cleft palate only). However, the current study does not support this. There were no differences in symptom reporting between children and parents based on cleft visibility, indicating that other factors than objective visibility may influence symptom reporting. Thought it has been well documented that other variables influence psychosocial functioning more than objective visibility (Feragen & Stock, 2014; Rumsey & Harcourt, 2005; Feragen, 2012), it still seems pertinent to highlight this finding. In a society where appearance plays a large role, this finding is somewhat contradicting to what one would expect. For health professionals working with children with differences, one should be careful to not judge a book by its cover, but rather be curious of the content of the book – just because a child is more objectively affected by their cleft in terms of appearance and speech, it is their subjective evaluation that one should pay attention to. One should attempt to be inquisitive of their subjective opinion of their own appearance and speech rather than make assumptions on the basis of objective appearance and speech.

Children with an additional condition and their parents had higher mean scores for symptoms, while children with a cleft alone and their parents reported means comparable to those reported by the reference study. This adds strength to the results found by Feragen and Stock (2014), indicating that those with an additional condition might be a particularly vulnerable subgroup. When working with children with CL/P, health professionals may want to be particularly observant of those who have an additional condition because this appears to have an effect on symptom reporting regarding psychological functioning.

In terms of informant agreement between children and parents, this study verifies that children with CL/P and their parents provide different information regarding the child's mental health. Correlations between child-parent scores on the SDQ were low to moderate, thus confirming the hypotheses of this study. Gender of the child, cleft visibility, and presence of additional condition did not affect the discrepancy between children's and parents' reporting; the scores between children and parents remained low to moderately

correlated. When comparing our results to those found in a large national sample of Norwegian children (Van Roy et al., 2010), children with CL/P and their parents have similarity in the pattern of agreement in terms of reporting symptoms on the SDQ.

It is reassuring to find that as a whole, children with CL/P and their parents follow the same patterns of agreement as the general population. Knowledge that the discrepancies are similar regardless of cleft visibility and additional condition is particularly noteworthy because it allows us to have more confidence that these factors do not influence informant agreement. Due to the vast research amount showing that other factors play a larger role than objective visibility, it was hypothesized that cleft visibility would not affect discrepancies between children and parents. However, the possibility that parents of children with visible clefts would report higher symptom levels than parents of children with nonvisible clefts could not be ruled out. In addition, because it has previously been found that the presence of an additional condition affects scores on the SDQ for children with CL/P (Feragen & Stock, 2014), we were uncertain if the presence of additional condition would affect agreement as well. It is reassuring that parents of children with additional conditions are able to identify more of the symptoms their children report. Presence of additional condition should warrant more caution around psychosocial difficulties, but there is no basis to say that this will result in higher levels of discrepancies.

These results add weight to the notion that children with CL/P and their parents may not be qualitatively different than other children and their parents. The main implication of this is likely that we can assume that overreporting or underreporting of symptoms is no more of an issue with this population than with the general population of children and parents. It has been found that children with CL/P and their parents provide different information on the SDQ, and that both self- and parent-reports are valuable in the assessment of children's mental health. As with the general population, we should base judgment on a mixture of both informants' reports (Offord et al., 1996).

Results have been mixed in terms of what child/parent factors contribute to agreement, so we can only speculate as to what factors contribute to the finding that children with CL/P and parents have similar agreement to the general population. Prior to completing the study explanations describing both higher and lower correlations were presented. Now that results have shown that children with CL/P and their parents are similar to the general population, an attempt to explain why is in order. Treatment for this CL/P starts from a very young age, and the family is very much involved, thus it is plausible that the child-parent relationship is different as a result of this. Several factors have previously been investigated

as a way to determine whether the relationship between a child with CL/P and their parent is different than a child without a cleft and their parent. The closeness of relationship between the child and parent has been identified as a factor that influences informant agreement (Duke et al., 2005), and one measure of closeness may be attachment style. Studies have shown that children with CL/P form secure attachments to their mothers similar to those without clefts (Endriga & Speltz, 1997; Slade, Emerson, & Freedlander, 1999). Raising a child with a difference may potentially cause strain both in terms of worrying more about the child and because of the need for follow-up care. Studies regarding whether caring for a child with a cleft can cause an emotional strain on parents have provided mixed results. Parents may have raised levels of emotional strain when their child is a toddler (Pope, Tillman, & Snyder, 2005; Speltz, Morton, Goodell, & Clarren, 1993), but these levels seem to be comparable to parents caring for a child without a cleft by the time the children are in preschool (Berger & Dalton, 2009; Slade et al., 1999). As with the individual focused research, a majority of studies regarding raising a child with a cleft have taken a pathologizing- approach. Whether having a child with a cleft may also make the more resilient as a parent has been investigated, highlighting that there are a range of positive outcomes as well (Baker et al., 2009). Studies on parenting a child with a cleft have primarily focused on mothers' views (e.g. Klein, Pope, Getahun, & Thompson, 2006; Nelson, Glenny, Kirk, & Caress, 2012), though it is likely that fathers have comparable experiences to mothers (Stock & Rumsey, 2015).

In conclusion, findings on symptom levels are consistent with findings from previous studies on the SDQ. Symptom reporting is not influenced by visibility of cleft for children or their parents. Children with an additional condition and their parents show higher scores compared to children with only a cleft and their parents, who score report means comparable to those reported in the general population. In the matter of informant agreement between children and parents, this study confirms that children with CL/P and their parents provide different information regarding the child's psychosocial functioning. Gender of child, cleft visibility, and presence of additional condition did not affect the discrepancy between children's and parents' reporting on the SDQ; scores were low to moderately correlated. The results may indicate that the relationship between children with CL/P and their parents is not qualitatively different than other children and their parents. Children with CL/P and their parents provide different information on the SDQ, signifying that both self- and parent-reports are valuable in the assessment of children's mental health. As with the general population, we should base judgment on a mixture of both informants' reports (Offord et al., 1996).

Strengths and Limitations

There are several strengths to this study. Looking at parent-child agreement and discrepancies in this population has not previously been studied, and findings will thus contribute beneficially to the field. The high participation rate and inclusion of participants from the whole country suggests that results from this sample are highly representative for the Norwegian CL/P population. Agreement between children and parents on SDQ scoring has been investigated in a large Norwegian sample, making comparison between this population and the general population more valid. In addition, the SDQ is a well-known and valid questionnaire, shown to provide accurate measures for identifying both clinical and sub-clinical groups of psychopathology in youth. The research in this area may potentially translate to other individuals that go though similar extensive treatment and to individuals that may have appearance related concerns.

Although the participation rate, representative sample, and comparison to large representative sample were the chief advantages of this study, there were some limitations. The first limitation concerns the methodology as a whole when investigating informant agreement. A question of whether the discrepancies are found based on the way the construct is measured (e.g. the wording of the questions tap into different constructs in the child/parent) or whether there exists actual differences (based on reporting bias, observational factors etc) remains unanswered. It is uncertain whether the generic scales that measure psychosocial functioning are sensitive enough to discover specific issues relevant to appearance (Rumsey & Harcourt, 2005).

