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Mental health problems in deaf and severely hard of hearing children and adolescents

Findings on prevalence, pathogenesis and clinical complexities, and implications for prevention, diagnosis and intervention

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Mental health problems in deaf and severely hard of hearing children and adolescents

Findings on prevalence, pathogenesis and clinical complexities, and implications for prevention, diagnosis and intervention

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voor Isa, Koen, Hannah, Veerle, Maarten en alle andere kinderen

Een klein meisje trekt het kleed van tafel

Je bent sinds ruim een jaar op deze wereld,
en op deze wereld is niet alles onderzocht
en onder controle gekregen.

Nu worden er dingen beproefd
die niet zelf kunnen bewegen.

Je moet ze daarbij helpen,
verschuiven, duwen,
wegnemen en verplaatsen.

Ze willen niet allemaal, de kast bijvoorbeeld,
het buffet, de onverbiddelijke muur, de tafel.

Maar neem het kleed op de koppige tafel
- als je de randen goed beetpakt,
lijkt het niet wars van een ritje.

En op het kleed glazen en bordjes,
een kannetje melk, schoteltjes, lepeltjes -
ze staan te popelen.

Heel interessant:
wat voor beweging zullen ze kiezen
wanneer ze eenmaal op de rand zullen wankelen:
een tochtje langs het plafond?
een vlucht rond de lamp?
een sprong op de vensterbank en vandaar in de boom?

Meneer Newton heeft hier nog niets te zoeken.
Laat hij maar toekijken uit de hemel en zwaaien.

Die proef moet worden genomen.
En zal.

Wisława Szymborska (2002). Uit: *Het moment* (2002), opgenomen in *Einde en begin. Verzamelde gedichten* (uit het Pools vertaald door Gerard Rasch), 14^e druk, uitgegeven bij Meulenhoff, Amsterdam

Chapter **1**

Introduction

Introduction

The target population of specialist mental health services for deaf and hard of hearing children and adolescents consists of those hearing impaired young people whose mental health needs can not be sufficiently met in regular mental health services. The reason that these young people are the target group for specialised mental health services is that they share the need for visual or otherwise adapted communication and special facilities which make communication and social interaction accessible and effective. A medical description of hearing impairment focuses primarily on the severity of hearing loss, quantified as the unaided pure-tone decibel (dB) hearing threshold level for noise in the better ear. Degrees of hearing impairment are generally categorised as mild, moderate, severe and profound but agreed threshold levels may vary across reports within and across countries. For instance, the classification of hearing impairment used by the World Health Organization (WHO: mild <30 dB; moderate 31-60 dB; severe 61-80 dB; profound \geq 81 dB loss) differs from others, such as common classifications used in the Netherlands (e.g., mild 20-40 dB; moderate 41-60 dB; severe 61-90 dB; profound \geq 91 dB) or the UK (mild: 20-40 dB; moderate 41-70 dB; severe 71-95 dB; profound \geq 96 dB). Conversational speech is approximately 50-70 dB. From a functional perspective, young people with a severe to profound hearing loss cannot hear normal conversational speech without additional facilities. Advanced hearing devices such as hearing aids or cochlear implants can give many, though not all of them, some degree of hearing. In this introduction we shall refer to this population simply as “deaf”. In Chapters 2 to 4 of this thesis the aforementioned British classification of hearing impairment was used because of the British background of the handbook (Chapter 2) and the journal (Chapter 3 and 4) in which they were originally published. Chapter 5 of this thesis is based on the same school sample as described in Chapters 3 and 4, and was described in a comparable manner in an American journal. In Chapter 6, based on the study of a Dutch clinical sample, terminology was used according to Dutch criteria for hearing impairment. Please note that the terms “deaf and hard of hearing” or “hearing impaired” are also used throughout the text to indicate a broader

group, for instance to include children or adolescents with a moderate hearing impairment for whom a hearing aid may be recommended.

The population of deaf people

The population of deaf people constitutes a small, very heterogeneous minority in a hearing world. Reported prevalence rates of deafness vary along with the included criteria used for hearing impairment. As indicated above a *medical definition of hearing impairments* primarily focuses on the severity of hearing loss. Taking into account the age of the population studied and the method of measurement, adjusted prevalence rates may vary from 0.74 (De Graaf, Knippers & Bijl, 1997) to 0.85 per 1000 live births (Fortnum, Summerfield, Marshall, Davis & Bamford, 2001). A rise with age to at least 1.65 per 1000 live births in prevalence rate among children 9 years of age and older may be explained by postnatally acquired impairments in 4-9% of overall prevalence (De Graaf et al., 1997; Fortnum et al., 2001), delayed confirmation of congenital cases, and postnatal manifestations of some inherited causes (Fortnum et al., 2001).

A socio-cultural perspective on deafness focuses on at least three characteristics of Deaf culture (with a capital D): a primarily visual experience of the world, the use of sign language, and the identification with a unique culture with its own language, historical traditions, art forms and values (e.g., see Maxwell-McCaw & Zea; Meadow-Orlans & Erting, 2000). Membership in that culture does not require a certain level of hearing loss, but some degree of hearing loss is often necessary to be fully accepted into the culture (Maxwell-McCaw et al, 2011). In fact, to varying degrees deaf people are effectively bilingual and bicultural (Padden, 1996) or still differently culturally oriented as the experience of interaction with both hearing, deaf and hard of hearing people around them may result in a large variation of acculturative styles, either more deaf oriented, bicultural, more hearing oriented or marginal, i.e without a distinct positive preference (Hintermair, 2007).

The heterogeneity of the population of deaf people also appears from considerable diversities in many other domains. Most deaf children are born deaf or become deaf shortly thereafter, and only a minority has had more functional experience with spoken language as they become deaf after the first years of life.

The large majority of parents of deaf children is hearing. So, only a minority of deaf children grows up as early native signers, with a naturally adapted visual communication pattern between parents and their newborn deaf child. Hearing parents have to adapt their communication to the needs, strengths and weaknesses of their deaf child to find a communicative balance to guarantee satisfying interaction in the family. This may require much emotional and interactional investment of all family members, as well as environmental support, of other parents of deaf children as well as professionals. Later in life it will become clear whether deaf people either prefer sign language, spoken language, or a combination of both depending on their conversation partners. Still others, such as individuals who have become deaf later in life, will make more use of sign supported spoken language. Another subpopulation may communicate by home signs, gestures, or a combination of signs, gestures and behaviour. Four hand signing may be used by deaf blind people. Differences in language and literacy skills, language modality, unaided or aided functional hearing capacity, variable early social interactions and educational background, may not only contribute to differences in cognitive functioning between deaf and hearing individuals but they are also likely to be related to in-group differences in cognitive functioning, problem solving, academic achievement and meta-cognition, including Theory of Mind (e.g., see Marschark & Wauters, 2011). In addition, particularly acquired or syndromal aetiologies of deafness may be related to underlying CNS disorders, concomitant cognitive impairment, or physical disorders in other organ systems which all may greatly affect physical and psychological development of deaf children, adolescents and adults. Finally, diversity in race/gender, socioeconomic status or educational placements may contribute to heterogeneity of the deaf population (Maller & Braden, 2011).

History of mental health care for deaf people

Systematic clinical and scientific interest in mental health problems with deaf and hard of hearing people originated in the 50s and the early 60s. However, the first study on deaf individuals with mental illness was probably a study on 36 deaf adult patients in regular psychiatric hospitals in Norway by the deaf psychiatrist Hansen

in 1929 (Remvig, 1972; Vernon & Daigle-King, 1999). Hansen reported that deaf adults were overrepresented in these psychiatric hospitals, and that the average duration of stay in hospital was significantly longer than that of hearing adults. Many patients were undiagnosed, reflecting the issue of performing adequate assessments with deaf people by hearing psychiatrists and psychologists without sufficient communication skills with deaf patients (Vernon et al., 1999). In fact, it was common practice worldwide that deaf people were assessed and treated in regular outpatient and inpatient mental health services without trained staff and proper facilities to receive deaf people and communicate with them effectively. In 1955 the first specialist mental health clinic for deaf and severely hard of hearing people opened in the U.S, their inpatient and outpatient services and patients being described in the early 60s (Rainer & Altshuler, 1966; Rainer, Altschuler & Kallman, 1963; Rainer & Altschuler, 1971). In 1963 Robinson established another inpatient program. In the same year Schlesinger & Meadow opened the first ambulatory treatment services for deaf children in the U.S. (Vernon, 1980). In 1972 Schlesinger and Meadow published a survey on 516 students at a state residential school for the deaf with teachers and school counsellors as informants. Nearly 12% of the students were found to have a severe emotional or behavioural disturbance, and nearly 20% showed a mild disturbance. Comparing results from a similar mental health survey with the much larger general population of hearing children in the region, Meadow & Schlesinger (1972) found a five times increased rate for severe disturbances and a three times increased rate for mild disturbances with deaf school children. In line with this finding others found a three to six times increased rate for emotional and behavioural problems for deaf children as compared to hearing children (Greenberg, 1986; Meadow & Trybus, 1979). Meadow and Schlesinger emphasized that such data indicates how much deaf children are in need of special mental health services, special training for teachers working with deaf children, early intervention programs and effective psychiatric consultation to contribute to a decrease in the high incidence of mental health problems. In the same time period that these services were set up and these early major research projects were conducted in the U.S. (e.g., Rainer, Altschuler, & Kallman, 1963; Grinker, 1969; Schlesinger & Meadow, 1972), interest in research

as well as setting up special services started to increase in Northern European countries and especially in Great Britain (e.g., Denmark & Warren, 1972; Mahapatra, 1974; Williams, 1970), Scandinavia (Basilier, 1964) and Denmark (Remvig, 1969; 1972). From that time on there has been a great number of studies on the prevalence of psychopathology and characteristics of deaf individuals with mental health problems. Although prevalence studies have varied considerably in the criteria used to indicate psychopathology, the samples in study, the informants and the measures in use, most comprehensive studies have demonstrated that the rate of psychopathology is increased in deaf and hard-of-hearing children and young people compared to hearing peers from the general population (Willis & Vernon, 2002; Hindley & Van Gent, 2002).

In The Netherlands, during the major part of the 20th century a small number of schools for the deaf, three of which had residential facilities, were the only institutions that organized special education for deaf children and young people. A minority of children attended schools for hard of hearing children and children with speech and language difficulties, and very few attended mainstream schools. The large institutions for the deaf were also the only organizations to deliver orthopedagogical care, i.e. support for social and educational learning difficulties, social work and welfare services, but until the 1980s there were no specialized mental health services for deaf people available.

In the 1970s new welfare services in The Netherlands were founded through the initiative of a growing interest organization for the Deaf (“The Dovenraad”, currently “Dovenschap”) which also founded a new independent social work organization in the late 80s. In particular the FODOK (Federatie van Ouders van DOve Kinderen), the Dutch federation of parents of deaf children, undertook pioneering work in bringing together interest organizations, the responsible Ministry of Public Health, the Inspection of Health, interested service providers, and the aforementioned educational organizations for the deaf to discuss the establishment of specialist mental health services. In 1984 the FODOK published “*En niemand heeft geluisterd*” (“And No One Listened”), written by W. Frenay, the mother whose deaf son died as a consequence of not being understood in a regular mental health hospital with professionals inexperienced in working

and communicating with deaf people. The booklet gave greater publicity to the extreme distress which deaf people may suffer through the absence of adequate communication in regular mental health services for deaf people, and helped to establish the Platform Psychische Hulpverlening aan Doven (PPHD; platform for mental health for deaf people) in 1985 when the significant, aforementioned organisations started to work together to set up specialist ambulatory and clinical services in The Netherlands. In 1987 an outpatient child and adolescent mental health service started as part of Academic Centre for Child and Adolescent Psychiatry, Curium in Oegstgeest. In 1991 the national specialist in- and outpatient mental health service for adult deaf and hard of hearing patients was opened (Sleeboom-van Raaij, 1991). In 1993 the new national specialist mental health service De Vlier, department of the Academic Centre for Child and Adolescent Psychiatry, Curium, opened her doors to deliver inpatient services, outpatient services and consultation services for deaf and hard of hearing children and adolescents in The Netherlands. It was one of the first specialist inpatient mental health services for deaf children and adolescents worldwide. From the beginning both specialised mental health centres have actively promoted cooperation with the five supra-regional ambulatory mental health services, the in- and outpatient mental health service for elderly deaf and hard of hearing patients and other new services in this relatively new specialist field in the country, as well as with regular mental health services, educational institutions and other organizations abroad, such as the European Society of Mental Health and Deafness.

Mental health services for deaf children and adolescents provide highly specialized cure and care in a low incidence area. Currently, the largest educational organization in The Netherlands, Royal Dutch Kentalis, and existing specialist mental health services are in the process of exploring the joint establishment of a coordinated network of cooperating services in The Netherlands, from school based mental health programs to ambulatory, outreach, and new inpatient services, for children, young people, adult and geriatric patients. The need to join forces in mental health and deafness and to bundle knowledge, clinical expertise and organisational power is as urgent as it was in the 70s (see Meadow & Schlesinger, 1972). Specialist mental health services, experienced professionals,

training facilities, and consultation facilities to generic services are still too scarce to meet the needs of deaf people with mild or more serious mental health problems sufficiently.

Research with deaf children and adolescents

In the second edition of the Oxford Handbook of Deaf Studies, Language, and Education, Marschark & Spencer (2011) describe how an interdisciplinary variety of hearing and deaf researchers has made considerable progress over the years in a broad range of scientific areas such as language, social-emotional, (neuro-) cognitive and cultural aspects of development, as well as educational issues and academic achievement. However, the editors also highlight the areas where more extensive research is needed, among which are the provision of mental health services for deaf individuals, and understanding the challenges of deaf children with multiple handicaps. To date, research in these two related areas has been conducted by a relatively small, but steadily growing group of researchers. Methodology is complex. Firstly, as the population is small and heterogeneous, it is difficult to obtain a sufficient homogeneous sample of sufficient size to conduct research. Secondly, in epidemiologic research large variations in reported prevalence have been reported which may be explained by differences in the measurement instruments used (e.g., questionnaires versus interviews; sufficiently adapted or specially developed and standardized for the use with deaf people; interviews with all participants or only with participants screened positive), differences in the choice of informants (e.g., parents, teachers, self-reports, clinical judgements, or a multi-informant approach), differences in the methods of ascertainment of problems or disorder (e.g., differences in cut-off scores for problems or disorder; using different criteria for clinical disorder; conducting interviews or testing procedures in the preferred mode of communication of the interviewee or not; making use of a qualified sign language interpreter in agreement with the interviewee or not), and differences in the homogeneity or composition of samples (e.g., with or without additional physical handicaps, with or without varying degrees of hearing impairment, with or without cochlear implantation, with or without varying types of schooling, different communicative modalities, or considerable variations in cognitive capacities)

(e.g., see Hindley & Brown, 1994; Hindley & Van Gent, 2002; Maller & Braden, 2011). Such differences between studies hamper the comparability of results. To date, relatively little is known about specific risk factors for psychopathology in deaf children and adolescents in addition to known general risk factors such as CNS damage, low cognitive capacities, additional physical disorder, low parental SES (afkorting zonder uitleg handiger voluit), poverty, family distress and stressful life events (e.g., Friedman & Chase-Lansdale, 2002). Many deafness- and context related findings in studies with deaf samples only explain a small portion of variance in psychosocial adjustment, suggesting that other factors are important (Polat, 2003), such as intrapersonal factors or intrapersonal factors interacting with environmental factors. In addition, little is known about characteristics of deaf children and adolescents who are referred to mental health services, as well as characteristics that may distinguish deaf referrals from hearing referrals in sufficiently large samples.

This thesis: Aims & Structure

The first aim of this thesis is to contribute to filling the gap in knowledge in the area of psychopathology, its correlates, intrapersonal risk factors, and characteristics in the population of deaf children and adolescents with psychiatric disorders. The second aim is to identify factors which may help to focus more specifically on prevention and early recognition of a psychiatric disorder. The third aim is to identify more specific focuses for the improvement of specialist mental health care for deaf children and adolescents and the planning of service provision for this population with special needs.

Chapter 2 is a recent and extensive update of a subchapter on mental health and deafness, which -in its first version- was written in *Child and Adolescent Psychiatry, fourth edition* (eds. M. Rutter and E. Taylor, 2002). The revised version provides an introduction in currently significant aspects of mental health in deaf children and adolescents. In Part I epidemiology, aetiology, cultural, linguistic, interactional, and developmental aspects of deafness are discussed. In Part II important aspects of psychopathology are highlighted. The main focus of the chapter is on severely and profoundly deaf children and adolescents, but the effects of otitis media, mental

health challenges for children with a multisensory impairment, i.e. deafblindness, for hearing children of deaf parents, and for children with a cochlear implantation are also discussed, as well as adult outcome of deafness.

This thesis contains five articles (chapters 2-6). Three chapters (chapters 3-5) concern research with the same population deaf adolescents. As all chapters are self-contained manuscripts, some overlap between them is inevitable.

Chapter 3 is a study on the prevalence and correlates of psychopathology in this population. It fills a number of gaps in the existing literature on prevalence and correlates of psychopathology in deaf children and adolescents. It is the first study to make use of a diagnostic interview with all of the participating adolescents in order to assess psychopathology in this type of study with deaf children and adolescents. Also novel in this field is the use of consensus expert rating of psychiatric caseness and DSM IV classification, bringing together information from parents, teachers, adolescents' self-reports clinical judgements and medical files, as is the comparison between the multi-informant expert ratings with the single ratings of problems and disorder by the separate informants. The significance of early recognition, of the contribution of a single- and multi-informant approach to the assessment of problems and disorders, and of the identification of specific correlates of psychopathology -which may be related to increased risk of psychopathology in deaf children and adolescents- are discussed in the light of these findings.

Chapter 4 concerns a study on possible moderating effects of putative chronic stressful conditions in the lives of deaf adolescents (e.g., peer problems, living in a mainly hearing world) on the associations between aspects of the self-concept and psychopathology. Based on findings from literature, moderating effects of chronic stressful conditions on the association between global self-worth and emotional disorders and on the association between self-perceived social acceptance and behavioural disorder are examined. The importance of considering self-concept dimensions and chronic aversive conditions in subgroups of deaf adolescents when assessing and treating deaf adolescents are discussed.

Chapter 5 concerns a study of two intertwined aspects of self, i.e. self-concept and ego development, in the same representative sample of deaf adolescents of

normal intelligence. Levels of self-concept and ego development in deaf adolescents were compared with levels found in hearing norm groups, and associations of self-concept and ego development with deafness- and context related variables (e.g., cause of deafness, identification with the deaf) are examined. In addition, social self-concept profiles of deaf adolescents are identified and the associations of the profiles with global self-worth, ego development and deafness and context related variables are explored. The findings are discussed in reference to interventions aimed at the well-being of deaf adolescents.

Chapter 6 contributes to the knowledge of characteristics of children and adolescents who are referred countrywide to a national specialist mental health service for deaf and hard of hearing children and adolescents over a time period of 15 years, as well as differences between hearing impaired and hearing referrals with mental health problems. In addition, differences between subgroups of referred patients with and without multiple disabilities, and between the subgroups of (i) hearing impaired children of hearing parents, (ii) hearing impaired children of hearing impaired parents, (iii) hearing children of hearing impaired parents, and (iv) hearing children of hearing parents are examined. Implications of findings for current and future service provision are discussed.

Chapter 7 addresses the main conclusions, limitations, and recommendations for future research and clinical practice.

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Chapter 2

Mental health problems in deaf children and adolescents

Tiejo van Gent

Renewed & adapted from:

Peter Hindley & Tiejo van Gent (2002)

Psychiatric Aspects of Specific Sensory Impairments. Hearing impairment. In:
Child and Adolescent Psychiatry, Fourth Edition (Eds. M. Rutter & E. Taylor), pp.
842-857. Oxford: Blackwell Publishing.

Part I

Mental health in deaf children and adolescents: Epidemiology, aetiology, cultural, linguistic and developmental aspects

Introduction

The consequences of being deaf in a world oriented to the needs of hearing people increases a child's vulnerability to mental health problems. Understanding why this is and how it happens throws light onto both normal development and psychopathology. Given that 90-95% of deaf children are born into hearing families, the response of their parents is likely to be particularly important. For deaf children, i.e. children with bilateral severe to profound hearing impairment, the major challenge is accessing meaningful communication, either in a visuo-spatial signed language, in spoken language or in both. Health professionals have to take into account that many deaf people do not view themselves as impaired or handicapped, but rather as individuals with their own language and culture. In this chapter we focus primarily on children with bilateral, permanent severe to profound hearing impairment, hence called "deaf". In addition we briefly discuss effects of Otitis Media with Effusion (OME), as well as the mental health of hearing children of deaf parents, and of children with multisensory impairment (MSI), i.e. a combination of hearing and visual impairments.

Epidemiology of deafness

A bilateral hearing impairment (HI), i.e. the bilateral lack of hearing speech and other sounds, is usually described quantitatively in terms of the unaided, averaged pure-tone decibel (dB) hearing threshold level for noise in the better hearing ear. Degrees of impairment may be categorized as mild, moderate, severe and profound, but corresponding standards for decibel threshold levels may vary

across reports (e.g., mild: 20-40 dB, moderate: 41-70 dB, severe: 71-95, profound: ≥ 96 dB respectively [see Stephens 2001] versus mild: 15-30 dB, moderate; 31-60 dB, severe: 61-90 dB, and profound ≥ 91 dB [see Walch et al 2000]). In European countries probably more than 1 in 1000 children will have permanent, bilateral congenital HI of moderate or greater severity (e.g., Davis & Parving 1994; Fortnum & Davis 1997). The prevalence of HI rises with another 50-90% among children 9 years of age and older (Fortnum et al. 2001). The post-natal rise in prevalence of HI can be explained by late onset or progressive inherited HI, and, to a lesser extent, by acquired HI (approximately 4-9 % of overall prevalence) and delayed confirmation of congenital HI (Fortnum et al. 2001). The prevalence of HI has not changed over time (De Graaf et al. 1997; Fortnum et al. 2001), but there is a change in the relative distribution of etiologies over the years, except for HI of genetic origin, remaining the most important cause of HI (average $>20\%$ for children with a loss of >40 dB; Fortnum et al. 2002). Cases of syndromic (average 9.5%; both genetic and non-genetic) and perinatal origin (average 8%, including severe prematurity), have increased, and HI of unknown (less than 50%), prenatal (average more than 4%; e.g., rubella) and postnatal (average $<7\%$; e.g., meningitis) etiologies have decreased (Fortnum et al. 2002). Reported rates of etiologies vary across the included categories of hearing level. They also vary with the inclusion of unknown etiologies (Fortnum et al. 2002). It is highly likely that technological improvements in diagnosis will reduce the number of cases of unknown aetiology in favor of cases with known causes including recessive hereditary causes, single gene mutations, subclinical viral infections, and inner ear malformations (Walch et al. 2000).

Nine out of 10 cases of hearing impairment are sensorineural. The most common cause of hearing loss is a sensory dysfunction in the inner ear. Less often the hearing loss involves the 8th nerve, the vestibulocochlear nerve, or more central auditory pathways in the central nervous system. The most common cause of a peripheral conductive hearing loss, i.e a loss caused by a defect in the middle or external ear, is otitis media, which may physically impede the conduction of sound. Acute otitis media (OM) is probably the commonest reason for consultation with general practitioners in the pre-school years (Haggard & Hughes 1991). It is a time

limited condition that usually does not cause permanent HI but the complication of otitis media with effusion (OME) can lead to fluctuating HI. Approximately 10-30% of 2-7 year old children will have fluctuating HI from middle ear disease (Haggard & Hughes 1991).

HI may also be further classified in non-syndromic and syndromic. 70% of hereditary HI is considered non-syndromic as it is not accompanied by other clinical symptoms, while the remaining 30% is considered syndromic as it is combined with abnormalities, malformations or dysfunctions in one or more organ systems (Walch et al. 2000). An important example of syndromic autosomal recessive HI is Usher's syndrome, the co-occurrence of sensorineural deafness and a gradual visual loss due to retinitis pigmentosa (RP). Another example is the Jervell and Lange-Nielsen syndrome, the combination of sensorineural HI and prolonged QT interval leading to arrhythmias, and - possibly dangerous - syncopal episodes. Examples of autosomal dominant syndromes are Waardenburg syndrome, with sensorineural HI, pigmentation abnormalities of the eyes (heterochromia of the iris), hair (usually a patch of white hair), and skin, and dystopia canthorum (wide space between the inner corners of the eyes), and Branchio-oto-renal syndrome, combining conductive, sensorineural or mixed HI with ear malformations, branchial fistulae and cysts, and renal malformations (Gorlin et al. 1995). Congenital rubella syndrome, the co-occurrence of profound HI with impairments in other organ systems such as the heart (congenital heart defects), the eyes (e.g., cataract, retinopathy), the brain (e.g., mental retardation, movement and coordination problems, microcephaly) is one of the examples of non-genetic syndromic HI (Gorlin et al. 1995). Other examples are very low birth weight and meningitis, both of which may be accompanied by brain abnormalities. The occurrence of additional impairments means that early screening for them is essential.

Cultural aspects

Deaf people are a heterogenous population in socio-cultural and linguistic aspects. For many, particularly hearing people, deafness and hearing loss are seen primarily as a disability, an impairment and a physical disorder. For many deaf

people however, being deaf means being part of a unique culture with its own language, traditions and values (eg., see Maxwell-McCaw & Zea 2011). In their comprehensive introduction to a sociocultural view of deafness, Meadow-Orlans & Erting (2000) suggest that deaf culture has three characteristic elements: a primarily visual experience of the world; membership of an oppressed minority; and the use of sign language. Because most deaf children have hearing parents, membership of the deaf community is mainly acquired outside the family. The community contains only few native speakers as only 5-10% of the deaf children are born to one or two deaf parents (Quigley & Paul 1984; Singleton & Tittle 2000). To varying degrees, deaf people, as well as their hearing family members, may identify with the Deaf community, with both the Deaf community and the hearing community, or predominantly with the majority culture of the hearing community (Hintermair 2007; Maxwell-McCaw & Zea 2011). A last subgroup may lack a clear preference for either a deaf, a combined, or a hearing acculturation style (Hintermair 2007). At present there are at least four developments influencing the process of identity formation. Firstly, the educational status of native sign languages has changed positively in the last 20 years with the development of bilingual/bicultural educational programs in many developed countries. At the same time, the social trend to create greater educational opportunities for handicapped children and to eliminate educational discrimination in many countries (eg., see Marschark 2007) has contributed to a current move towards more inclusive forms of education, aiming at more social integration and better academic involvement for all. Thirdly, the development of early, newborn hearing screening programs has strongly contributed to earlier identification of hearing loss and early intervention programs aimed at family support and communication. Finally, the introduction of the cochlear implant (CI), an electronic device that delivers hearing sensations by electrically stimulating the auditory nerve inside the inner ear, has provided many children with more access to the world of sound and spoken language. In summary, deaf children may benefit from these and other developments as long as their strengths and special needs (see below) are sufficiently met.

Sign Languages

Sign languages develop naturally wherever groups of deaf people come together (Groce & Whiting 1988). They differ according to national groups, not necessarily relating to the dominant spoken language. British Sign Language (BSL) and American Sign Language (ASL) have little in common at a lexical level in as much as ASL is historically influenced by the Langue des Signes Française (LSF). Nevertheless, the one thing all sign languages have in common is the expression of semantic and grammatical concepts by movements of the hands, face and upper body. They differ from spoken languages in that they are visuo-spatially organized languages in which meaning can be transferred by the hands, face (i.e. eye gaze and facial expression) and body movements in the visual sign space simultaneously, in contrast to the more sequential transfer of meaning in words in spoken languages. Most signed sentence structure follows a topic-comment structure in contrast to the subject-object-verb structure of most spoken languages. Typically, sign language distinguishes sentences using spatial descriptors to map spatial relations topographically (using many classifier signs, referring to subjects as well as nouns), and non-topographic sentences using fewer classifiers (MacSweeney et al. 2002). The study of sign language provides insights into the ontology of language (Stokoe 1998) and the neural processes that underpin language function (Corina 1999). Evidence suggests that language preference in early infancy is not speech specific (Krentz & Corina 2008), and that hearing and deaf children are equally predisposed to attend to linguistic and prosodic features of motherese in speech or sign (Masataka 2003) It is also suggested that both deaf and hearing infants exposed to sign language from birth acquire sign language along the same developmental timeline as infants acquiring spoken language (e.g., Petitto et al. 2004). In their first year of life infants specialize in processing either visual or auditory linguistic signals as their native language, while their abilities in distinguishing other linguistic signals decline at the end of the first year (eg., Baker et al 2006; Krentz & Corina 2008). Neural systems underlying signed and spoken language processing show many similarities. Both make special use of the left perisylvian regions of the brain. In their review of the literature Campbell and coworkers (Campbell et al 2008) note that specialization of language circuits in the brain reflect the visuospatial

or auditory input modalities for signed and spoken language respectively. This specialization is most likely determined by requirements of the perceptual task of visual-spatial or auditory language processing itself, such as “compositionality, syntax, and requirements of mapping coherent concepts onto a communicable form”, rather than by acoustic or articulatory requirements for hearing or speaking respectively (Campbell et al., 2008). Recent studies also suggest right hemisphere involvement in signed languages but whether this reflects visuospatial modality-specific or non-modality-specific functions, extra-grammatical, prosodic or topic coherence functions or still others remains to be elucidated (e.g., Rönnerberg et al, 2000; Campbell et al, 2008).