Besides this, there are other limitations in the current study. Firstly, the SDQ also includes an extended impact supplement. Unfortunately, this data was not collected from the current CL/P sample. This would have been interesting to explore in order to determine the degree of impact the children and parents felt the difficulties had. Secondly, degree of visibility was not assessed, but was rather categorized by the basis of presence of cleft lip or lack thereof. As we know that the individuals' subjective view matters, it would be interesting to see whether levels of discrepancies were affected by subjective rating of visibility. Thirdly, results are cross-sectional and thus cannot test the longitudinal effect on discrepancies between children/adolescents and their parents. Though it is probable that the CL/P population would be similar to the normal populations, future investigations would be beneficial to confirm this.

Lastly, the scope of this study limited investigations of possible factors associated with agreement patterns. The study showed that children with CL/P and their parents follow the same patterns in agreement as the general population, and this was not influenced by cleft visibility or presence of additional condition. However, which factors in the CL/P population contribute to similarity remains unanswered, in addition to explaining why these discrepancies exist and how to facilitate better agreement. Further research in needed in order to highlight which parent/child factors are central for this population, and to investigate whether these differ from the general population.

References

Achenbach, T. M., Becker, A., Döpfner, M., Heiervang, E., Roessner, V., Steinhausen, H. C., & Rothenberger, A. (2008). Multicultural assessment of child and adolescent psychopathology with ASEBA and SDQ instruments: Research findings, application, and future directions. *Journal of Child Psychology & Psychiatry, 49 (3),* 251 – 275.

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.

American Cleft Palate – Craniofacial Association (2010). Standards for cleft palate and craniofacial teams. *American Cleft Palate – Craniofacial Association.* Retrieved on March 27, 2014 from http://www.acpa-cpf.org/team_care/standards/

Baker, S. R., Owens, J., Stern, M., & Willmot, D. (2009) Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *The Cleft Palate – Craniofacial Journal, 46 (3),* 229 – 236.

Berger, Z. E. & Dalton, L. J. (2009). Coping with a cleft: Psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *The Cleft Palate – Craniofacial Journal, 46,* 435 – 443.

Bernheim, N., Georges, M., Malevez, C., De Mey, A., & Mansbach, A. (2006). Embryology and epidemiology of cleft lip and palate. *B-ENT, 2 (4),* 11 – 19.

Brown B., Moss T., McGrouther D., & Bayat A. (2010). Skin scar pre-conceptions must be challenged: Importance of self-perception in skin scarring. *Journal of Plastic, Reconstructive & Aesthetic Surgery, 63,* 1022 – 1029.

Cleft Lip & Palate Association (2015). Repair Surgery. Retrieved on April 15, 2016, from the Cleft Lip and Palate Association website: https://www.clapa.com/treatment/repair-surgery/

Cleft Lip and Palate Association. (n.d.). Diagram of cleft lip and/or palate. Retrieved on March 14, 2015, from the Cleft Lip and Palate Association website: http://www.clapa.com/medical/cleft_lip_article/107/

Cleft Palate Foundation (2007). Information about submucous cleft palate. Retrieved on April 16, 2016, from the Cleft Palate Foundation website: http://www.cleftline.org/parents-individuals/publications/submucous-clefts/

De Los Reyes, A. & Kazdin, A. E. (2005). Informant discrepancies in the assessment of childhood psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin, 131 (4),* 483 – 509.

different. (n.d.). Dictionary.com Unabridged. Retrieved March 14, 2014, from Dictionary.com website: http://dictionary.reference.com/browse/different

Draaijers, L. J., Tempelman, F. R. H., Botman, Y. A., M., Tuinebreijer, W E., Middelkoop, E., Kreis, R. W., &van Zuijlen, P. P. M. (2004). The Patient and Observer Scar Assessment Scale: A feasible tool for scar evaluation. *Plastic & Reconstructive Surgery, 113 (7),* 1690 – 1965.

Duke, N., Ireland, M., & Borowsky, I. W. (2005). Identifying psychosocial problems among youth: Factors associated with youth agreement on a positive parent-completed PSC-17. *Child Care Health Development, 31,* 563 – 573.

Edelbrock, C. S., Costello, A. J., Dulcan, M. K., Conover, N. C., & Kala, R. (1986). Parent-child agreement on child psychiatric symptoms assessed via structured interview. *Journal of Child Psychology & Psychiatry, 27,* 181 – 190.

Endriga, M. C. & Kapp-Simon, K. A. (1999). Psychological issues in craniofacial care: State of the art. *The Cleft Palate – Craniofacial Journal, 36,* 3 – 9.

Endriga, M. C. & Speltz, M. L. (1997). Face to face interaction between infants with orofacial clefts and their mothers. *Journal of Pediatric Psychology, 22,* 439 – 453.

Feragen, K. B. (2009). Psychosocial adjustment in children and adolescents with cleft lip and/or palate: Exploring risk and protective factors (Doctoral dissertation). Retrieved from BIBSYS (UMI 102084556)

Feragen, K. B. (2012). Congenital conditions. In N. Rumsey & D. Harcourt (Eds.), *Oxford handbook of the psychology of appearance* (353 - 371). Oxford, UK: Oxford University Press.

Feragen, K. B., Borge, A. I. H., & Rumsey, N. (2009). Social experience in 10-year old children born with a cleft: Exploring psychosocial resilience. *The Cleft Palate – Craniofacial Journal, 46 (1)*, 65 – 74.

Feragen, K. B. & Stock, N. M. (2014). When there is more than a cleft: Psychological adjustment when a cleft is associated with an additional condition. *The Cleft Palate – Craniofacial Journal, 51 (1),* 5 – 14.

Goodacre, T. & Swan, M. C. (2011). Cleft lip and palate: Current management. *Journal of Paediatrics and Child Health, 22 (4),* 160 – 168.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38 (5),* 581 – 586.

Goodman, R. (1999). The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden. *Journal of Child Psychology and Psychiatry, 40 (5),* 791 – 799.

Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of American Academy of Child and Adolescent Psychiatry, 40 (11),* 1337 – 1345.

Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2000). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *British Journal of Psychiatry, 177,* 534 – 539.

Goodman, R., Renfrew, D., & Mullick, M. (2000). Predicting type of psychiatric disorder from the Strengths and Difficulties Questionnaire (SDQ) scores in child mental health clinics in London and Dhaka. *European Child &Adolescent Psychiatry, 9,* 129 – 134.

Goodman R. & Scott S. (1999) Comparing the Strengths and Difficulties Questionnaire and the Child Behavior Checklist: Is small beautiful? *Journal of Abnormal Child Psychology, 27,* 17 – 24.

Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: A systematic review. *European Journal of Orthodontics, 27,* 274 – 285.

Hunt, O., Burden, D., Hepper, P., Stevenson, M., & Johnston, C. (2006). Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *The Cleft Palate – Craniofacial Journal, 43 (5),* 598 – 605.

IPDTOC Working Group (2011). Prevalence at birth of cleft lip with or without cleft palate: Data from the International Perinatal Database of Typical Oral Clefts (IPDTOC). *The Cleft Palate – Craniofacial Journal, 48 (1)*, 66 – 81.

Klasen H., Woerner, W., Wolke, D., Meyer, R., Overmeyer, S., Kaschnitz, W., … Goodman, R. (2000). Comparing the German versions of the Strengths and Difficulties Questionnaire (SDQ-Deu) and the Child Behavior Checklist. *European Child and Adolescent Psychiatry, 9,* 271 – 276.

Klassen, A. F., Tsangaris, E., Forrest, C. R., Wong, K. W. Y., Pusic, A. L., Cano, S. J., … Goodacre, T. (2012). Quality of life of children treated for cleft lip and/or palate: A systematic review. *Journal of Plastic, Reconstructive & Aesthetic Surgery, 65,* 547 – 557.

Klein, T., Pope, A. W., Getahun, E. & Thompson, J. (2006). Mothers' reflections on raising a child with a craniofacial anomaly. *The Cleft Palate – Craniofacial Journal, 43,* 456 – 464.

Koskelainen, M., Sourander, A., & Kaljonen, A. (2000) The Strengths and Difficulties Questionnaire among Finnish school-aged children and adolescents. *European Child and Adolescent Psychiatry, 9,* 277 – 284.

Leppe-ganespalteforeningen (n.d.). Leppe – kjeve – ganespalte: Informasjonsbrosjyre om LKG. Retrieved on May 2, 2014, from http://www.lgs.no/images/pdf-files/informasjonsperm/1.lkgbrosjyre.pdf

Levenson, J. L. (2007). Psychiatric issues in surgical patients - Part I: General issues. *Primary Psychiatry, 14 (5),* 35 – 39.

Lockhart (2003). The mental health needs of children and adolescents with cleft lip and/or palate. *Clinical Child Psychology and Psychiatry, 8,* 7 – 16.

Mani, M., Morén, S., Thorvardsson, O., Jakobsson, O., Skoog, V., & Holmström, M. (2010). Objective assessment of the nasal airway in unilateral cleft lip and palate – A long-term study. *The Cleft Palate – Craniofacial Journal, 47 (3),* 217 – 224.

Mars, M., Plint, D. A., Houston, W. J. B., Bergland, O., & Semb, G. (1987). The Goslon Yardstick: A new system of assessing dental arch relationships in children with unilateral clefts of the lip and palate. *The Cleft Palate Journal, 24 (4),* 314 – 322.

Martelli, D. R., Machado, R. A., Swerts, M. S., Rodrigues, L. A., Aquino, S. N., & Martelli, H. (2012). Non syndromic cleft lip and palate: Relationship between sex and clinical extension. *Brazilian Journal of Otorhinolaryngology, 78 (5),* 116 – 120.

Mathai J., Anderson P., & Bourne A. (2003) Use of the Strengths and Difficulties Questionnaire as an outcome measure in a child and adolescent mental health service. *Australasian Psychiatry, 11,* 334 – 337.

Mayo Clinic Staff (2012). Cleft lip and cleft palate: Causes. *Mayo Clinic.* Retrieved on March 26, 2014 from http://www.mayoclinic.org/diseases-conditions/cleft-palate/basics/causes/con-20024619

Milerad, J., Larson, O., Hagberg, C., & Ideberg, M. (1997). Associated malformations in infants with cleft lip and palate: A prospective, population-based study. *Pediatrics, 100,* 180 – 186.

Morris, S. B. & DeShon, R. P. (2002). Combining effect size estimates in meta-analysis with repeated measures and independent-groups designs. *Psychological Methods, 7,* 105 – 107.

Moss, T. P. (2005). The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment. *Body Image, 2,* 151 – 159.

Mossey, P. A. Little, J., Munger, R. G., Dixon, M. J. & Shaw, W. C. (2009). Cleft lip and palate. *The Lancet, 374,* 1773 – 1785.

Murray, J. C. (2002). Gene/environment causes of cleft lip and/or palate. *Clinical Genetics, 61,* 248 – 256.

Nelson, P., Glenny, A. M., Kirk, S., & Caress, A. L. (2011). Parents' experiences of caring for a child with a cleft lip and/or palate: A review of the literature. *Child: Care, Health, and Development, 38 (1),* 6 – 20.

Obel, C., Heiervang, E., Heyerdahl, S., Smedje, H., Sourander, A., Gudmundsson, O. O., … Olsen, J. (2004). The Strengths and Difficulties Questionnaire in the Nordic Countries. *European Child & Adolescent Psychiatry, 13,* 32 – 39.

Offord, D. R., Boyle, M. D., Racine, Y., Szatmari, P., Fleming, J. E., Sanford, M., & Lipman, E. L. (1996). Integrating assessment data from multiple informants. *Journal of American Academy of Child and Adolescent Psychiatry, 35 (8),* 1078 – 1085.

Ong, J., Clarke, A., White, P., Johnson, M., Withey, S., & Butler, P.E. (2007) Does severity predict distress? The relationship between subjective and objective measures of appearance and psychological adjustment during treatment for facial lipoatrophy. *Body Image, 4,* 239 – 248.

Pope, A. W. & Snyder, H. T. (2005). Psychosocial adjustment in children and adolescents with a craniofacial anomaly: Age and sex patterns. *The Cleft Palate – Craniofacial Journal, 42 (4),* 349 – 354.

Pope, A., Tillman, K., & Snyder, H. T. (2005). Parenting stress in infancy and psychosocial adjustment in toddlerhood: A longitudinal study of children with craniofacial anomalies. *The Cleft Palate – Craniofacial Journal, 42,* 556 – 559.

Ramstad, T., Ottem, E., & Shaw, W. C. (1995). Psychosocial adjustment in Norwegian adults who had undergone standardized treatment of complete cleft lip and palate. *Scandinavian Journal of Plastic and Reconstructive and Hand Surgery, 29,* 329 – 336.

Rumsey, N. & Harcourt, D. (2005). The psychology of appearance. New York, NY: Open University Press.

Rønning, J. A., Handegaard, B. H., Sourander, A., & Mørch, W. (2004). The Strengths and Difficulties Self-Report Questionnaire as a screening instrument in Norwegian community samples. *European Child & Adolescent Psychiatry, 13,* 73 – 82.

Saxe, G., Vanderbilt, D., & Zuckerman, B. (2003). Traumatic stress in injured and ill children. *The National Center for Post-Traumatic Stress Disorder PTST Research Quarterly, 14 (2),* 1 – 3.

Semb, G., Åbyholm, F., Tindlund, R. S., & Lie, R. T. (2000). Leppe-kjeve-gane-spalte: En oversikt. *Norske Tannlegeforenings Tidende, 110,* 800 – 804

Shaw, W. C., Semb, G., Nelson, P., Brattström, V., Mølsted, K., Prahl-Andersen, B., & Gundlach, K. K. H. (2001). The Eurocleft project 1996 – 2000: Overview. *Journal of Cranio-Maxillofacial Surgery, 29,* 131 – 140.

Slade, P., Emerson, D. J. M. & Freedlander, E. (1999). A longitudinal comparison of the psychological impact on mothers of neonatal and 3 month repair of cleft lip. *British Journal of Plastic Surgery, 52,* 1 – 5.

Sosial- og helsedirektoratet (2007). Tilbudet til pasienter med leppe-kjeve-ganespalte, herunder velocardiofacialt syndrome: Faglig gjennomgang. Oslo, Norway: Sosial- og helsedirektoratet

Speltz, M. L., Morton, K., Goodell, E. W., & Clarren, S. K. (1993). Psychological functioning of children with craniofacial anomalies and their mothers: Follow-up from late infancy to school entry. *The Cleft Palate – Craniofacial Journal, 30,* 482 – 489.