Deaf children and deaf parents

The language development of deaf children of deaf parents is comparable to that of hearing children (Pettito & Marentette, 1991; Caselli & Volterra, 1989). Deaf parents tend to have greater sensitivity to the early communicative efforts of their infants than do hearing parents of deaf infants (Smith-Gray & Koester, 1995), and deaf infants are more likely to use bodily movements than auditory signals to attract their mothers’ attention. In turn, deaf mothers are more likely to perceive these signals as attempts to communicate and so reciprocate. They use a variety of methods to gain their infants’ attention (Harris, 1999), to make communication salient and contingent upon the child’s activity and to create joint attention (Loots & Devisé, 2003). Deaf mothers are more consistent in signing in the child’s signing space, using visual (moving hands) or tactile signals (touching physically) to attract visual attention, and waiting to obtain the child’s visual attention before signing (Loots & Devisé, 2003). They adapt their signing in ways that may be considered to be parallel to hearing parents spoken “motherese” (Erting et al 1989; Masataka, 1996) and show greater sensitivity in regaining their child’s attention (Koester et al. 1998) as well as a greater capacity for repair and discourse maintenance (Prendergast & McCollum, 1996). Visual and communicative attunement may advantage a child’s development in many ways. For instance, early signers have been found more proficient in learning spoken language than late signers (Mayberry et al. 2002). Moreover, visual-tactile communication and especially sign language

facilitates inter-subjectivity, i.e. the exchange and sharing of both linguistic and symbolic meaning between parents-deaf child pairs (Loots et al. 2005). In their overview of social cognitive studies on deafness, Corina & Singleton (2009) note how exposure to a visual language and culture may promote the development of visual engagement, executive functions such as attention regulation, inhibitory control and self-monitoring, and socio-cognitive skills such as Theory of Mind (TOM; see below). However, programs for neonatal hearing screening and early intervention have strongly contributed to the provision of early social support and information to hearing parents. It also has contributed to the promotion of effective communication between hearing parents and their deaf child. By consequence such programs have favoured language development, both in visual and spoken language, and social-emotional development (eg., Moeller 2000; Sass-Lehrer & Bodner-Johnson 2003; Yoshinaga-Itano 2003). Even more than the age of detection and early enrollment, parental involvement (including emotional connectedness and effective communicative interaction) has been found to be a powerful predictor of language development, rather than SES, degree of hearing loss or communication modality (Calderon 2000; Moeller 2000; Yoshinaga-Itano 2003).

Both socio-cultural and linguistic background affect the child's ability to understand their own and other's minds. Studies suggest that native signers, i.e. deaf children of deaf parents, perform comparably to hearing peers on a variety of tasks measuring Theory of Mind, the ability to attribute mental states to others as well as to oneself (e.g., Courtin & Melot 1998; Peterson & Siegal 1998; Meristo et al. 2007; Schick et al 2007). This holds for deaf children with at least one other native signer in the direct household instead of one or two native signing parents (Peterson & Siegal 2000). Native, i.e. early signers, outperform late signing deaf children, i.e. deaf children of hearing parents, on both verbal and less verbal TOM tasks (eg. Courtin et al. 1998; Peterson et al 2005; Meristo et al. 2007; Schick et al. 2007). This difference persists even after effects of language ability, non-verbal mental age and executive functioning have been taken into account (Woolfe et al. 2002). However, longitudinal research on sequential TOM-progression in deaf children suggest that children who missed early conversational inputs, such as

deaf children of hearing parents, may continue to improve TOM-understanding at advanced ages (Pyers & Senghas 2009; Wellman, Fang & Peterson 2011). Thus, the pace of TOM development in deaf children is not associated with deafness as such, but to factors such as the presence or absence of the positive impact of early access to a fluently shared common language (Peterson & Slaughter 2006; Morgan & Kegl 2006), early exposure to dyadic conversation focusing on mental states (Meins et al. 2002; Moeller & Schick 2006), a bilingual context (Goetz 2003), or a normal course of experience with social interaction, language and conversation (Wellman et al 2011) in general. Rieffe and Meerum-Terwogt (Meerum-Terwogt & Rieffe 2004; Rieffe & Meerum-Terwogt 2000) investigated deaf children's spontaneous negotiation strategies in false-belief situations. Deaf children of hearing parents were found to use an abundance of references to their own desires and needs combined with a lack of perspective, as compared to hearing age peers. The authors suggest that an understanding of other people's emotions in deaf children may be hampered as a consequence of limited interaction with their hearing parents.

Hearing parents of deaf children

The vast majority of parents of deaf children is hearing, i.e. in about 90-95% of cases. Most of these parents will not have had prior contact with deaf people. They may experience considerable shock on realizing that their child is deaf (e.g., Freeman et al. 1975), and both may respond differently, in terms of anxiousness and guilt feelings, to the deafness of their child (Marschark 2007). From a cultural perspective on deafness, they, then, have to come to terms with their child as different, not disabled (Young 1999). The family response to the consequences of deafness of a child in general reflects their coping skills and their social network (Danek 1988), as well as their cultural background and belief system. Many parents come to embrace a cultural construction of deafness but many struggle with the notion of it as much as with disability (Hindley 1999). In general, parents who receive adequate social and emotional support (eg., Calderon & Greenberg, 1999) may be very capable of coping with the demands of having a deaf child (Marschark 2007) and do not necessarily exhibit more stress than hearing parents of hearing

children (Pipp-Siegel et al. 2002). However, the experience of having a deaf child may be difficult to cope with as hearing parents experience hearing and speaking as an innate, core aspect of their self, and consequently of their expectations of their child and their interaction with him/her (Erting 1982). Pipp-Siegel et al. (2002) list a number of risk factors for high stress among parents including lower income, lower perceived support, serious daily hassles, the presence of disabilities in addition to hearing loss, serious language delay, and less severe hearing loss. The hidden handicap of a relative hearing loss and profitable residual hearing in a hearing environment may make it more difficult to estimate the impact of the loss on the child's functioning and to recognize its special needs (Pipp-Siegel et al. 2002) as with children with other hidden and relative disabilities (Miyahara & Piek 2006).

Particularly older studies have highlighted obstacles in parenting for hearing parents. Hearing mothers of deaf infants have been found to be less responsive to their child than either deaf mothers of deaf infants or hearing mothers of hearing infants (Spencer & Meadow-Orlans 1996). This diminished responsiveness may stem from a lesser sensitivity to the deaf infants' visual signals (Spencer et al. 1992; Prendergast et al. 1996; Harris 2000) and is likely to have implications for the child's development in all domains. Many hearing parents also have been found to be more directive and controlling in their interactions with their deaf children when compared with hearing:hearing dyads and with deaf:deaf dyads (see Marschark 1993). This could derive from difficulties in managing divided attention (Harris 2000) but could also be a response to the children's delayed language development (see below). Interestingly, despite these interactive features, deaf children have not been found to show an increased vulnerability to anxious attachments (Van IJzendoorn et al. 1992; Hadadian 1995). Early identification and early family focused interventions have now created many more possibilities for parents to find effective support in adapting to the needs of their deaf child.

These days, the use of cochlear implants (CI) with younger children has raised parental expectations for their children's potential to develop spoken language. After initial opposition many Deaf communities support CI as one of the communicative alternatives for deaf children (e.g., Christiansen & Leigh 2004).

Marschark (2007) stresses that cochlear implants do not change deaf children into hearing ones, and implanted children and adolescents remain at a disadvantage compared with hearing peers when it comes to acquiring speech perception, spoken language and academic skills. Firstly, with a functioning implant most of them will experience an improved hearing loss of a moderate to severe degree with estimated improvements of nearly 30 dB (Blamey et al. 2001), and so they will have to rely on more limited information than hearing children. Secondly, many of them already have a delay in spoken language development before the implant, thus lacking understanding of the structure of information (Marschark 2007). Although language development of implanted children shows more progression than the development of children with conventional hearing aids a CI rarely corrects for delays prior to implantation (Bat-Shava et al. 2004). Recent studies show advantages in speech perception, production, spoken language, reading abilities and academic achievement (Beadle et al 2005; Spencer & Marschark 2003). A variety of variables have been reported to have beneficial effects on speech and language performance of implanted children. Examples include degree, age of onset and aetiology of hearing impairment, age at implantation (the younger the better), the length of CI experience, increased involvement in spoken language before and following operation, total daily time of CI use, non-verbal intelligence (Wie et al. 2007), pre- and postoperative sign language experience (Connor et al. 2000; Yoshinaga-Itano 2006), parental support for and quality of guidance and therapy following CI, the child's cognitive abilities and other factors, such as the quality of mother-child communication, parental hearing status and the child's temperament (Marschark 2007).

Language development in deaf children

Early infants have the innate capacity to learn any language regardless of modality (e.g., Baker et al. 2006; Marschark 2007). The onset of babbling marks one of the earliest stages of linguistic development (Schick 2003). Babbling with the hands, a rhythmic, syllabically organized linguistic activity with the hands, has been observed in both deaf and hearing very young infants who learn sign language from birth (Baker et al. 2006; Petitto et al. 1991; Petitto et al. 2004), and has also been

demonstrated in hearing infants without prior exposure to signing (Baker et al. 2006). In deaf children, vocal babbling decreases over the first year of life, unlike in hearing children (Marschark 2007). In general, a gradual decline in the capacity to discriminate and produce language elements (phonetic units) in the least familiar, i.e. least practiced, non-native language has been observed in both deaf infants and in hearing infants at the end of the first year of life (Baker et al. 2006; Krentz & Corina 2008). Taken into account a considerable variation across children, deaf children of deaf parents produce sign language at about the same mean age as hearing children of hearing parents produce spoken language (Marschark 2007), but the communicative circumstances are less favourable for the majority of deaf children, i.e. deaf children of hearing parents. There are two features of the language that hearing parents use with their deaf child (Marschark 1993). Firstly, hearing parents tend to simplify both their spoken and signed language and, in the case of sign language, drop important function signs. Secondly, interactions between deaf children and hearing parents tend to be shorter, less complex and contain fewer questions and self-references. As a result, communication is frequently impoverished, and deaf children of hearing parents may refer more frequently to concrete themes and less to more abstract concepts as a reflection of patterns of communication with their parents (Marschark 2007). Many hearing parents experience considerable difficulties in acquiring fluent signing skills and only gain limited proficiency in sign language. Much the same applies to hearing teachers of deaf children. They tend to be more controlling, use more conversational repair strategies and initiate fewer interactions. This controlling style is often associated with fewer questions from pupils and less elaborate answers from them. In fact, as compared to hearing peers, deaf children who are subject to more restricted communication discourse patterns with hearing parents and teachers (Hauser et al. 2008) are at risk of enduring less diversity in early experience (Marschark 2007), less incidental learning (Calderon & Greenberg 2003), and less exposure to a variety of cause-effect relationships reflecting differences in problem solving and a tendency to focus on individual item processing rather than on sequential processing and relations among them (Marschark 2003; 2007). These differences may interfere with problem solving. Notwithstanding advances in visual spatial

processing, deaf children may be less likely to focus on sequential processing and relations among concepts but rather on individual items (e.g., Marschark 2003; 2007; Marschark & Wauters 2008).

Deaf children using spoken language appear to have particular difficulty in understanding questions beginning with “wh”, relative clauses and embedded questions (De Villiers et al. 1994). This may lead to poor understanding even when their spoken language is reasonable. Geers & Nicholas (1997) found that “heuristic” communication functions (questions and answers rather than repetitions and imitations) at age 3 predicted better language development at 5 years in deaf children.

Family involvement is one of the most powerful predictors of language outcome, while limited parental engagement is correlated with significant language delays at age 5, especially when enrollment in intervention programs is late (Moeller 2000). Moreover, it has become apparent that early and later sign language learning does not impede the learning of spoken language, but, on the contrary, *favours* later learning of spoken and written English (Spencer et al. 2004; Yoshinaga-Itano 2006). In general, bilingualism promotes the development of executive functions such as attention, planning and categorisation (Baker 2007), but it may have disadvantages, for instance in the field of naming (Bialystok 2007). In summary, there are two recent developments affecting the course of deaf children’s spoken language. Firstly, early ascertainment (below 6 months) is associated with better receptive and expressive spoken language development (Yoshinaga-Itano & Apuzzo 1998). Secondly, the use of CI also leads to significant gains in language development. (Meyer et al. 1998).

Delayed linguistic input affects language acquisition, and with increasing ages of exposure there is a gradual decline in average proficiency (Newport et al. 2001). When deaf children are exposed to gestures but not to formal signing they tend to develop their own gestural systems, often called “homesign”. Homesign contains many properties of natural languages and appears to convey second language learning advantage when formal sign language is encountered later in life (Morford 1998). Even a new sign language may develop through interaction between previously isolated adult homesigners and young deaf children exposed

to the gestural system in a new deaf community, as has been shown to happen in Nicaragua (e.g., Goldin-Meadow 2010; Kegl et al. 1999; Senghas 2010) When deaf children are presented with signed versions of spoken language, their expressive signing increasingly approximates to native sign language, particularly in the use of spatial grammatical principles (Supalla 1991). When deaf children of hearing parents receive good-quality sign input, their sign language development mirrors spoken language development in hearing children in sequence, but not always in rate (Marschark 1993).

Some early intervention programs provide mentorship from a deaf person; their support with respect to communication and to cultural awareness of deafness seems to foster the children's language development (Watkins et al. 1998; Young 1999).

Social and emotional development

Deaf infants appear to show the same range of emotional states as hearing infants (Snitzer et al. 1989). But as they develop, many of the former tend to have smaller emotional vocabularies and are less good in recognizing other people's emotional states (Greenberg & Kusché 1993). For a number of deaf children, the inability to articulate experience linguistically and to label emotional states may be one of the factors leading to gaps in social-emotional development (Calderon & Greenberg 2003). However, the impact of deafness is influenced by various factors such as quality of family environment, parental adaptation to and coping with deafness, the nature of school and community resources, characteristics of the child and his interactions with his environment (see Calderon & Greenberg 2003)

Lederberg & Mobley (1990) observed that deaf children of hearing mothers showed less social initiative, less compliance, creativity and enjoyment in their interactions with their mothers and more behavioural problems than their hearing peers, while Harris (1978) found that deaf children of deaf parents showed less impulsive, and more reflective, cognitive styles than deaf children of hearing parents. Many of these and similar differences found in older studies may be the consequence of communicative and social deprivation and distorted parent-child interaction (Feinstein 1983), which may diminish when communication

between parents and child improves (Sinkkonen 1994). Reduced communication, miscommunications, and difficulties in gaining and sustaining visual attention with a deaf child due to lack of communicative skills or to communicative insecurity on the part of hearing caregivers may hamper opportunities of developing shared meaning and interactional reciprocity (Koester 1994; Steinberg 2000; Traci & Koester 2003).