Stanford Children's Health (2014). Cleft Lip/Palate. *Stanford Children's Health.* Retrieved on March 26, 2014 from http://www.stanfordchildrens.org/en/topic/default?id=cleft-lipcleft-palate-90-P01847

Stock, N. M. & Feragen, K. B. (2016). Psychological Adjustment to cleft lip and/or palate: A narrative review of the literature. *Psychology & Health.* DOI: http://dx.doi.org/10.1080/08870446.2016.1143944

Stock, N. M., Feragen, K. B., & Rumsey, N. (2016). Adults' narratives of growing up with a cleft lip and/or palate: Factors associated with psychological adjustment. *The Cleft Palate – Craniofacial Journal, 53 (2),* 222 – 239.

Stock, N. M. & Rumsey, N. (2015). Parenting a child with a cleft: The father's perspective. *The Cleft Palate – Craniofacial Journal, 52 (1),* 31 – 43.

Swanenburg de Veye, H. F., Beemer, F. A., Mellenbergh, G. J., Wolters, W. H., & Heineman-de Boer, J. A. (2003). An investigation of the relationship between associated congenital malformations and the mental and psychomotor development of children with clefts. *The Cleft Palate – Craniofacial Journal, 40 (3),* 297 – 303.

Tedstone, J. E. & Tarrier, N. (2003).Posttraumatic stress disorder following medical illness and treatment. *Clinical Psychology Review, 23 (3),* 409 – 448.

Thompson, A. & Kent, G. (2001). Adjusting to disfigurement: Processes involved in dealing with being visibly different. *Clinical Psychology Review, 21 (5),* 663 – 682.

Thomas, P. T., Turner, S. R., Rumsey, N., Dowell, W., & Sandy, J. R. (1997). Satisfaction with facial appearance among subjects affected by a cleft. *The Cleft Palate – Craniofacial Journal, 34 (3),* 226 – 231.

Turner, S. R., Rumsey, N., & J. R. Sandy (1998). Psychological aspects of cleft lip and palate. *European Journal of Orthodontics, 20,* 407 – 415.

Tørdal, I. B. & Kjøll, L. (2010). Talevansker hos barn med leppe-kjeve-ganespalte: Innføring og veiledning i undervisning og behandling. Oslo: Bredtvet kompetansesenter.

van der Meer, M., Dixon, A., & Rose, D. (2008). Parent and child agreement on reports of problem behavior obtained from a screening questionnaire, the SDQ. *European Child and Adolescent Psychiatry, 17,* 491 – 497.

Van Roy, B., Grøholt, B., Heyerdahl, S., Clench-Aas, J. (2010). Understanding discrepancies in parent-child reporting of emotional and behavioral problems: Effects of relational and socio-demographic factors. *BMC Psychiatry, 10,* 56 – 68.

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 & Psychiatry, 49 (12),* 1304 – 1312.

van Widenfelt, B. M., Goedhart, A. W., Treffers, P. D. A., & Goodman, R. (2003) Dutch version of the Strengths and Difficulties Questionnaire (SDQ). *European Child and Adolescent Psychiatry, 12,* 281 – 289.

Venkatesh, R. (2009). Syndromes and anomalies associated with cleft. *Indian Journal of Plastic Surgery, 42,* 51 – 55.

Verhulst, F. C. & van der Ende, J. (1992). Agreement between parents' reports and adolescents' self-reports of problem behavior. *Journal of Child Psychology and Psychiatry, 33,* 1011 – 1023.

Versnel, S. L., Duivenvoorden, H. J., Passchier, J., & Mathijssen, I. M. J. (2010). Satisfaction with facial appearance and its determinants in adults with severe congenital facial disfigurement: A case-referent study. *Journal of Plastic, Reconstructive, & Aesthetic Surgery, 63,* 1642 – 1649.

Vostanis, P. (2006). Strengths and Difficulties Questionnaire: Research and clinical applications. *Current Opinion in Psychiatry, 19,* 367 – 372.

Wintgens, A., Boileau, B., & Robaey, P. (1997). Posttraumatic stress symptoms and medical procedures in children. *Canadian Journal of Psychiatry, 42,* 611 – 616.

Appendix A. Oslo CL/P Treatment Protocol

OSLO-TEAMETS BEHANDLINGSTILBUD FOR BARN FØDT MED LEPPE-KJEVE-GANESPALTE (LKG)

Oslo-teamet består av fagpersoner innen plastikkirurgi, kjeveortopedi, tannlege i protetikk, logopedi, otologi (øre-nese-hals) og psykologi. Kirurger og kjeveortopeder er ansatt ved Oslo Universitetssykehus - Rikshospitalet, logopeder, øre-nese-halslege og psykologer er ansatt ved Bredtvet kompetansesenter. En av kjeveortopedene har delt stilling mellom disse to institusjonene.
Teamet suppleres med andre fagpersoner etter behov, som for eksempel sosionom, genetiker, radiolog.

Skjematisk oversikt over rutinemessig tverrfaglig behandling

(L = leppespalte; K = kjevespalte; G =ganespalte)

Alder	Spalte-type	Kirurg	Kjeve-ortoped	Logoped	Øre-nese-halslege	Psykolog
0-3 mnd	Alle	Dagskurs	Dagskurs	Dagskurs		Dagskurs
3-5 mnd	L-LK-LKG	Leppelukking				
12 mnd	LKG og G	Ganelukking		Tilbud om foreldresamtale	Undersøkelse v/ganelukking	Tilbud om foreldresamtale
2 år	LKG og G			Undersøkelse og veiledning. Kurssamling		Kurs for foreldre, i samarbeid med logopeder
4 år	L-LK-LKG og G	Vurdering av behov for leppe-nesekorreksjon L-LK og LKG	Vurdering av tann- og bittforhold L-LK og LKG	Undersøkelse og veiledning	Undersøkelse i samarbeid med logoped	
6 år	L-LK-LKG og G		Undersøkelse av tann- og bittutvikling	Undersøkelse av LKG og G	Undersøkelse ved behov	
7-10 år	L-LK-LKG og G	Ben-transplantasjon LKG og LK	Undersøkelse og evt. behandling			
10 år	L-LK-LKG og G		Undersøkelse og evt. henvisning for behandling	Undersøkelse av LKG og G		Undersøkelse og samtale
16 år	L-LK-LKG og G	Undersøkelse	Undersøkelse og behandling	Undersøkelse av LKG og G	Undersøkelse	Undersøkelse og samtale
16år +	LK-LKG		Oppfølging til hhv 18 -21 år			

Tilleggsundersøkelser avtales ved behov.

I Oslo-regionen tilbys besøk på barselavdelingen for informasjon og veiledning til foreldre.

Sist oppdatert 22.05.11 ved LKG-teamet Bredtvet kompetansesenter

Appendix B. Strengths and Difficulties Questionnaire – Self-Report

Sterke og svake sider (SDQ-Nor)

Vennligst kryss av for hvert utsagn: Stemmer ikke, Stemmer delvis eller Stemmer helt. Prøv å svare på alt selv om du ikke er helt sikker eller synes utsagnet virker rart. Svar på grunnlag av hvordan du har hatt det de siste 6 månedene.

Ditt navn ..... Gutt/Jente

Fødselsdato .....