Although pre-school friendship patterns do not differ between deaf and hearing children, deaf pre-school children are more likely to use visual communication with their deaf than with their hearing peers (Lederberg et al. 1986). Studies examining social-emotional functioning of HI students in different school settings have yielded mixed results. Although attending mainstream schools has been associated with the experience of loneliness, social rejection and low global self-esteem among deaf students (Farrugia & Austin 1989), more recent studies found no relation between type of school setting and loneliness (Kluwin 1999) or global self-esteem (Van Gurp 2001; Kluwin et al. 2002). Multidimensional self-concept studies suggest that populations of deaf children or adolescents may show low self-perceived competence in the social domains only (Capelli et al. 1995; Van Gent et al. in revision). Low global self-esteem may be selectively found in a subgroup of deaf adolescents that regards unfavourable social circumstances as important, unavoidable and an inescapable threat to their global self-worth (Van Gent et al. in revision). As both deaf and hearing children tend to interact more intensely with peers of similar hearing status, intervention programs have been developed to increase social interaction between deaf and hearing peers. Interventions based on promoting integrated activities rather than social skills appear to have short term positive effects on deaf:hearing peer relationships (Antia et al. 1993). More intensive interventions to increase familiarity between deaf and hearing peers seem to have longer lasting success (Antia & Kreimeyer 2003). Co-enrollment or co-teaching programs at school, where deaf and hearing peers learn together, are jointly taught by a team consisting of a general education teacher, a teacher of deaf students and an interpreter,

Cognitive development

Historically, deafness has been seen as an opportunity to study cognitive development in the “absence of language” but this fails to acknowledge the relevance of sign language (Marschark & Everhart 1997). An increasing awareness, from the 1950s onwards, of the effects of language on cognitive assessment led to the development of specific non-verbal intelligence tests (e.g., Snijders Oomen; Leiter; Hiskey Nebraska; see Blennerhasset 2000) for deaf children, and standardisation procedures of performance scales of other instruments such as the WISC.

Comparable performal IQ scores in the same range as those of hearing peers have been reported (e.g., Maller 2003; Mayberry 2002; Vernon 1968/2005), but verbal IQs tend to be one standard deviation below the mean of hearing examinees (Maller 2003). Verbal IQ may be used as a measure of literacy skills and academic achievement with deaf people rather than as a measure of intelligence (Blennerhasset 2000). Nevertheless, even on non-verbal tests, deaf children have been shown to score below the level of same age hearing children (e.g., see Braden, 1994; Marschark 1993). Such apparent discrepancies might be explained by factors related to the tests in use (eg. not truly language- or culture- independent) and/ or characteristics of the heterogeneous deaf population in study. Lower performance by deaf children of hearing parents may be explained by late or incomplete language exposure in sign or spoken language and by consequence by poor development of mental language representations and working memory (Mayberry 2002). There are several explanations to account for the high performal IQ scores in children with (non-syndromal) hereditary deafness (Kusché et al. 1983) and children with signing deaf parents (Sisco & Anderson 1980; Zwiebel 1987) as compared to other deaf children. Intelligence may be partly inherited. Alternatively early language exposure may facilitate intelligence (Vernon 2005), deaf parents may be better prepared to meet the early learning needs of a deaf child (Sisco & Anderson 1980), or learning a visuospatial language may stimulate visuospatial abilities in a deaf child (Bellugi et al. 1990).

Possible risk factors for cognitive development in (subpopulations of) deaf children include: central nervous system damage; lack of communication and limited social interaction; over-control by caregivers; restriction of experiences

as a result of language deprivation and restricted incidental learning; lack of exposure to sound (e.g., Marschark 1993), affecting the ability to integrate distal and proximal events (Campbell 1998).

Studies have shown both similarities and differences in cognitive functioning of deaf and hearing individuals. Deaf children may lag behind hearing children in their development of conversation. In addition signing deaf individuals may show shorter memory spans than hearing individuals, perhaps because of less efficient retrieval strategies, lesser reliance on relations among concepts, or lower strength in associative connections (Marschark 2003). On average, deaf children show less verbal creativity only when assessed through spoken language tests but not so when assessed using sign language (Marschark 2007). Deaf children rely more than hearing children on visual-perceptual thinking and visual memory, and less on abstract thinking. Especially deaf individuals who use sign language have been found to be at an advantage to non-signing hearing and deaf people in regard to visual-spatial processing and learning. For instance, native signers are better in distinguishing facial features related to sign language information (Bettger et al. 1997; McCullough & Emmory 1997). All signers are better than non-signers in generating mental images on the basis of information in long-term memory. They are better in manipulating them visually in physical space, i.e. using space to encode spatial information, especially by shifting reference and perspective of referents during discourse, and by exact representation of visual-spatial relations within scenes (e.g., Emmory et al. 1993; Emmory & Kosslyn 1996; Talbot & Haude 1993). Moreover, native signers, both deaf and hearing, are more aware of movement (Neville & Lawson 1987a; 1987b) in the visual periphery than other non-signing individuals, but this might be more the result of early auditory deprivation rather than language modality (Proksch & Bavelier 2002). The impact of such visual-spatial, memory and attentional differences on daily problem-solving and learning is complex and warrants further study (Rönnerberg et al. 2000; Marschark 2007).

Academic achievement in deaf children

Even when deaf children are found to show comparable non-verbal IQ scores

to hearing peers, some cognitive skills and knowledge are transferred through language, and better language is associated with better cognitive and school-related academic performance. This may put deaf children at a disadvantage. Many deaf children significantly underachieve in reading, writing and mathematical concepts (Stinson & Kluwin 2003; Traxler 2000) with reading probably being most difficult for many students (Antia et al. 2009). 50% of 18 year old deaf and hard of hearing adolescents' reading is equivalent to a hearing 9 year old child, compared to 1% of hearing peers (Traxler 2000). An early cochlear implant cannot eliminate lags in literacy, but does have a positive effect. It is probably relevant that most, i.e. prelingually, deaf children learn to read and write in what is effectively a second language. For some deaf children there is no basic problem with phonological coding but there is restricted vocabulary knowledge and syntactical ability. Differences in the amount and organization of knowledge in semantic memory (Marschark 2003) and diminished experience of the interaction among the semantic, syntactic and pragmatic components of spoken language (Campbell 1998) may be influential.

Strategies to improve deaf children's reading and writing skills include accessing reading through sign language (Prinz & Strong 1998; Hoffmeister et al. 1997) and offering spoken language by presenting phonological code in the form of hand shapes held alongside the face (Campbell, 1998). Hoffmeister et al (1997) suggested that detailed knowledge of sign language syntax enhances children's meta-linguistic skills and so enables them to decode English. However, many deaf children need further "bridging" skills (Prinz & Strong 1998) such as enhancing recognition of phonological code (Campbell 1998) and recognizing letter-word patterns through the use of finger spelling and sign initialization (Padden & Ramsey 1998). Probably the best outcomes for literacy in deaf children occur when children are exposed at an early age to fluent language in general, either signed or spoken (Mayberry 2002) as well as to the language in which they will learn to read (Marschark 2007).

As a result of earlier educational experience at home and at school many deaf children and adolescents demonstrate a cognitive style characterized by an example-bound or instrumentally dependent approach to his environment

(Marschark 2007). The tendency to focus on individual items rather than on relations between items may affect performance in a variety of domains such as reading, recalling and interpreting content, and recognizing relational information. Deaf children may be especially at risk of underachieving in settings which are primarily hearing oriented and relatively unfamiliar with differences in cognitive styles and learning strategies used by deaf children and young people (Marschark & Wauters 2008; Hauser & Marschark 2008). Thus, an important focus for educational intervention would be to find ways to enhance reflective problem solving and to help deaf children become more aware of and involved in their own learning (Marschark 2007), in addition to mobilizing support and promoting acceptance and validation for personal competencies (Calderon & Greenberg 1993; Marschark 2007; Van Gent et al. in revision). Longitudinal research suggests that cochlear implantation has important long-term benefits for social participation, academic achievement and later employment (Beadle et al. 2005). However, implanted children still need as much support as other hard of hearing children require (Marschark 2007). It warrants further research into how such effects compare to long-term outcome for unaided young people or young people with hearing aids in educational settings with appropriate academic and social support services. As mentioned previously, early identification and early intervention have been related to successful developmental outcome (Yoshinaga-Itano 2003) as well as parental communication skill and participation (Calderon 2000; Moeller 2000).

Deaf-blind children

Epidemiology

Best (1983) estimated that 0.01/1000 children are deaf-blind but this is likely to be an underestimate. In the past congenital rubella has accounted for a third to a half of cases (Trybus, 1985) but this has fallen as a result of universal rubella immunisation in many countries. Both genetic conditions such as Usher syndrome and CHARGE syndrome (an acronym for the combination of Coloboma, Heart defects, Choanal Atresia, Retardation of growth after birth, Genital hypoplasia and

Ear malformations), and deafness in the majority of cases (Verloes 2005; Pauli et al. 2006), and non-genetic conditions like brain abnormalities associated with very low birthweight are now likely to account for the majority. In general, additional impairments are very common, with intellectual impairment in a third to a half and brain abnormalities in a quarter (Trybus 1985) of cases. The impact of deaf-blindness greatly depends on the timing and progression of the respective losses of vision and hearing, as well as the order of appearance. The balance between carrying capacity and burden is totally different for a child which is born deaf-blind and cognitively handicapped as a result of intrauterine rubella infection than for a child born deaf, having balance problems, and becoming progressively visually restricted due to the Usher syndrome, the most common cause of deaf-blindness (1/10.000). Often the latter children develop night blindness at about the age of ten years, followed by a progressive peripheral vision loss in puberty. These children may become very anxious and isolated as they have to face this progressive loss in this phase of development.

Cultural aspects

In areas where there is high incidence of Usher syndrome, deaf-blind communities have formed such as in the Cajun community of Louisiana, USA. A similar community has formed in Seattle, Washington DC, primarily through migration. Miner (1999) provided essential guidance on therapeutic techniques when working with deaf-blind people (see also www.deafblind.com).

Impact of multi-sensory impairment

Multi-sensory impairment (MSI) is one of the most devastating (Adler 1987) and least understood (McInnes & Treffry 1982) of handicapping conditions. Children with multisensory impairment face challenges that are often greater than the sum of the hearing and visual impairments because sensory information needs to be integrated. Their main difficulties lie in accessing experience as such and that experience often has to be mediated through adults.

However, its impact on children and their families is influenced by the severity of the sensory impairments and the nature and severity of associated

impairments (Jenkins & Chess 1996). Responses to sensory losses may include feelings of anxiety, isolation, denial, resentment, or distortion of body image. MSI children demand an enormous adaptation from their parents. In the case of Usher syndrome, many parents appear devastated and unable to imagine the future life of their child when they are informed that their already deaf child may well go progressively blind (Miner 1995).

Part II

Mental health problems in deaf children and adolescents:

Aspects of psychopathology

According to most studies, deaf children have a greater rate of psychopathology compared with the general population, although the majority does not have a mental disorder (see Hindley 1997). However, several mechanisms are likely to contribute to variations in the reported prevalence.

Firstly, the method of assessment and the choice of informants varied from single ratings based on questionnaire – reports from parents (Vostanis et al. 1997; Van Eldik et al. 2004; Hintermair 2007), or teachers (Schlesinger & Meadow 1972; Fundudis et al. 1979; Aplin 1985; 1987; Sinkkonen 1994) or self-reports (Van Eldik 2005; Cornes et al. 2006) to ratings based on parental interviews (Fellinger et al. 2009), a two stage design combining information from parents and teachers with interviews with a selection of deaf participants (Rutter et al. 1970; Freeman et al. 1975; Hindley et al. 1994) or a one-stage multiple-informant approach combining and weighing relevant information from parents, teachers, deaf participants, clinicians and medical files (Van Gent et al. 2007).

Firstly, the method of assessment and the choice of informants varied from single ratings based on questionnaires to ratings based on diagnostic interviews with children, adolescents or their parents. The questionnaires covered reports from parents (Vostanis et al. 1997; Van Eldik et al. 2004; Hintermair 2007), or teachers (Schlesinger & Meadow 1972; Fundudis et al. 1979; Aplin 1985; 1987; Sinkkonen 1994) or self-reports (Van Eldik 2005; Cornes et al. 2006). Ratings were based either on parental interviews only (Fellinger et al. 2009), a two-stage design combining information from parents and teachers with interviews with a selection of deaf participants (Rutter et al. 1970; Freeman et al. 1975; Hindley et al. 1994) or a one-stage multiple-informant approach combining and weighing relevant information from parents, teachers, deaf participants, clinicians and medical files (Van Gent et al. 2007).

Secondly, variations of findings in studies using both the same instrument and the same method of calculating prevalence rates suggest that differences in the composition of the study samples contribute to differences in outcome. For instance, a small number of hearing impaired participants (N=13) in the whole population study by Rutter et al. (1970) may lead to a relatively less reliable outcome. Furthermore, while most studies concentrated on both children and adolescents, some focussed either on adolescents (Hindley et al 1994; Van Eldik 2005; Cornes et al 2006; Van Gent et al. 2007) or on children (Fundudis et al 1979), a factor that may have influenced the distribution of disorders. For example, in one study more internalizing problems were found among adolescents than among younger children (Van Eldik et al 2004), but in other studies no significant age related significant differences were found (e.g., Aplin 1985; 1987). Study samples also varied across two other characteristics: the degree of hearing loss in the participants (see table 1), and the type of school. Degree of hearing loss has been associated with rate of psychopathology (Fundudis et al 1979), but other studies can not confirm this (e.g., Fellingner et al. 2009; Hintermair 2007; Van Eldik et al. 2004; Van Gent et al. 2007). Hindley, Hill, McGuigan & Kitson (1994) have suggested that degree is not a significant factor on its own, but associated factors such as type of school are. The samples assessed students who attended special schools for deaf children and adolescents (Aplin 1985; Hintermair 2007; Sinkkonen 1994; Van Eldik et al. 2004; Vostanis et al. 1997), ordinary school only (Aplin 1987), or more than one type of school (Fundudis et al. 1979; Hindley et al. 1994; Van Eldik. 2005; Cornes et al. 2006; Van Gent et al. 2007).

Although lower levels of mental health problems have been found among children visiting ordinary schools as compared to those attending special schools (e.g., Aplin. 1987; Van Eldik. 2005), there are other factors that may influence such findings, such as IQ, communication mode, physical health factors (Van Gent et al. 2007), and referral bias (Hindley et al. 1994; Van Gent et al. 2007).

Finally, discrepancies in findings may be related to the extent to which instruments and assessment procedures have been adapted for use with deaf people. However, recent studies that adapted the same instrument in different ways (i.e. Youth Self- Report, YSR, see Van Eldik, 2005; Cornes, 2006) have found comparably increased prevalence rates (see table 1).

Table 1.

Studies of prevalence of mental health problems in children and adolescents with hearing impairment (HI) and hearing controls.

Study	HI sample: Number, age range & range of HI ¹	Methods of assessment ²				Prevalence mental health problems or disorder		
		child	parents	teacher	clinician	measure	HI sample (%) ³	Hearing control or norm group (%)
Rutter et al. (1970)	13; 5-14y; HI 2-4	I	I+R	R		combined	15	7
Freeman et al. (1975)	115; 5-15y; HI 3-4	O	I+R	R		combined	23	-
Fundudis et al. (1979)	54; 7-10y; HI D/HH			R			Deaf: 54 / HH: 28	18
Aplin (1985)	61; 7-15y; HI 1-4			R			36	-
Aplin (1987)	42; 7-16y; HI 1-4			R			17	-
Kammerer (1988)	183; 10-13y; HI 1-4		I				54	-
Arnold et al. (1991)	23; 4-10y; HI D/HH			R			0	-
Hindley et al. (1994)	81; 11-16y; HI 2-4	I	I+PCL	TCL		combined	Deaf: 42 / HH unit: 61	-
Sinkkonen (1994)	294; 6-16y; HI D/HH			R			Deaf: 19 / HH: 25	16
Mitchell et al. (1996)	39; 6-14y; HI 3-4		CBCL	TRF			48 / 35	-
Vostanis et al. (1997)	84; 2-18y; HI 3-4		CBCL / PCL				43 / 77	-
Van Eldik et al. (2004)	238; 4-18y; HI 3-4		CBCL				41	16
Van Eldik (2005)	110; 11-18y; HI 3-4	YSR					37	16
Cornes et al. (2006)	54; 11-18y; HI 3-4	YSR					43	19
Van Gent et al. (2007)	68; 13-21y; HI 3-4	I	CBCL	TRF	I	Expert rating	63 / 28 / 32 / 49 / 46	CBCL 16 / TRF 17
Hintermair (2007)	213; 4-13y; HI D/HH		SDQ				36	15
Fellinger et al. (2009)	95; 6-16y; HI 2-4		I				33	

¹Hearing Impairment range (decibel loss in the unaided better ear): D = Deaf without further specification; H/H = hard of hearing without further specification; HI 1 = mild (20-40 dB); HI 2 = moderate (41-70 dB); HI 3 = severe (71-95dB); HI 4 = profound (≥ 95 dB). ²Assessment methods: I = psychiatric interview; O = psychiatric observation; R = Rutter scales (Rutter et al. 1970); PCL = Parent's Checklist and TCL = Teacher's Checklist (Hindley et al. 1994); SDQ = Strength and Difficulties Questionnaire (Goodman 1997); Combined = interviews in subjects screened positive; Expert rating = multi-informant expert rating of caseness and diagnosis. ³Data given in order of method of assessment or category of HI.

The range of psychiatric disorders in deaf children and adolescents is the same as in hearing peers (Hindley et al. 1994). Deaf children are exposed to a number of additional risk factors including communication problems, CNS disorders, physical health problems and intellectual impairment (Hindley 1997). Pervasive developmental disorders are more common amongst deaf children than among hearing peers (see below). Although there is a greater proportion of disruptive than emotional disorders amongst children referred to specialist services (Van Gent & Hendriks 1994; Hindley & Van Gent 2000) higher rates of emotional disorders are found in general populations of deaf children in comparison to hearing children (Van Eldik 2004).

Findings are inconclusive as to whether disorders are more common amongst HI children in mainstream or special schools. Smith & Sharp (1994) found that deaf children in mainstream schools were particularly likely to be bullied. On the other hand, deaf children in residential schools are vulnerable to abuse (Sullivan et al. 2000).

Psychiatric assessment

Deaf children rely on visual communication. When interviewing them, the room needs to be uncluttered and well lit but without a bright light, such as a window behind the interviewer. Lip-reading requires a clear view of the lips, and facial obstacles like bushy beards and moustaches, and objects in the visual space between interviewer and interviewee can cause problems. No more than 25% of spoken language is seen through lip patterns alone (Conrad 1979). Deaf people have to make educated guesses when lip-reading (Beck & de Jong 1990), and a strong foreign accent can make that more difficult.

One of the primary goals for clinicians should be to minimize the impact of language barriers during the assessment and treatment process (Mathos & Broussard 2004). When clinicians have limited signing skills, their efforts to engage signing deaf children can blunt their capacity to detect subtle affective signals, thereby missing affective disorders (Hindley et al. 1993). Even more experienced clinicians may misjudge the linguistic capacities of a deaf child in either signed or spoken language within the first interviews, for instance when dealing with children with cochlear implants. In those cases, and in doubt, it is preferable to

engage a professional sign language interpreter, preferably with experience of child mental health. Aspects of communication, content of the interview, procedure and cooperation with the interviewer must be discussed before and after the interview. Most important, the interpreter will have the child's eye contact and may pick up subtle emotional cues (see Turner et al. 2000), which may help the clinician to assess the nature of problems. In general, the coexistence of deafness and psychiatric disorder can lead clinicians to an unwarranted assumption that deafness explains all - the phenomenon of 'diagnostic shadowing' (Kitson & Thacker 2000), a similar pitfall which may complicate assessment and treatment with children with other handicapping conditions (e.g., see Volkmar & Dykens 2002). A diagnostic family interview may be even more essential in dealing with deaf children and their family, as well as with hearing children with their deaf parents or deaf siblings, than with hearing child-parents couples. It may give vital information on the impact of communication patterns on interactions, involvement and intimacy within the family. Psychiatric evaluation may be especially difficult when deafness is combined with an intellectual disability. For deaf individuals with a profound disability it may be wise to consider other communicative strategies, including the use of carers as interpreters of communication, and careful observation of behavior in different contexts (e.g., Carvill 2001). In all cases a multi-informant approach to assessment, including reports of parents, teachers and others, and significant data on background history are essential. The differential diagnostic problems may be especially difficult in children and young people with a combined hearing and visual impairment. One should always be quite sure that a visual disorder can be ruled out in children and adolescents with a hearing loss. One should take particular concern not to miss sensory impairments when there is a complex multi-causal neuropsychiatric syndrome combined with serious communicative problems. More frequently than in the examination or treatment of a deaf child, the clinician will encounter dependency needs. Over 60% of deaf-blind people have been found to have IQ's lower than 50 in a nation-wide survey in the USA (Klein Jensema 1980), indicating that serious intellectual disability often complicates the clinical picture with deaf-blind children and young people.

Psychological tests

Caution is needed in interpreting psychological test findings in deaf children because most tests have been validated exclusively in hearing populations. A knowledge of developmental and cultural aspects of deafness is also essential (Blennerhassett 2000; Orr et al. 1987).

Autism and related disorders

Studies of deaf children attending audiology clinics found autism and related disorders to be more common than in hearing children. Juré and coworkers (1991) estimated a diagnosis of autism in 5.3% of moderately to profoundly hearing impaired children. Rosenhall (1999) observed a moderate to profound hearing loss in 3.5% of autistic children. In the latter study, intellectual impairment did not account for the raised rates. One of the assumed causes of an increased prevalence of autism in deaf children is a common underlying cause arising from brain damage. For instance, several studies have suggested that deafness as well as autism spectrum disorder may be markers of brain damage in children with congenital rubella (Chess 1977), cytomegalovirus (eg., Steinlin et al 1996; Yamashita et al 2003), or CHARGE association (Johansson et al. 2006) as a consequence of interference with prenatal central nervous system development. A link between prenatal viral infections without interference with central nervous system development and autism spectrum disorders is controversial (e.g., Van Gent et al. 1997)

The age of diagnosis of autism spectrum disorder is frequently later in deaf children than for hearing children (Juré et al. 1991; Roper et al. 2003), in part reflecting 'diagnostic shadowing'. Equally important, early diagnosis of autism spectrum disorder in deaf children is complicated by the combined presence of communicative problems as a consequence of deafness, and the restricted social involvement and often occurring atypical sensory responses (Rogers & Ozonoff 2005) as a consequence of autism spectrum disorder. The basic impairments associated with autism are qualitatively different from what is seen in other deaf children. Absent or otherwise abnormal involvement with the social world may distinguish autistic deaf children and adolescents from non-autistic deaf children

with or without concomitant cognitive impairment (e.g., Van Gent & Hindley 2000; Rogers & Ozonoff 2005). Social impairments may include deficient contacts with adults and peers, disordered social imitation, impaired joint attention, problems using eye-gaze to regulate social interaction and impaired social reciprocity. Other symptoms associated with abnormal joint attention may be a failure to look at people, a lack of social smiling, and a lack of pointing which would indicate an interest in objects (e.g., see Vig & Jedrysek 1999). A preference for the world of objects and physical attributes (Rogers & Ozonoff 2005) and impaired imaginative play in children of appropriate mental age may also be of differential diagnostic value. However, stereotypes or abnormal response to sensory stimuli may show considerable overlap between autism and mental retardation (Vig & Jedrysek 1999), blindness (Jan et al. 1977) or serious deprivation (O'Connor et al. 2000).

Nevertheless, poor language skills stemming from deafness may be associated with delayed but not with impaired imaginative play. Unusual communication patterns and passivity without a discrepant social delay may be common in deaf children with intellectual impairment who are not autistic, and even clinicians with good signing skills can have difficulty in detecting language disorder in sign. Some autistic deaf children show significant improvements in social functioning when educated in signing environments (Juré et al. 1991; Roberts & Hindley 1999). This would suggest that the use of eye-gaze as defined by the rules of signed languages is emotionally less confusing than the much more ambiguous and thus possibly distressing social eye-gaze (see Woll in Hindley 2000). Indeed, there is a body of research which suggests an abnormal face processing ability in children with autism spectrum disorder, including reduced attention or a lack of interest to the face and an aversion to the eyes (see for an overview Denmark 2011). Denmark (2011) herself did not find a general face processing impairment in signing deaf children with autistic spectrum disorder as compared to non-autistic signing deaf controls, suggesting that experience with observing faces for communication purposes during development may compensate for the autistic tendency to avoid looking at faces. With signing autistic children deficits in processing specific emotional facial expressions were found, while no impairments in linguistic face expressions were found with the exception of a deficit in processing adverbials.

These findings suggest a selective impairment in face processing in signing deaf children with autistic spectrum disorder for emotions which require attributions of emotional meaning and the mental state of others (Denmark 2011).

The diagnosis of autism may be very difficult in children with a dual sensory impairment, especially when these are also intellectually handicapped. For instance, self-destructive behaviour and other impulse control disorders may be a symptom of an autism spectrum disorder, a mood or anxiety disorder or a psychosis, but such problem behaviour may also point at severe social deprivation and unmet communicative needs, that warrant specialist training in communication and social skills tailored to the socio-emotional and communicative levels of the individual child. In a study with deaf-blind children with a profound intellectual disability (Hoevenaars-van den Boom et al. 2009) all deaf-blind participants showed social, communicative and language impairments. Autistic participants with deaf-blindness demonstrated significantly more impairments in social reciprocity, in social initiatives and the use of communicative signals and functions. No differences were found in stereotyped behaviour, quality of play, exploration and problem-solving strategies.

Disruptive behaviour

The over-representation of HI children and adolescents with disruptive behaviour among those referred to clinics may partially reflect referral patterns. However, there may also be associations with brain pathology that occur in some types of deafness (Kelly et al. 1993). In a longitudinal study of children affected by congenital rubella, Chess and coworkers (Chess et al. 1971; Chess & Fernandez 1980) found that early impulsiveness in those with deafness alone disappeared as the children acquired language and self-control skills. By contrast, impulsiveness persisted in deaf children with additional impairments. Oppositional behaviour can be an expression of underlying feelings of impotence, anxiety or sadness, or an expression of frustration with difficulties of communication (Kelly et al. 1993). Symptoms of distractibility and over-activity may reflect a distracting visual environment or poor language matching in the classroom leading to boredom (Hindley & Kroll. 1998) or undetected intellectual, language impairments, seizure

disorders or the side-effects of drugs (Kelly et al. 1993). Finally, there may be a link between positively biased self-perceptions in the social domain and behavioural disorders in deaf adolescents, as in hearing peers (Van Gent et al. 2011).

Emotional disorders

The under-representation of emotional disorders in HI children and adolescents seen in the specialist services runs counter to the epidemiological evidence. Studies using a combination of parental and teacher's questionnaires and diagnostic interviews (Hindley et al. 1994; Van Gent et al. 2007), parental (eg., Van Eldik et al. 2004) and self-reports (eg., Van Eldik 2005; Cornes et al. 2006) all found that rates of emotional and behavioral mental health problems in deaf children and adolescent populations as compared to those in hearing age peers groups are –at least- increased, refuting the idea that deaf children and young people are more likely to display more behavioural than emotional mental problems. The risk of emotional disorder is increased in children and adolescents who are rejected (Van Gent et al. 2011), teased, isolated or maltreated (Fellinger et al. 2009) as reported by others, but causal relations have to be studied further. Fellinger et al. (2009) found a modest correlation between the probability of being bullied, isolation or maltreatment and the ability to make oneself understood. Emotional problems may also be missed because poor signing skills may prevent hearing parents, teachers, as well as professionals recognizing the mood disturbance. As in hearing peers, emotional disorders in deaf adolescents are better detected at personal interview (Hindley et al. 1994; Van Gent et al. 2007). Evidence suggests that a less severe degree, acquired or otherwise complicated deafness moderate the association between low self-esteem and emotional disorder (Van Gent et al. 2011). The display of emotion used to illustrate narratives in sign must not be confused with an affective disorder. The latter is pervasive and persistent; whereas the former changes rapidly and is congruent with the narrative (Roberts & Hindley 1999). Behavioural problems that have distinct beginnings and endings, with no clear response to changes in circumstance may derive from depression (Kitson & Thacker 2000).

Schizophrenia and other psychoses

Psychotic disorders are not more common in deaf young people than in hearing adolescents (Kitson & Thacker 2000). Because the syntax of sign language is very different from spoken language, disorders of thinking can be misattributed (Evans & Elliott, 1987; Jenkins & Chess, 1996). Equally, accurate assessments of thought disorder and abnormal experiences can be difficult (Kitson & Thacker 2000). Nevertheless, phenomena such as clang associations and flight of ideas have been clearly identified in deaf adults with psychotic disorders (Kitson & Thacker 2000). Visual or somatic hallucinations are more often observed in deaf patients with schizophrenia, i.e. in about 50% of cases, as compared to hearing patients, i.e. in about 15% or 5% respectively (Cutting 1985). Contrary to expectations, auditory hallucinations, some of which are verbal, do occur in deaf patients with schizophrenia (Du Feu & Mc Kenna 1999). Atkinson and colleagues (Atkinson, 2006; Atkinson et al. 2007) suggest that a distinction can be made between subvisual voice imagery and true visual hallucinations, and that deaf individuals who report seeing an image of a voice may in fact experience a visual percept of voice articulations. In line with the subvocal thought hypothesis (Frith & Done, 1988) the perception of voices may be the result of failing to recognise one's own subvocal thoughts but instead perceive them as having an external locus of control (Atkinson et al., 2007). According to Atkinson et al. (2007), the perceptual characteristics of voice-hallucinations probably closely reflect the variety of experience of real life communication, language and sound among deaf individuals. Profoundly deaf individuals without auditory memory may experience seeing an image of a voice signing or lips moving in their mind. But patients with experience and memory of hearing speech, either due to acquired deafness or the profitable use of residual hearing, may describe voices in auditory terms. Moreover, patients with severe language deprivation and impoverished acquisition of speech or sign may be incapable of experiencing either auditory characteristics or perception of subvisual imagery of voice articulation (Atkinson 2006; Atkinson et al. 2007).