	Stemmer ikke	Stemmer delvis	Stemmer helt
Jeg prøver å være hyggelig mot andre. Jeg bryr meg om hva de føler	☐	☐	☐
Jeg er rastløs. Jeg kan ikke være lenge i ro	☐	☐	☐
Jeg har ofte hodepine, vondt i magen eller kvalme	☐	☐	☐
Jeg deler gjerne med andre (mat, spill, andre ting)	☐	☐	☐
Jeg blir ofte sint og har kort lunte	☐	☐	☐
Jeg er ofte for meg selv. Jeg gjør som regel ting alene	☐	☐	☐
Jeg gjør som regel det jeg får beskjed om	☐	☐	☐
Jeg bekymrer meg mye	☐	☐	☐
Jeg stiller opp hvis noen er såret, lei seg eller føler seg dårlig	☐	☐	☐
Jeg er stadig urolig eller i bevegelse	☐	☐	☐
Jeg har en eller flere gode venner	☐	☐	☐
Jeg slåss mye. Jeg kan få andre til å gjøre det jeg vil	☐	☐	☐
Jeg er ofte lei meg, nedfor eller på gråten	☐	☐	☐
Jeg blir som regel likt av andre på min alder	☐	☐	☐
Jeg blir lett distrahert, jeg synes det er vanskelig å konsentrere meg	☐	☐	☐
Jeg blir nervøs i nye situasjoner. Jeg blir lett usikker	☐	☐	☐
Jeg er snill mot de som er yngre enn meg	☐	☐	☐
Jeg blir ofte beskyldt for å lyve eller jukse	☐	☐	☐
Andre barn eller unge plager eller mobber meg	☐	☐	☐
Jeg tilbyr meg ofte å hjelpe andre (foreldre, lærere, andre barn/unge)	☐	☐	☐
Jeg tenker meg om før jeg handler (gjør noe)	☐	☐	☐
Jeg tar ting som ikke er mine hjemme, på skolen eller andre steder	☐	☐	☐
Jeg kommer bedre overens med voksne enn de på min egen alder	☐	☐	☐
Jeg er redd for mye, jeg blir lett skremt	☐	☐	☐
Jeg fullfører oppgaver. Jeg er god til å konsentrere meg	☐	☐	☐

Din underskrift ..... Datoen i dag .....

Tusen takk for hjelpen

Appendix C. Strengths and Difficulties Questionnaire – Parent-Report

Sterke og svake sider (SDQ-Nor)

Vennligst kryss av for hvert utsagn: Stemmer ikke, Stemmer delvis eller Stemmer helt. Prøv å svare på alt selv om du ikke er helt sikker eller synes utsagnet virker rart. Svar på grunnlag av barnets oppførsel de siste 6 månedene eller dette skoleåret.

Barnets navn ..... Gutt/Jente

Fødselsdato .....

	Stemmer ikke	Stemmer delvis	Stemmer helt
Omtenksom, tar hensyn til andre menneskers følelser	☐	☐	☐
Rastløs, overaktiv, kan ikke være lenge i ro	☐	☐	☐
Klager ofte over hodepine, vondt i magen eller kvalme	☐	☐	☐
Deler gjerne med andre barn (godter, leker, andre ting)	☐	☐	☐
Har ofte raserianfall eller dårlig humør	☐	☐	☐
Ganske ensom, leker ofte alene	☐	☐	☐
Som regel lydig, gjør vanligvis det voksne ber om	☐	☐	☐
Mange bekymringer, virker ofte bekymret	☐	☐	☐
Hjelpsom hvis noen er såret, lei seg eller føler seg dårlig	☐	☐	☐
Stadig urolig eller i bevegelse	☐	☐	☐
Har minst en god venn	☐	☐	☐
Slåss ofte med andre barn eller mobber dem	☐	☐	☐
Ofte lei seg, nedfor eller på gråten	☐	☐	☐
Vanligvis likt av andre barn	☐	☐	☐
Lett avledet, mister lett konsentrasjonen	☐	☐	☐
Nervøs eller klengete i nye situasjoner, lett utrygg	☐	☐	☐
Snill mot yngre barn	☐	☐	☐
Lyver eller jukser ofte	☐	☐	☐
Plaget eller mobbet av andre barn	☐	☐	☐
Tilbyr seg ofte å hjelpe andre (foreldre, lærere, andre barn)	☐	☐	☐
Tenker seg om før hun / han handler (gjør noe)	☐	☐	☐
Stjeler hjemme, på skolen eller andre steder	☐	☐	☐
Kommer bedre overens med voksne enn med barn	☐	☐	☐
Redd for mye, lett skremt	☐	☐	☐
Fullfører oppgaver, god konsentrasjonsevne	☐	☐	☐

Underskrift ..... Dato .....

Mor / Far / Lærer / Andre (vennligst beskriv):

Tusen takk for hjelpen

Appendix D. Semi-Structured Interview for Children at the Age 10 Assessment

Spørreskjema for 10-åringer

Navn:.....

Familien din og deg

1. Har du brødre eller søstre du bor sammen med?.....
2. Hvem andre bor du sammen med?
   - ☐ Mor og far
   - ☐ Mor
   - ☐ Far
   - ☐ Omtrent like mye hos mor og far
   - ☐ Andre.

3. HER VIL JEG GJERNE AT DU TEGNER FAMILIEN DIN:

SKOLEN og VENNER og DEG ☺

4. Hvilken skole går du på? .....

5. Liker du å gå på den skolen?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Liker det veldig godt **Liker det ikke i det hele tatt**

6. Hvor bra synes du at du klarer deg på skolen?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Veldig bra **Ikke veldig bra**

7. Noen gutter eller jenter er glad for å være som de er, andre kunne tenkt seg å forandre seg på en eller annen måte. Hva føler du?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Veldig glad for å være som jeg er **Veldig lite glad for å være som jeg er**

Hva kunne du tenkt deg å forandre?.....

.....

8. Hvis jeg kunne gitt deg en tryllestav! - og du kunne ønsket deg hva du ville annerledes: enten ved deg selv, eller rundt deg, eller i verden, hva hadde du ønsket deg da?

.....

.....

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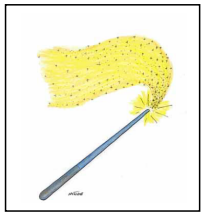


9. I forhold til andre barn, hvor lett synes du det er å få nye venner?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Jeg synes det er veldig lett **Jeg synes det er veldig vanskelig**

10. Har du/hvor mange bestevenner har du? .....

11. Hvem er de? .....

12. Er du med på noe etter skolen (trening, klubb eller sånn)? ☐ Ja ☐ Nei
    Hvis ja, hva er du med på?
    .....
    .....

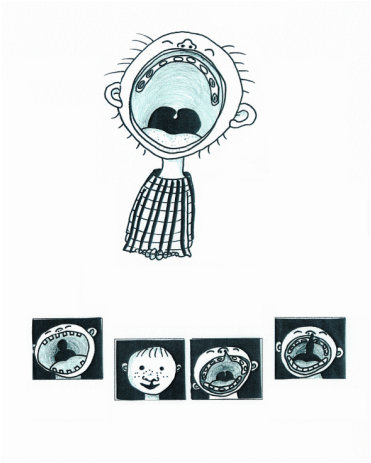
13. Hva liker du ellers å gjøre når du ikke er på skolen eller i ferien?
    .....
    .....

14. Vet du hvorfor du kommer hit i dag?

.....

.....

.....



15. Hva kaller du det du er født med?

.....