Intervention

In the early 1960s, Rainer & Altschuler (1966) described the then revolutionary service for deaf adults in New York State; and more recently Sleeboom-van Raaij (1991) offered her experience in setting up a similar unit in The Netherlands. To date specialist services for children and adolescents are better developed in Western European countries and the USA than in other countries. However, specialist services are still few and too scattered to cover the need for services nationwide. Following the example of the special interest group for deaf children and families of the European Society for Mental Health and Deafness, the foundation of international networks of professionals promotes the exchange of information, resources and experience among practitioners, thus creating an international platform for cooperation and support in this low incidence, highly specialized area of care. Most services emphasize the importance of the social/cultural model of deafness, consultation with the deaf community and parents of HI children, and a combined team of deaf and hearing professionals. Hearing professionals are expected to achieve high levels of sign language proficiency.

After an initial assessment, the same range of outpatient treatments must be provided as for hearing children and their families. Treatment often has to be organized nearer to the child's home because of the distance to the specialized service. Because of their scarcity, specialized services are often brought in as consultants to local clinics (Van Gent 1999).

Elliott et al.(1987) describe specific pitfalls in the psychotherapy of HI children as well as the value of deaf therapists. Interpreters in family and group therapy may become incorporated into transference relationships (Hoyt et al. 1981). Medication may produce side-effects, such as extra-pyramidal side effects and sedation, that impede communication because they influence visual alertness, motor-function and coordination, and consequently the skills needed for signing, speech reading, speaking and writing (Sleeboom-van Raaij 1997). Also, HI children may be unable to disclose the effects and side effects of the medication prescribed. Because of the increased occurrence of physical co-morbidity contraindications must be taken into careful consideration. In addition, the brains of children with cognitive impairments may put them at higher risk of the side-

effects of medication. The inpatient treatment of HI children usually involves more or less structured programs which are tailored to the individual child within a small and well-organized community.

Specialist or generic services

Specialist services for deaf children do not fit neatly into existing models of services. Unlike other specialist services, this specialism does not involve a particular group of disorders, but rather, communication and visual-spatial aspects of containment – a fundamental aspect of all service provision. Two considerations should guide the referral to specialist services: the communication needs of the child and the complexity of the case. Where there are no specialist services, clinicians should seek help with signing from interpreters but should also be prepared to use non-verbal means of communication.

Special groups of deaf or hard of hearing children

Children with otitis media with effusion

Otitis media with effusion (OME) can lead to transient, sometimes severe, conductive hearing impairment. Earlier reports suggested that this could result in long lasting impaired language skills and behavioural difficulties (e.g., Chalmers et al. 1989). However, the weight of evidence now indicates that the recurrent or chronic hearing impairment through OME less often causes serious speech or language disorder (Haggard et al. 1990; Bennett & Haggard 1999), although it may temporarily lead to problems and even delays in speech, language and academic skills, which can be caught up later (Roberts et al. 2002). In addition, recurrent or chronic physical illness and temporary hearing impairment through Otitis media may lead to communication problems, altered social responses, emotional distress, including mood and anxiety problems, irritability and other behavioural problems such as problems with attention, concentration, and activity, as well as sleep and balance problems (eg., Brouwer et al. 2005). Temporary or recurrent hearing loss may be especially distressing for young children with an already existing hearing impairment of another aetiology as they may feel particularly anxious about

losing residual hearing and they may not be capable of communicating on what is happening.

Hearing children of Deaf parents

Knowledge concerning the development of hearing children of deaf parents is relatively limited (see Meadow-Orlans 1995; Singleton & Tittle 2000). The most comprehensive report is an anthropological study of 150 grown children of signing deaf parents (Preston 1994).

Most deaf parents are competent and caring but they experience stress as a result of being deaf in a hearing world (Singleton & Tittle 2000).

Hearing children of deaf parents are at the centre of interaction between deaf and hearing cultures. Although the use of sign language is a central component of being deaf and often a source of pride, some deaf people see their sign language as less valued than spoken language and they may experience shame when signing outside their deaf community. This may lead some to choose not to sign with their hearing child and to rely on inadequate spoken language. In other circumstances hearing children are drawn into the role of communicator/interpreter for their parents. These experiences can be seen as adverse, “parentifying” the child at an early age, but to others these experiences lead to “greater adaptiveness, resourcefulness, curiosity and “worldliness” (Singleton & Tittle 2000).

Deaf parents may have difficulty in accessing information about parenting, and their own childhood within a hearing family may not have provided them with good models of parenting. This may lead to their feeling insecure or incompetent as parents (Singleton & Tittle 2000).

In some respects, the experience of deaf parents of hearing children can be compared to that of parents raising children from different ethnic backgrounds to their own (Singleton & Tittle 2000).

Most of the grown hearing children of deaf parents studied by Preston (1994) acknowledged some difficulties in their childhood but attributed these as much to the hearing society’s response to their parents as to their parent’s failings. Their roles as interpreters and advocates were linked to experiences that were both fulfilling and hurtful. In a similar vein many described loyalties that were divided between their deaf parents and their hearing grandparents.

Little is known about the psychological wellbeing of hearing children of deaf parents but perhaps a characteristic pattern should not be expected. Clinical experience in specialist services suggests that emotional difficulties and family problems are relatively common. In a recent survey of referrals to the Dutch national mental health service for deaf and hard of hearing children and their families over 15 years (Van Gent et al. submitted) hearing children of one or two hearing impaired parents appeared to grow up much more often in a one-parent family than referred hearing children of hearing parents. As compared to the reasons for referral for either hearing children of hearing parents or deaf children, those for hearing children of hearing impaired parents were much more often an emotional disorder, and less often a behavioural disorder, autistic spectrum disorder or another disorder. Hypothetically this could partly reflect higher distress among these children but whether this also applies to non-referred children is not known.

Mental health aspects of cochlear implantation

Effects of cochlear implantation (CI) may vary considerably among children and adolescents. In general, the effects of CI are most marked in the least adverse communicative circumstances (e.g., not hindered by background noise, simultaneous group conversations, joining and maintaining interaction in larger groups; Bat-Shava & Deignan 2001; Martin et al. 2010; Punch & Hyde 2011). There are still few studies on the longer-term effects of CI on psychosocial development. In a longitudinal Swedish study (Preisler et al. 2002; Tvingstedt & Preisler 2006) implanted children reported a positive appreciation of their implant, but they shared the awareness with their parents that they are still deaf. Conclusions of studies on psychosocial well-being may vary considerably, but recent findings suggest that language ability irrespective of modality is an important predictor of psychosocial well-being (Dammeyer 2009). In one study (Bat-Shava et al. 2004) implanted children demonstrated a faster improvement in social skills following the improvement of communication skills over time than children with conventional hearing aids. Whether this reflects an improvement in the forming of a mental perspective, as has been suggested by the authors and others (e.g., Rimmel &

Peters 2011), remains a subject for further research. Compared to hearing children, comparable delays in Theory of Mind (TOM) development were reported for deaf children with CI and children with conventional hearing aids (Peterson 2006; Wellman et al. 2011). In two studies no differences in executive functions were found between implanted and non-implanted children (Figueras et al. 2008; Hintermair et al. 2011), despite the finding of a positive association between language ability and executive functioning in one of these studies (Figueras et al. 2008). CI definitively changed the face of deafness (Marschark 2007), but from a perspective based on a combination of current cultural values and empirical findings, a bilingual approach to the education of most deaf children is advocated (Petitto & Holowka 2002; Marschark 2007; Preisler 2007). So far, findings are rather inconsistent on the effect of CI on self-concept (e.g., Martin et al 2010; Leigh et al. 2009; Nicolas & Geers 2003; Schorr 2006), as well as on psychosocial problems as measured by parents, teachers or self-reports (e.g., Dammeyer 2009; Edwards et al. 2006; Fellingner et al. 2009; Huber & Kipman 2011; Knutson et al. 2000a; Knutson et al. 2000b; Leigh et al. 2009). Differences in study design, measures, informants and composition of samples hamper comparisons across studies. No effect of CI on psychiatric diagnosis was observed in a population based study with children and adolescents (6-16 years of age), using diagnostic parental interviews and parental and teachers' questionnaires (Fellinger et al. 2009). In another study the degree of hearing loss and CI use were unrelated to the increased level of self-reported depression in HI children (Theunissen et al. 2011). Findings should be interpreted with caution. Failure to control for additional variables, such as gender, age of onset, co-occurring disabilities, and socioeconomic status may lead to overestimation of the effectiveness of CI (Stacey et al. 2006). Failure to control for other factors, such as average hearing level and age (Stacey et al. 2006) or shorter use of CI (Figueras, 2008) may lead to underestimation. It can be concluded that more research on psychological development and prevalence of mental health problems in well-described homogenous samples of children with and without a CI is much needed.

Adult outcome of deafness

Findings from a study of the deaf population in upper-Austria (Fellinger et al. 2005) suggest that deaf adults are more likely to experience higher levels of mental distress and poorer quality of life in the physical and psychological domains than hearing adults from the general population, but not in the domain of social relationships. However, hard of hearing adults were found to have less satisfying social relationships than the signing deaf (Fellinger et al 2007). In a Norwegian survey deaf adults were found to have more symptoms of anxiety and depression than hearing individuals (Kvam et al. 2006). A community survey of deaf adults (Checinski 1993) has suggested that the rate of psychiatric disorder is increased, with perhaps a third experiencing an episode of depression. In London, referrals for depression and for anxiety disorder have increased in relation to improvements in service provision (Kitson & Thacker 2000). In line with the clinical experience with adolescents, an increased drug use (Austen & Checinski 2000) and abuse (Vernon & Daigle-King 1999) amongst deaf adults has been reported. Comparing populations of severely hearing impaired and hearing inpatients in a state hospital in the US, Black & Glickman (2006) found less psychotic disorders and more posttraumatic stress disorder, developmental disorder, mood disorder, anxiety disorder, or personality disorders among the deaf inpatients in the deaf unit than among the hearing patients from other units. They suggested that, as specialist deaf units are few, specialist mental health services for deaf people serve a much broader range of clients than regular psychiatric inpatient units, including patients with dangerous and violent behavior, serious social skills deficits and language dysfluency related to longstanding language deprivation which affects their development and functioning.

Evaluating 13 years of ambulatory mental health care for HI adults, De Bruin & De Graaf (2005) note that to date the majority of adult referrals to their service is deaf, and they conclude that specialist mental health services should also focus on the promotion of the accessibility of specialist services for postlingually, partially and progressively hearing impaired clientele, as this subgroup is highly likely to experience high rates of mental health problems, partly due to the problem of losing one's hearing and having to accept this impairment, without having

the support of a socio-cultural group to identify with, such as the signing Deaf community.

Conclusions

Our knowledge of the developmental pathways of deaf children continues to grow. Uncertainties remain about the optimal balance between specialist and local services, but the main goal should be to improve accessibility and quality of these for all deaf people. Until recently, the main psychological focus has been on the effects of deafness and hearing loss on key developmental experiences and on the effects of society's response to sensory deficits. Currently, governmental initiatives to ban educational discrimination and to promote integration of deaf children and others, the development of early newborn hearing screening and intervention programs, the introduction of CI, and insights from neuroscience and developmental psychology have a great impact on the changing challenges for deaf children and their parents to life in two worlds, and not getting stuck in between (Marschark, 2007). Health and mental health professionals should be aware of the differences between deaf and hearing people in social, cultural, cognitive and other psychological domains. They should also be aware of the fact that deafness and hearing loss may be viewed as a cultural difference by some, and as a disability by others, depending on background and focus of the deaf individual and his family. An integrated approach to mental health issues will continue to be crucial. It is promising that there is a growing body of studies specifying physical, environmental, deafness related and intrapersonal risk factors which may help to identify more specific focus for preventive, diagnostic and treatment interventions.

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Chapter 3

Prevalence and correlates of psychopathology in a sample of deaf adolescents

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Abstract

Aims: To examine prevalence and correlates of psychopathology in deaf adolescents using a multi-method multi-informant approach. **Methods:** Data for the study came from checklist assessments by parents (CBCL) and teachers (TRF) of 70 deaf adolescents aged 13 to 21 years, from semi-structured clinical interviews of the adolescents (SCICA), and from expert ratings of dossier data. **Results:** The percentages of Total Problems scores in the borderline clinical range in this population as found with CBCL, TRF and SCICA are 28%, 32% and 49-63% respectively. Expert dossier ratings identified psychiatric caseness in 49% and DSM-classifications in 46% of the adolescents (primary classifications: emotional disorder 27%, behavioral disorder 11%, other disorder 7%). Cross-informant agreement between single ratings and expert dossier ratings was better than agreement between single ratings. Logistic regression analyses revealed that low IQ, a signing mode of communication and a history of three or more physical disorders were associated with psychiatric caseness. **Conclusions:** Findings suggest a high prevalence of psychopathology in the population studied and argue for a special focus on the early detection of significant emotional and behavioral problems as well as a multi-informant approach to the assessment of disorder in deaf children and adolescents. The correlational findings support the view that it is not deafness per se that contributes to psychiatric problems. **Keywords:** psychopathology, deaf, adolescents.

Introduction

In the past thirty-five years there have been more than twenty studies investigating the prevalence of general psychopathology in deaf and hard of hearing children and adolescents. Table 1 summarizes thirteen studies which meet the following inclusion criteria: 1. samples representing whole populations or school populations; 2. subjects below 22 years of age; 3. subjects with a roughly normal level of intelligence; 4. use of validated instruments for the assessment of psychopathology; and 5. prevalence rate reported as a percentage of the sample. The prevalence of psychopathology reported in these studies varies from 0% to 77%.

The results of the studies presented in Table 1 show that the choice of informants contributes to variations in reported prevalence. This underscores the need to use several informants. However, the level of agreement between parent, child and teacher is generally low and there is no generally accepted standard scheme for combining information from multiple informants (e.g., Fombonne, 2002). Instead, the strategy used in the Development and Well-Being Assessment (DAWBA; Goodman, Ford, Richards, Gatward & Meltzer, 2000), that is: bringing together data from multiple informants and weighing the relative contribution of informant specific information by clinicians, has been shown to be both reliable and valid (e.g., Goodman, Yude, Richards & Taylor, 1996).

The reported prevalence rates in the studies using the Rutter Scale completed by teachers (Rutter et al., 1970), vary from 0% to 54% (see Table 1), indicating that discrepancies may also be related to differences in the composition of the samples. The results of research into the correlates of psychopathology offer some insight into such potential differences. Studies with deaf children have shown higher prevalence rates of psychopathology in deaf children with brain pathology (e.g., Chess & Fernandez, 1980), additional physical handicaps (Sinkkonen, 1994) and intellectual impairment (Van Eldik, Treffers, Veerman, & Verhulst, 2004; Van Eldik, 2005). More discrepant findings have been reported with regard to directly deafness-related variables. Fundudis, Kolvin, and Garside (1979) found an association between psychopathology and the degree of hearing loss, others did not (e.g., Sinkkonen, 1994; Hindley et al, 1994). Specific etiological categories

Table 1.

Studies of the prevalence of mental health problems in hearing impaired (HI) children and adolescents

Study	Nature HI sample	HI sample: Number, age range, range ¹ of HI	Methods of assessment ²			Prevalence mental health problems		
			Child	Parent	Teacher	Measure	HI group	Hearing control or norm group
Rutter et al. 1970	Population	N=13; 5-14y; HI 2-4	I	I+R	R	Combined	15%	7%, control group N=2189
Freeman et al. 1975	Population	N=115; 5-15y; HI 3-4	O	I+R	R	Combined	23%	-
Fundudis et al. 1979	1. special school 2. HI unit	1. N=33; 7-10y; D 2. N=21; 7-10y; H/H			R		1. 54% 2. 28%	18%, control group N=102
Aplin 1985	Special school	N=61; 7-15y; HI 1-4			R		36%	-
Aplin 1987	Ordinary school	N=42; 7-16y; HI 1-4			R		17%	-
Kammerer 1988	Special school	N=183; 10-13y; HI 1-4		I			54%	16%, norm group
Arnold and Atkins 1991	Ordinary school	N=23; 4-10y; H/H-D			R		0%	0%, control group N=23
Hindley et al. 1994	1. special school 2. HI unit	1. N=46; 11-16y; HI 3-4 2. N=35; 11-16y; HI 2-4	I	I+PCL	TCL	Combined	1: 33-42% ^a 2: 57-61% ^a	-
Sinkkonen 1994	Special school	1. N=203; 6-16y; D 2. N=91; 6-16y; H/H			R		1. 19% 2. 25%	16%, control group N=234
Mitchell and Quittnier 1996	Special school	N=39; 6-14y; HI 3-4		CBCL	TRF	Separate	48% / 35%	-
Vostanis et al. 1997	Special school	N=84; 2-18y; HI 3-4		CBCL / PCL		Separate	43% / 77%	-
Van Eldik et al. 2004	Special school	N=238; 4-18y; HI 3-4		CBCL			41%	16%, norm group
Van Eldik 2005	Special & ordinary schools	N=110; 11-18y; HI 3-4	YSR				37%	17%, norm group

¹: Hearing impairment: D= Deaf without further specification; H/H = Hard of Hearing without further specification; HI 1 = Mild (20-40 dB); 2 = Moderate (41-70 dB); 3 = Severe (71-95 dB); 4 = Profound (>95 dB); ²: Assessment methods: I = diagnostic interview; O = psychiatric observation; R = Rutter Scales (Rutter et al., 1970); PCL = Parent's Checklist and TCL = Teacher's Checklist (Hindley et al., 1994). ^a: adjusted minimum & maximum prevalence rates of borderline and definite psychiatric disorder.

of deafness, such as rubella, have been associated with an elevated prevalence of mental health problems in some studies (e.g., Trybus, Karchmer, Kerstetter, & Hicks, 1980) but not in others (e.g., Freeman et al., 1975). Furthermore some researchers found links with communication related factors (e.g., Vostanis, Hayes, Du Feu, & Warren, 1997), whereas others did not (Hindley et al. 1994). Finally, in some studies (Aplin, 1987; Arnold & Atkins, 1991; Van Eldik, 2005) relatively low levels of psychopathology were found among deaf children attending mainstream schools compared to special school populations of deaf children.

This study fills a number of gaps in the existing literature on the prevalence and correlates of psychopathology in deaf children and young people. To the best of our knowledge the present study is the first to make use of a diagnostic interview with all the participating children to assess psychopathology. In addition, the use of consensus expert ratings of psychiatric caseness and DSM-IV classification (American Psychiatric Association, 1994), bringing together information from parents, teacher, the adolescent and his/her medical record, is novel in this field. We hypothesized that the prevalence of scores in the borderline clinical range on symptoms rating scales by single informants would be increased compared to the prevalence of these scores in the Dutch hearing norm groups. We predicted that expert ratings would identify more adolescents with psychopathology than the single ratings. Finally, we investigated the associations between psychopathology and demographic, deafness and physical health related, cognitive and communication variables, as these associations might help to explain a higher prevalence of psychopathology among deaf and hard of hearing children. We expected to find differentiated associations between psychopathology and these variables.

Method

Participants

Participants were recruited from the total secondary school population of one of the three large organizations in the Netherlands that offer special education and educational counseling for deaf children and adolescents. Dutch law allows parents

and deaf children to choose between mainstream schools and special education. Deaf pupils in mainstreaming receive extra educational counseling. To attain a sample comparable with samples used in previous studies, adolescents receiving education for children with cognitive handicaps as well as adolescents receiving junior vocational education were excluded. As the educational organizations are very comparable, this sample may be regarded as representative of the population of deaf adolescents of normal intelligence in the Netherlands. However, it should be noted that oral communication (speech and speech reading) is more common in this educational organization. We obtained informed consent from 70 (74%) of the remaining 94 students and their parents. Permission to use information from their medical dossier was obtained with 18 of the 24 non-responders. Non-response analysis revealed three significant differences. The non-responders were older (average age 18.1 versus 16.9 years; $t(82)=3.44$, $p<0.001$). The average intelligence quotient (IQ) of 11 non-responders (for whom IQ was available) was lower (89.4 versus 109.8; $t(77)=5.14$, $p<0.0001$). Relatively more non-responders (8 [44%] versus 12 [17%] responders) had psychosocial stressors, such as ongoing conflicts between or with parents, a history of penal violation, sexual abuse, reported in their dossiers: ($\chi^2(1)=7.58$, $p<0.01$).

Table 2 gives an overview of deafness related (degree, cause and age of onset of deafness) and other characteristics of the participants. Deafness, i.e. the permanent, bilateral, severe or profound lack of hearing speech and other sounds, was quantified as the unaided average hearing impairment for the better ear of more than 70 decibels (dB), according to the available audiological information in the medical file of the participants. Parental education was used as a measure of socio-economic status. The preferred mode of communication was classified as oral communication or signing + (i.e. use of signing and/or speech and speech reading depending on their conversation partners). Physical disorders included ophthalmic, neurological, cardiovascular, pulmonary, or other physical disorders for which specialist medical care was provided, or had been provided in the past.

Table 2.

Demographic profile of research group

Characteristic	N	%	Characteristic	N	%
<i>Age (average 16.9 years)</i>			<i>Cause of hearing loss</i>		
13-16 years	37	53	Hereditary	24	34
17-21 years	33	47	Rubella	8	11
<i>Sex</i>			Postnatal	14	20
Boy	33	47	Unknown	24	34
Girl	37	53	<i>Age at onset of deafness</i>		
<i>Performance IQ*</i>			Before 19 months (prelingual)	48	68
80-100	20	30	After 19 months (postlingual)	9	13
101-140	47	70	Unknown	13	19
<i>Ethnicity</i>			<i>Communication Mode</i>		
Dutch	53	76	Speaking and speech reading	37	53
Other (e.g., Turkish, Surinamese)	17	24	Signing+	33	47
<i>Family with:</i>			<i>Highest educational level parents</i>		
Two biological parents	51	73	Low	11	16
Other	19	27	Middle-Low	16	23
<i>Place of residence</i>			Middle-High	15	21
Parental home	42	60	High	20	29
Residential setting	28	40	Unknown	8	11
<i>Type of school</i>			<i>Actual physical disorders*</i>		
Special school for the deaf	52	74	None	43	63
Ordinary school	18	26	One or more	25	37
<i>Hearing loss*</i>			<i>History of physical disorders*</i>		
73-95 dB	13	19	0-2 different disorders	41	59
≥96 dB	54	81	3 or more different disorders	28	41

* missing data with 1-3 cases

Measures

Cognitive Testing. In accordance with best practice in testing intelligence of deaf persons (Blennerhassett, 2000), the performance scales from the Wechsler series were used in this study.

Symptom Scales. The Child Behavior Checklist (CBCL; Achenbach, 1991a; Verhulst, Van der Ende, & Koot, 1996) and the Teacher's Report Form (TRF; Achenbach, 1991b; Verhulst, Van der Ende, & Koot, 1997a) were used to assess problem behavior as reported by parents and teachers respectively. The problem items of the CBCL and the TRF generate a Total Problems scale, the "broad band" syndrome scales Internalizing and Externalizing, and eight "narrow band" syndrome scales: withdrawn, somatic complaints, and anxious/depressed (constituting the internalizing scale), delinquent behavior, and aggressive behavior (constituting the externalizing scale), and social problems, thought problems, and attention problems. The Semi-structured Clinical Interview for Children and Adolescents (SCICA; McConaughy & Achenbach, 1994; Kasius, 1997), based on the CBCL, was used to assess problem behavior as reported by clinicians and adolescents. The SCICA is scored quantitatively on the Observation form and the Self-Report form. In this study we used the SCICA Total Observations scale, the Total Self-Reports scale, the Internalizing and the Externalizing scales. In order to prevent unrealistically high scores because of the deafness of the participants, the score on the item 79 (speech problems) of the CBCL and TRF Total Problems scale was substituted by the item mean of the Dutch norm group, the scores on 5 SCICA items concerning speech and language problems (items 13, 44, 45, 88 and 108) were substituted by the mean scores of the remaining items of their scales.

Kasius (1997) reported good inter-rater agreement with the SCICA. In the present study comparable results were found for the two interviewers, a psychiatrist and a psychotherapist, both experienced with deaf adolescents and trained in using the SCICA, who attended the first 17 interviews and independently scored them. The intra-class correlation coefficients for the reliability of single ratings (Bartko & Carpenter, 1976) ranged from 0.85-0.94, indicating good agreement. The remaining 53 participants were interviewed by one of them.

Operational definitions of caseness, emotional and behavioral problems for the CBCL, TRF and SCICA. For the CBCL and TRF, an adolescent was considered a case when scoring in the borderline clinical range on the Total Problems scale. Because Kasius' (1997) sample of clinically referred adolescents is the only sample on which we have SCICA data, we used the frequency distributions from Kasius'

sample. The cut-off points for the borderline clinical range were based on results with the Youth Self-Report (YSR; Achenbach, 1991c) in the Dutch normative sample of clinically referred adolescents, as the SCICA has many items in common with the YSR and as adolescents are the source of both. Verhulst, Van der Ende, & Koot (1997b) found a YSR Total Problems score in the borderline clinical range with 41% of the clinically referred boys and 54% of the clinically referred girls. Consequently, the $(100-41)=59^{\text{th}}$ (boys) or $(100-54)=46^{\text{th}}$ (girls) percentile score in Kasius' sample of clinically referred adolescents, were used as cut-off scores for the Total Observations scale and for the Total Self-Reports scale.

For the CBCL and TRF, an adolescent was considered to have a clinically significant emotional or a behavioral problem when scoring in the clinical range of the Internalizing or the Externalizing scale respectively. The cut-off scores for the Internalizing and the Externalizing scales of the SCICA were defined as the percentile scores in Kasius' sample of clinically referred adolescents that correspond to the percentage of scores in the clinical range of the YSR Internalizing and Externalizing scales, respectively, in the Dutch norm groups of clinically referred adolescent girls and boys.

Caseness Rating and Psychiatric Classification. Two child psychiatrists (TVG, PDAT) used the scoring procedure of Goodman, Yude, Richards, and Taylor (1996) to assess psychiatric caseness on the basis of dossier data. These included demographic, deafness-related, medical and audiological variables and IQ; transcripts of written accounts of two semi-structured interviews on the psychosocial consequences of deafness with parents and their deaf adolescents (Gregory, Bishop, & Sheldon, 1995); CBCL and TRF forms without scale scores; teacher's impressions of the interactions of the adolescent with teachers and peers; transcripts of written accounts of the SCICA interview (without scale scores). Only when the caseness score indicated a definite case (original score 2A and higher), the presence of a DSM-IV classification was assessed. Following independent ratings of every ten cases, cases were discussed by the clinicians and disagreements were resolved. The DSM-IV diagnoses were grouped into (1) emotional disorders, including anxiety and mood disorders, (2) behavioral disorders, including attention-deficit and disruptive behavior disorders, and (3)

other disorders (e.g., psychosis, somatoform disorder, pain disorder). Cohen's kappa for interrater agreement was 0.83 for caseness, 0.47 for emotional disorders, and 0.36 for behavioral disorders. Shrout (1998) regards kappa values 0.11-0.40 as "slight", 0.41-0.60 as "fair", 0.61-0.80 as "moderate", and above 0.80 as "substantial" agreement. In addition Yule's Q was computed because kappa shows a downward bias when distributions deviate substantially from a 50-50% distribution. Values of 0.89 (emotional disorders) and 0.85 (behavioral disorders) were found, indicating good agreement (Spitznagel & Helzer, 1985).

Procedures

The communication mode during the interviews was determined by the interviewee. A sign-language interpreter assisted in agreement with the deaf interviewee. Both Gregory's interviews with parents and adolescents were conducted by a child psychologist. At the end of the interview parents were asked to complete the CBCL at home. Due to practical reasons – among which language difficulties (including for one of the three deaf parental couples) and the primary place of residence being the residential setting of the school - 12 parental couples did not complete the CBCL. TRF's and school reports were gathered for 68 of the participating adolescents. The intelligence of 67 participants (3 refused) was tested by a psychologist. The SCICA was administered and scored without knowledge of other sources of information about the participant.

Results

Prevalence

Table 3 shows that the CBCL- and TRF-based prevalence rates are 1.5 – 1.7 times higher than in the norm-group, that the SCICA-based prevalence rates are equal (Total Observations scale) to or even higher (Total Self-Reports scale) than in Kasius' sample of clinically referred hearing adolescents.

Table 3.

Observed and Expected Prevalence of Caseness and concordance between dossier rating and other estimates of caseness.

Scale	Caseness-criterion satisfied			χ^2 one sample test (1 df)	Concordance with dossier rating (kappa)
	Observed n (%)	Expected n (%)			
		Dutch normgroup ¹	Clinical sample ²		
CBCL (N=58)					
- Total Problems in borderline clinical range	16 (28%)	9.3 (16%)		5.79*	.57***
TRF (N=68)					
- Total Problems in borderline clinical range	22 (32%)	11.6 (17%)		11.36***	.35**
SCICA (N=70)					
- Total Observations in borderline clinical range	34 (49%)		33.5 (48%)	0.83	.43***
- Total Self-Reports in borderline clinical range	44 (63%)		33.5 (48%)	6.31*	.38***
Dossier rating of caseness	34 (49%)				

Note: Significant differences between observed and expected frequencies are denoted with *($p < 0.05$), ** ($p < 0.01$), or *** ($p < 0.001$).

¹: Verhulst et al. (1996, 1997).

²: expected percentage is weighted mean of the following percentages in Kasius (1997) sample of clinically referred adolescents: 41% boys and 54% girls

Table 4 reveals that the CBCL- and TRF-based prevalence rates of emotional problems are more than 2 times higher than in the general population of hearing adolescents. The SCICA based prevalence rate is equal to the prevalence rate in Kasius' clinical sample. For behavioral problems, the CBCL and TRF based prevalence rates are slightly (i.e. not significantly) higher than in the hearing norm groups, while the SCICA estimate is slightly (i.e. not significantly) lower than in Kasius' clinical sample (Table 4).