.....

16. Hva vet du om spalte?

.....

.....

.....

17. Hva vet du om operasjoner og behandling du har hatt? Hva husker du?

.....

.....

.....

18. Synes du at det å ha en spalte gjør livet ditt annerledes nå for tiden?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Gjør ingen forskjell **Gjør en veldig stor forskjell**

a) På hvilken måte synes du det blir en forskjell?

.....

.....

19. Er det noen som spør eller sier noe om nesen/arret/leppen/talen?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

a) Hvis **JA**: Hva spør de om? ……..

b) Hvis andre spør, hvor mye bryr du deg om det?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Bryr meg ikke i det hele tatt **Bryr meg veldig mye**

c) Hvordan er det for deg dersom noen spør eller kommenterer noe?

☐ Blir lei meg/trist
☐ Blir sint/irritert
☐ Later som ingenting
☐ Går min vei
☐ Jeg svarer/forklarer
☐ Sier fra til noen
☐ Tankestrategier
☐ Annet……

d) Hjelper det deg? (Hva virker, hva virker mindre)

……

24. Opplever du at andre stirrer på deg av og til? ☐ JA ☐ NEI

a) Hvis Ja, Hvem stirrer? Når?

……

b) Hvis **JA**: hvor mye bryr du deg om det?

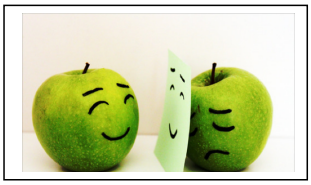
10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Bryr meg ikke i det hele tatt **Bryr meg veldig mye**

25. Er det ting du ikke gjør pga. arret/nesen/leppen/talen? ☐ JA ☐ NEI

a) Hvis **JA**, hva er det du unngår (for eksempel snakke høyt i klassen, være med på bilder eller video…)

……



20. Blir du ertet/mobbet **nå** for tida?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

21. Har du blitt ertet/mobbet **tidligere**?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

Når? ☐Barnehagen ☐1.klasse ☐2.klassel ☐3.klasse ☐ 4.klasse ☐ 5.klasse

Hvis **JA**:

a) Hva er det som skjer? Hvem er det som plager deg?

.....

.....

b) Hva blir du ertet for?

.....

.....

b) Hvis du blir ertet, hvor mye bryr du deg om det?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Bryr meg ikke i det hele tatt **Bryr meg veldig mye**

c) Hvordan er det for deg? Hva gjør du da?

☐ Blir lei meg/trist
☐ Blir sint/irritert
☐ Later som ingenting
☐ Går min vei
☐ Tar igjen
☐ Jeg svarer/forklarer
☐ Sier fra til noen
☐ Tankestrategier
☐ Annet.....

b) Hvilke strategier hjelper deg?

.....

.....

22. Hvis det hadde kommet en pappa eller en mamma bort til deg nå, og de hadde sagt: "Vi har fått en liten gutt/jente som er født med spalte akkurat som deg. Hvordan tror du det går?" Hva hadde du sagt da?

.....

.....

23. Hva ville du har sagt er viktig for at det skulle gå best mulig?

.....

.....

Nå kan du snu arket
Og vi skal se på noen spørreskjema

24. CEQ-10

Vi ber deg svare på følgende spørsmål ved å krysse av på én av rutene for hvert av dem. Det er viktig at du svarer på alle spørsmålene. Bruk helst ikke så lang tid på hvert av dem.

	Aldri	Nesten aldri	Av og til	Ofte	Veldig ofte
Jeg går i selskaper					
Jeg kommer opp i slåsskamper					
Jeg leker med venner på skolen					
Jeg blir ertet					
Jeg overnatter hos venner					
Jeg blir valgt først når andre velger lag					
Andre ler av meg når jeg ikke er der					
Jeg har venner med hjem for å leke					
Jeg leker med andre som bor i nærheten					
Etter skolen bruker jeg mye tid på å se på TV					
Jeg prøver å gjemme meg bort for andre					
Andre synes synd på meg					
Jeg drar på handletur med min familie					
Jeg blir valgt sist når andre velger lag					
Jeg holder meg for meg selv					
Jeg drar til nye steder					
Folk stirrer på meg					
Jeg møter nye mennesker					
Jeg later som jeg er syk for å slippe å gå på skolen					
Jeg organiserer spill og aktiviteter for venner og klassekammerater					

Tilfredshet med utseendet

Noen barn er fornøyd med hvordan de ser ut. Andre barn kunne tenkt seg å se annerledes ut på en eller annen måte. Hva føler du i forhold til ditt eget utseende?

1. Hva synes du om hvordan du ser ut?

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10 0

2. Hva synes du om ansiktet ditt?

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10 0

3. Hvor pen synes du at du er?

Veldig pen ☐☐☐☐☐☐☐☐☐☐☐ Veldig lite pen

10 0

Hva føler du i forhold til disse delene av ansiktet ditt?

4. Nesen:

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10 0

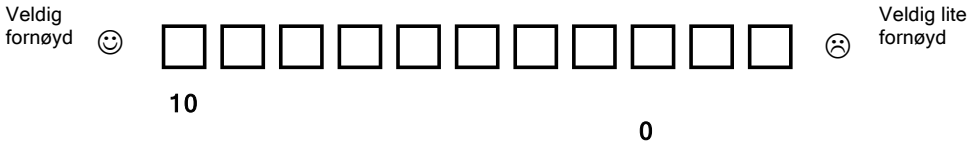
5. Leppen:

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10

0

6. Haken:



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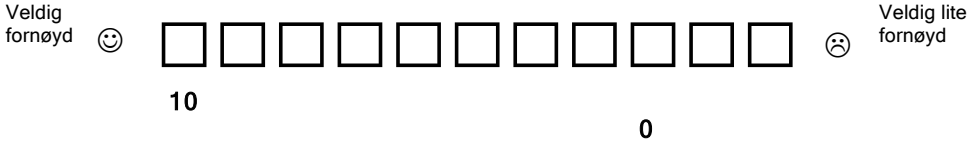
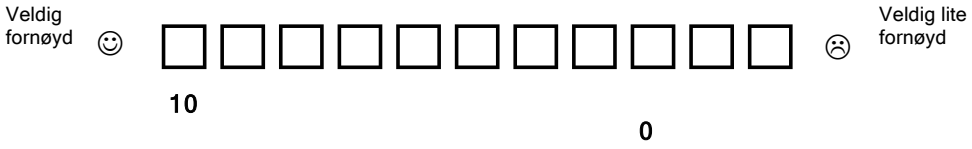
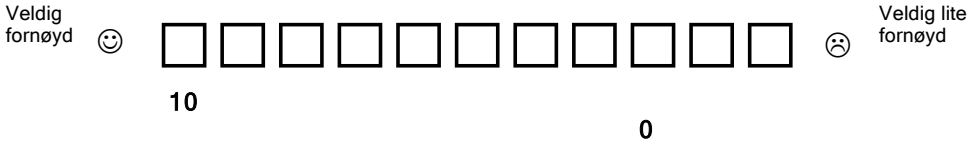


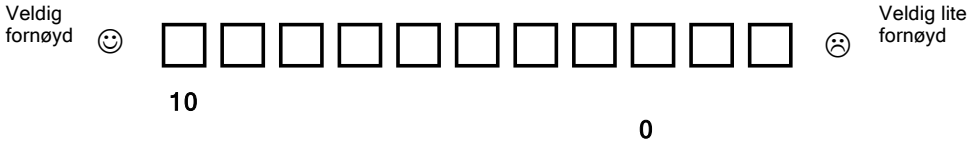
8. Håret:



9. Ørene:



10. Øynene:



11. Hvor fornøyd er du med talen din (lydene når du snakker)?

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10 0

12. Hvor fornøyd er du med hørselen din?

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

10 0

13. Bruker du regulering? JA NEI

14. Hvis JA: Hvor fornøyd er du med hvordan den ser ut?

Veldig fornøyd ☺ ☐☐☐☐☐☐☐☐☐☐☐ ☹ Veldig lite fornøyd

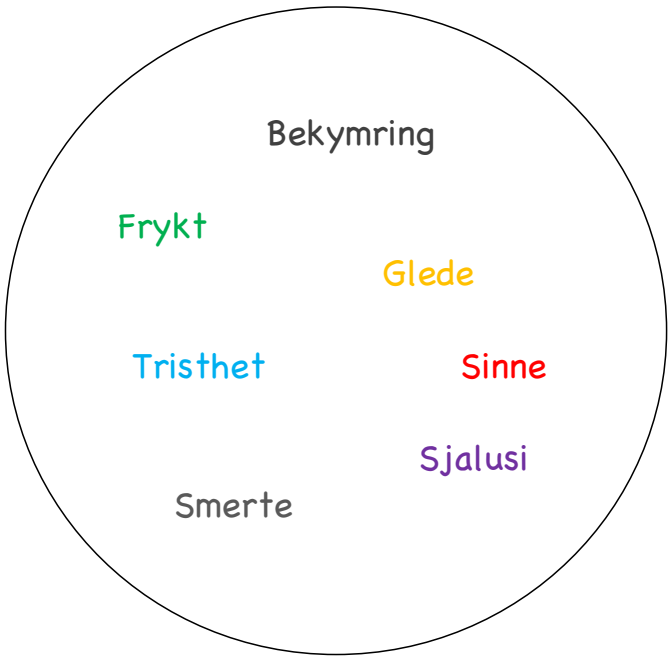
10 0

15. Hvor mye tror du andre legger merke til at du er født med en spalte?

Veldig lite synlig ☐☐☐☐☐☐☐☐☐☐☐ Veldig synlig

10 0

Følelser



25. Hvem snakker du med hvis noe er vanskelig for deg?

☐ Venner
☐ Familie
☐ Læreren
☐ Andre. Hvem?.....

26. SDQ-Nor

Vennligst kryss av for hvert utsagn: Stemmer ikke, Stemmer delvis eller Stemmer helt. Prøv å svare på alt selv om du ikke er helt sikker eller synes utsagnet virker rart. Svar på grunnlag av hvordan det har vært for deg de siste 6 månedene eller dette skoleåret.

	Stemmer ikke	**Stemmer delvis**	**Stemmer helt**
Jeg prøver å være hyggelig mot andre. Jeg bryr meg om hva de føler	☐	☐	☐
Jeg er rastløs. Jeg kan ikke være lenge i ro	☐	☐	☐
Jeg har ofte hodepine, vondt i magen eller kvalme	☐	☐	☐
Jeg deler gjerne med andre (mat, spill, andre ting)	☐	☐	☐
Jeg blir ofte sint og har kort lunte	☐	☐	☐
Jeg er ofte for meg selv. Jeg gjør som regel ting alene	☐	☐	☐
Jeg gjør som regel det jeg får beskjed om	☐	☐	☐
Jeg bekymrer meg mye	☐	☐	☐
Jeg stiller opp hvis noen er såret, lei seg eller føler seg dårlig	☐	☐	☐
Jeg er stadig urolig eller i bevegelse	☐	☐	☐
Jeg har en eller flere gode venner	☐	☐	☐
Jeg slåss mye. Jeg kan få andre til å gjøre det jeg vil	☐	☐	☐
Jeg er ofte lei meg, nedfor eller på gråten	☐	☐	☐
Jeg blir som regel likt av andre på min alder	☐	☐	☐
Jeg blir lett distrahert, jeg synes det er vanskelig å konsentrere meg	☐	☐	☐
Jeg blir nervøs i nye situasjoner. Jeg blir lett usikker	☐	☐	☐
Jeg er snill mot de som er yngre enn meg	☐	☐	☐
Jeg blir ofte beskyldt for å lyve eller jukse	☐	☐	☐
Andre barn eller unge plager eller mobber meg	☐	☐	☐
Jeg tilbyr meg ofte å hjelpe andre (foreldre, lærere, andre barn/unge)	☐	☐	☐
Jeg tenker meg om før jeg handler (gjør noe)	☐	☐	☐
Jeg tar ting som ikke er mine hjemme, på skolen eller andre steder	☐	☐	☐
Jeg kommer bedre overens med voksne enn de på min egen alder	☐	☐	☐
Jeg er redd for mye, jeg blir lett skremt	☐	☐	☐
Jeg fullfører oppgaver. Jeg er god til å konsentrere meg	☐	☐	☐

Tusen takk for at vi fikk bli litt kjent med deg!!

Appendix E. Parent Questionnaire at the Age 10 Assessment

Foreldreskjema – ved 10 og 16 år

Dette skjemaet er et ønske om å ha en dialog med dere som er foreldre til barn eller ungdom som får behandling av LKG-teamet på Rikshospitalet og Bredtvet kompetansesenter.

Vi ønsker gjennom dette skjemaet å høre litt om deres erfaringer i hverdagen, og i hvilken grad dere opplever at barnets spalte eller eventuelt en tilleggsvanske påvirker barnet. Vi håper også å høre hva dere synes har vært til hjelp, og hva som kunne ha blitt gjort annerledes og/eller bedre. ***På forhånd takk!***

Barnets/ungdommens navn: ……

Skjemaet er fylt ut av barnets:

☐ Mor

☐ Far

☐ Andre: ……

Velg et tall på linjen som passer for deg/dere og kryss av et sted mellom 0 og 10. Dersom du/dere har tilleggsinformasjon eller kommentarer er det veldig fint om du/dere skriver på de stiplede linjene. Takk.

1. Hvordan synes dere foreldre det er å komme til undersøkelser i teamet?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

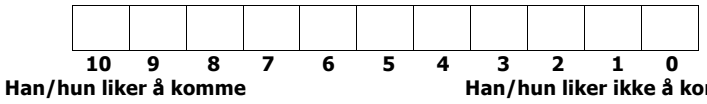
Jeg liker å komme **Jeg liker ikke å komme**

Hvorfor?

……

……

2. Hvordan tror dere deres sønn/datter synes det er å komme til undersøkelser?



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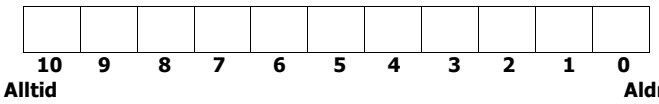
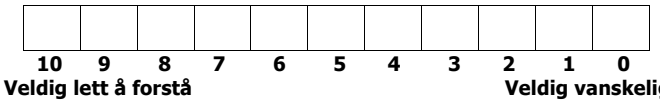
3. Har dere fått nok informasjon om deres sønn/datters behandling?



Dersom dere synes dere har fått for lite informasjon, hvilken informasjon har dere savnet? .....

.....

4. Hva synes dere om forklaringer om behandling dere får av teamet?



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.....

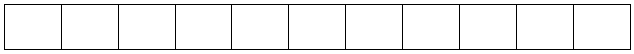
5. Er det noe dere kunne tenkt dere hadde vært annerledes i teamet eller behandlingen? Hvor fornøyd er dere med behandlingen?

……

……

Forrige avsnitt tok opp behandlingen av spalten. Nå ønsker vi å høre om deres erfaringer i hverdagen, og om dere tenker spalten på en eller annen måte påvirker barnet/ungdommen eller dere.

6. Hvordan synes dere barnet/ungdommen trives med andre barn?



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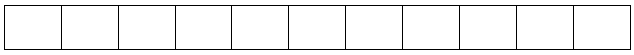
.....

7. Føler dere at deres sønns/datters selvfølelse er blitt påvirket av spalten?



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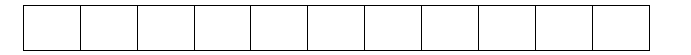
8. Hvor lett synes dere barnet/ungdommen får nye venner, i forhold til andre barn/ungdommer på samme alder?



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9. Noen barn opplever erting/mobbing. Blir dere sønn/datter ertet eller mobbet?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

a) Hvis JA: Hva blir barnet/ungdommen ertet eller mobbet for?

.....

.....

b) Hvor gammelt var barnet/ungdommen da det begynte? Varighet?

.....

c) Hvilke mestringsstrategier bruker barnet (later som ingenting, sier fra, svarer, bryr seg ikke....)? .....

d) Hjelper det? .....

e) Hvordan føler barnet seg når det skjer (blir sint, trist, redd, usikker....)?

.....

f) Har barnet blitt ertet tidligere? .....

g) Hvor mye tror du/dere dette bekymrer deres sønn/datter?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Bekymrer ham/henne ikke i det hele tatt — **Bekymrer ham/henne veldig**

10. Opplever barnet at andre sier noe/stiller spørsmål om nese/arr/leppe/talen?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

a) Hvis JA, hva spør de om?

.....

.....

b) Hvilke mestringsstrategier bruker barnet (later som ingenting, sier fra, svarer, bryr seg ikke....)? .....
....

c) Hjelper det? .....

d) Hvordan føler barnet seg når det skjer (blir sint, trist, redd, usikker....)?

.....

e) I hvilken grad tror dere spørsmålene/kommentarene plager din sønn/datter?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Plager ham/henne ikke i det hele tatt — **Plager ham/henne veldig mye**

11. Opplever dere at noen ser/stirrer påtrengende på barnet?

☐Aldri ☐Nesten aldri ☐Av og til ☐Ofte ☐ Veldig ofte

Hvor mye plager det barnet?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Ikke i det hele tatt — **Plager ham/henne veldig mye**

12. Opplever dere at deres sønn/datter unngår enkelte aktiviteter pga. spalten (for eksempel å stå fram for andre, bli kjent med andre, fotografering, video…)?
    ……
    ……

13. Tror du/dere at det ville være en hjelp for deres sønn/datter å kunne snakke med en fagperson om eventuelle vansker? ☐JA ☐ NEI ☐ Kanskje seinere

14. Har dere noen bekymringer knyttet til deres sønn/datters framtid?

……

15. Påvirker spalten deres liv for tiden?

10	**9**	**8**	**7**	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Ingen påvirkning i det hele tatt **Veldig stor påvirkning**

16. Har barnet/ungdommen andre vansker? ☐ JA ☐ NEI

Hvis **Ja** – tilleggsvanskene er (flere kryss om aktuelt):

- ☐ AD/HD
- ☐ Lese- og skrivevansker (dysleksi)
- ☐ Spesifikke språkvansker (ikke uttalevansker)
- ☐ Forsinket/forstyrret utvikling
- ☐ Tourette syndrom
- ☐ Autismerelaterte vansker eller Asperger
- ☐ Syndrom. Hvilket?.....
- ☐ Annet? Hva:……

17. Er disse diagnosene diagnostisert (evt. under utredning)? ☐ JA ☐ NEI
    Spesifiser ved behov:.....

18. Føler dere at dere får nødvendig oppfølging lokalt, der dere bor?
    ☐ JA ☐ NEI ☐ Ikke behov

19. Barnet følges opp av (flere kryss dersom aktuelt):

☐PPT ☐BUP ☐Barnevern ☐Helsesøster ☐Privat ☐Familievernkontor

☐Annet?: .....

20. Har en eller flere perioder i barnets liv vært spesielt utfordrende for dere?

(*dersom ingen, la det stå blankt, dersom flere, kryss av flere):*

- ☐ Før fødsel (dersom diagnose før fødselen)
- ☐ Barsel
- ☐ Barnets første leveår
- ☐ Førskolealder
- ☐ Skolestart
- ☐ 7-12 år

Sterke og svake sider (SDQ-Nor)

Vennligst kryss av for hvert utsagn: Stemmer ikke, Stemmer delvis eller Stemmer helt. Prøv å svare på alt selv om du ikke er helt sikker eller synes utsagnet virker rart. Svar på grunnlag av barnets oppførsel de siste 6 månedene eller dette skoleåret.

	Stemmer ikke	Stemmer delvis	Stemmer helt
Omtenksom, tar hensyn til andre menneskers følelser	☐	☐	☐
Rastløs, overaktiv, kan ikke være lenge i ro	☐	☐	☐
Klager ofte over hodepine, vondt i magen eller kvalme	☐	☐	☐
Deler gjerne med andre barn (godteri, leker, andre ting)	☐	☐	☐
Har ofte raserianfall eller dårlig humør	☐	☐	☐
Ganske ensom, leker ofte alene	☐	☐	☐
Som regel lydig, gjør vanligvis det voksne ber om	☐	☐	☐
Mange bekymringer, virker ofte bekymret	☐	☐	☐
Hjelpsom hvis noen er såret, lei seg eller føler seg dårlig	☐	☐	☐
Stadig urolig eller i bevegelse	☐	☐	☐
Har minst én god venn	☐	☐	☐
Slåss ofte med andre barn eller mobber dem	☐	☐	☐
Ofte lei seg, nedfor eller på gråten	☐	☐	☐
Vanligvis likt av andre barn	☐	☐	☐
Lett avledet, mister lett konsentrasjonen	☐	☐	☐
Nervøs eller klengete i nye situasjoner, lett utrygg	☐	☐	☐
Snill mot yngre barn	☐	☐	☐
Lyver eller jukser ofte	☐	☐	☐
Plaget eller mobbet av andre barn	☐	☐	☐
Tilbyr seg ofte å hjelpe andre (Foreldre, lærere, andre barn)	☐	☐	☐
Tenker seg om før hun/han handler (gjør noe)	☐	☐	☐
Stjeler hjemme, på skolen eller andre steder	☐	☐	☐
Kommer bedre overens med voksne enn med barn	☐	☐	☐
Redd for mye, lett skremt	☐	☐	☐
Fullfører oppgaver, god konsentrasjonsevne	☐	☐	☐

21. Er det noe vi ikke har spurt om som dere tenker det er viktig at vi vet om?

.....

.....

Takk for at du/dere deler din/deres erfaring med oss