Table 4.

Observed and Expected prevalence of emotional and behavioral problems and concordance between dossier diagnosis of emotional and behavioral disorder and CBCL-, TRF- and SCICA estimates of clinical problems.

Diagnosis/Scale	Diagnostic criterion satisfied		χ^2 one sample test (1 df)	Concordance with dossier diagnosis (kappa)
	Observed n (%)	Expected n (%) Dutch normgroup ¹ Clinical sample ²		
Emotional problems				
CBCL Internalizing score in clinical range (n=58)	11 (19%)	5.2 (9%)	7.03**	.44***
TRF Internalizing score in clinical range (n=68)	17 (25%)	6.1 (9%)	21.26***	.17
SCICA Internalizing score in clinical range	26 (37%)		27.2 (39%)	.09
Dossier DSM-diagnosis of primary emotional disorder	19 (27%)			.58***
Behavioral problems				
CBCL Externalizing score in clinical range (N=58)	8 (14%)	5.2 (9%)	1.63	.51***
TRF Externalizing score in clinical range (N=68)	10 (15%)	6.1 (9%)	2.70	.74***
SCICA Externalizing score in clinical range	12 (17%)		17.1 (24%)	2.01
Dossier DSM-diagnosis of primary behavioral disorder	8 (11%)			.42***

Note: Significant differences between observed and expected frequencies are denoted with** (p<0.01), or *** (p<0.001).

¹: Verhulst et al. (1996, 1997).

²: expected percentages are weighted means of the following percentages in Kasius (1997) sample of clinically referred adolescents: for SCICA internalizing scale 32% boys and 44% girls; for SCICA externalizing scale 26% (boys) and 23% (girls).

Agreement

The agreement between dossier ratings and the other measures was slight to fair, with a mean kappa of 0.43 for dossier rating of caseness and the other caseness-estimates (see Table 3), a mean kappa of 0.40 for dossier rating of emotional disorder and the estimates of emotional problems, and a mean kappa of 0.56 for dossier rating of behavioral disorder and the estimates of behavioral problems (see Table 4). The agreement between the single CBCL, TRF and SCICA estimates was generally lower, with a mean kappa of 0.30 for agreement between the single estimates of caseness, a mean kappa of 0.25 for the single estimates of emotional problems and a mean kappa of 0.33 for the single estimates of behavioral problems.

The TRF measure of emotional problems showed relatively low agreement with expert rating of emotional disorders (kappa=0.17). Therefore, we explored whether the level of agreement between the TRF measure of emotional problems and the other comparable measures (of emotional problems/disorder) might be related to characteristics of the adolescents presented in Table 2. Significant differences between kappa values ($p < 0.05$) were found exclusively with communication mode. Within the sub-sample of signing+ adolescents slight levels of agreement (mean kappa=0.36) were found between TRF and all other measures. Within the sub-sample of orally communicating adolescents virtually no agreement was found (mean kappa= -0.05). This finding casts some doubts on teacher's ratings of emotional problems with orally communicating adolescents.

Associations of participant characteristics with caseness, problems and disorder.

A series of univariate logistic regressions revealed that age, deafness-variables, present physical disorders, place of residence, parental SES and immigrant status were not related to any of the assessments of caseness, emotional and behavioral problems or disorder. Gender appeared to be significantly associated with only two measures: SCICA Total Self-Reports (29 [78%] girls and 15 [46%] boys showed scores in the borderline clinical range: OR= 4.35, $p < 0.01$) and Internalizing scales (22 [60%] girls and 4 [12%] boys had scores in the clinical range: OR= 10.63, $p < 0.0001$). The same trend was found for the SCICA Total Observations scale, and experts ratings of caseness and emotional disorder.

Table 5.

Results of Univariate Logistic Regression Analyses to predict Dossier Rating of Caseness and DSM-IV Classification of Emotional or Behavioral Disorders from Selected Variables.

	Ordinary school (n=18) ² OR (95% CI)	Performal IQ > 100 (n=47) ² OR (95% CI)	Oral communication (n=37) ² OR (95% CI)	History of >2 physical disorders (n=28) ² OR (95% CI)	2 biological parents (n=51) ² OR (95% CI)
Dossier Caseness & Diagnosis	0.14** (0.35-0.53)	0.12** (0.03-0.41)	0.18** (0.07-0.51)	3.66* (1.32-10.12)	0.32* (0.11-0.98)
Dossier Caseness	0.45 (0.11-1.78)	0.36 (0.11-1.12)	0.41 (0.14-1.21)	7.20** (2.18-23.74)	0.53 (0.17-1.64)
DSM Emot. Dis.	-- ^b	0.27 (0.06-1.35)	0.10* (0.01-0.89)	0.85 (0.19-3.95)	0.32 (0.07-1.43)

Note: OR < 1 indicates less pathology; OR > 1 indicates more pathology for specified subgroup. * p<0.05; ** p<0.005; CI= confidence interval.

²: n is the number of participants belonging to the specified subgroup

^b: OR not computable: one cell with zero frequency

Table 5 shows the associations between the remaining characteristics and experts ratings of caseness and DSM disorder. Caseness was associated with all independent variables presented in Table 5. Therefore, a multivariate logistic analysis with these variables, was performed to further explore their relative importance. Now type of school and family composition were no longer significant, indicating that the differences in prevalence of caseness with adolescents from mainstream versus special schools and adolescents from families with 2 biological parents versus other families, are captured by the remaining variables, i.e. IQ, communication mode and a history of physical disorder.

The only variable significantly associated with a dossier diagnosis of a primary emotional disorder appeared to be a history of three or more physical disorders. Contrary to the finding of others (Rutter et al., 1970) separating out neurological disorder did not produce a significant association with disorder. Neither type of school nor communication mode appeared to be associated with primary emotional disorders but primary behavioral disorders were found less often in the subgroup of orally communicating adolescents than in the signing subgroup. Behavioral disorders were even absent in the subgroup of adolescents attending ordinary schools.

Discussion

This study is the first in which use has been made of both source-specific information (CBCL, TRF, SCICA) and clinically informed ratings synthesizing multi-source information to identify psychiatric caseness and disorder in a sample of deaf adolescents of normal intelligence. The expert ratings are probably the most reliable and well-founded estimates of the prevalence rates of caseness (49%), and DSM-IV disorder (27% emotional, 11% behavioral and 7% other disorders). This is because of: (1) good inter-rater reliability was found for the expert ratings; (2) the agreement between expert ratings and the judgments by single informants was overall higher than the agreement between the judgments of the single informants; (3) previous studies showed evidence for the validity of a comparable method of integrated assessment (i.e. DAWBA; Goodman et al., 2000), as well as evidence for reliability of the clinical rating system (Goodman et al, 1996); and (4)

relying on multiple sources is generally regarded as the method of choice for the identification of caseness in epidemiological settings (e.g., Fombonne, 2002).

The prevalence rates of Total Problems found with the CBCL (28%) and the TRF (32-34%) were lower than the prevalence rate of caseness found with expert ratings. Linguistic communication problems between hearing environment and deaf adolescent may have impeded the sharing of problems by the adolescent as well as recognizing and exploring these problems by parents or teachers. Our finding of virtually no agreement between the reports of the –predominantly hearing- teachers on total and emotional problems with orally communicating adolescents and all other sources of information might be an example of the effect of communicative and cultural differences between deaf adolescents and their hearing environment, as suggested by Hindley et al. (1993). In addition, coexistence of deafness and psychiatric problems may have led caregivers and teachers to the unwarranted assumption that deafness explains all, the phenomenon of diagnostic shadowing (Kitson & Thacker, 2000).

The SCICA based rates of Total Problems were equal (Total Observation 49%) to, or higher (Total Self-Reports 64%) than the rates based on expert dossier rating of caseness, contrary to our expectations. One of the mechanisms to explain the high rate of SCICA based caseness may be the willingness of the participants to discuss their problems more openly both as participants in a study and in a safe interview situation where communication was tuned to their needs. In addition, it should be noted that higher rates were not found with boys. The observed significant preponderance of girls with SCICA based self-reported total problems as well as internalizing problems may reflect the interference of heightened affiliative needs with specific biological and social transition difficulties for adolescent girls as compared to boys (Cyranski, Frank, Young & Shear, 2006). As compared to hearing peers, deaf girls might be even more vulnerable to the social challenges due to communication problems within a hearing world.

Another distinct contribution of this study is our findings on the relationship between clinical ratings of caseness and disorder on the one hand and a large number of demographic, deafness-related, medical and audiological variables on the other. Multiple logistic regression revealed three factors to be significantly

associated with psychopathology: Lower IQ, a signing mode of communication and three or more physical disorders in the past were associated with dossier rating of caseness. A history of physical disorders was the only variable associated with emotional disorder. This is in line with the replicated finding that factors interfering with physical health are risk factors of emotional dysregulation and psychopathology in hearing children (see Friedman & Chase-Lansdale, 2002). Likewise, low IQ is a known risk factor with both hearing (e.g., Friedman et al, 2002) and deaf children (e.g., Van Eldik et al., 2004; van Eldik, 2005). The association between communication mode and psychopathology is less clear. Only behavioral disorders were found more often among signing adolescents as well as adolescents in special school, while emotional disorders were more equally distributed among these subgroups. It could be hypothesized that pupils with more externalizing, disturbing behavior are more likely to be referred to special schools, where signing is the dominant communication mode between deaf pupils. Simultaneously, deaf pupils with non-disturbing behavior and conforming coping strategies might adapt more successfully in mainstreaming, as has been suggested by Lynas (1985). Summarizing, the correlational findings in this study support the view that it is not deafness per se that contributes to psychiatric problems (Hindley & Van Gent, 2002), but that additional factors, such as communication problems, physical health problems, adverse living conditions and other factors may increase the risk of psychiatric disorders in this population.

Limitations

The limitations of this study include small sample size, 26% refusal rate and a relatively high rate of oral communication. However, in view of the characteristics of the non-responders (e.g., lower IQ) and the lower prevalence of caseness among orally communicating adolescents, it seems unlikely that the prevalence of psychopathology is overestimated. Another limitation concerns the restriction to deaf adolescents of average intelligence. Finally, it must be noted that in twelve cases both the SCICA and the dossier rating were scored by the same psychiatrist (TvG). The effect of this is likely to be limited due to the considerable lapse of time between the SCICA scoring and dossier rating, and the fact that the dossier rating was based on consensus between two psychiatrists.

Implications

Our results indicate a high prevalence of psychopathology, especially emotional disorders. In addition, we found that only 3 of 32 adolescents with DSM disorders had had contact with a specialist mental health service before the time of study.

These findings illustrate the need to identify children and adolescents at risk for psychopathology more effectively and preferably in an early stage. One of the targets for the future development of mental health care for deaf children and young people should be the organization of cooperation between institutions for deaf children, existing local specialist mental health services and specialist mental health services for deaf and hard of hearing children and adolescents to promote early and adequate help seeking and referral.

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Chapter 4

Self-concept and Psychopathology in Deaf Adolescents: preliminary support for moderating effects of deafness- related characteristics and peer problems

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Abstract

Background: High rates of psychopathology were found amongst deaf adolescents, but little is known about the psychosocial risk factors. This study investigated whether (1) less severe deafness and/or acquired or otherwise complicated deafness, and (2) having mainly contacts with hearing people, each represent chronic stressful conditions that moderate the associations between self-esteem and emotional problems. In addition the moderating effect of observed peer rejection on the association between social acceptance and behavioural problems was explored. **Method:** Deaf adolescents of normal intelligence (N=68) completed the Self Perception Profile for Adolescents. Psychopathology was assessed using a semi-structured interview with adolescents and reports by parents, teachers and expert ratings. Data on moderator variables were collected from school records, parental and teachers' reports. **Results:** Emotional mental health problems were negatively associated with self-esteem and positively with peer rejection. The association between self-esteem and emotional problems was moderated by the deafness variable less severe deafness or acquired or otherwise complicated deafness. Behavioural mental health problems were positively associated with social acceptance and peer rejection but negatively with the amount of involvement with hearing people. Peer rejection moderated the association between social acceptance and behavioural problems. **Conclusions:** The findings emphasize the importance of considering self-concept dimensions, peer problems and deafness- and context-related characteristics when assessing and treating deaf adolescents. **Key words:** self-esteem, stress, mental health, hearing loss, adolescence

Introduction

Rates of emotional and behavioural disorders are higher in deaf children and adolescents than in hearing peers (Hindley, Hill, McGuigan & Kitson, 1994; Van Gent, Goedhart, Hindley & Treffers, 2007). Research findings suggest that not deafness as such, but other risk factors contribute to psychopathology in deaf adolescents (Van Gent et al, 2007). First of all, central nervous system disorders and other physical health problems have repeatedly been associated with psychopathology among deaf populations (e.g., Sinkkonen, 1994; Van Gent et al., 2007), as well as in general populations (e.g., Wallander, Varni, Babani & Wilcox, 1988). Secondly, previous research has identified chronic stressors that are unique to deaf people, i.e. characteristics of deafness such as the degree, cause and age of onset, and factors related to environmental context such as parental hearing status and the type of school attended (e.g., Dammeyer, 2009; Hindley et al., 1994; Polat, 2003). However the results of this research are inconsistent. For example, an association between mental health problems and communication mode was found in some studies (Vostanis, Hayes, Du Feu & Warren, 1997; Van Gent et al., 2007) but not in others (Hindley et al., 1994; Polat, 2003). Such inconsistencies may be due to differences in sample composition, methods or informants (e.g., Dammeyer, 2009; Van Gent et al., 2007), or may indicate the impact of other possible significant factors (Polat, 2003). Following the suggestion of Polat and in accordance with self-esteem vulnerability models (e.g., Hammen, 2005), we examined the association between self-esteem, unique stress factors and psychopathology among deaf adolescents.

Self-esteem, chronic stress and emotional mental health problems

A substantial body of evidence from studies with general, i.e. hearing, populations indicates that low self-esteem is related to emotional mental health problems (Baumeister, Campbell, Krueger & Vohs, 2003; Harter, 2006). In addition, evidence from longitudinal studies suggests that low self-esteem in adolescence is an independent predictor of depression (Orth, Robins, & Roberts, 2008) and anxiety (Trzesniewski et al., 2006). Two studies found negative associations

between self-esteem and total mental health problems (Mejstad, Heiling & Svedin, 2009) or unspecified psychiatric caseness (Hindley et al., 1994) in samples of hearing-impaired youth. To the best of our knowledge, no studies have examined associations between self-esteem and emotional or behavioural mental health problems among deaf adolescents in greater detail. Studies in samples of children and adolescents with other physical handicaps have documented small to moderate negative associations between self-esteem and emotional (e.g., Dahlbeck and Lightsey, 2008; Bilboul, Pope & Snyder, 2006) or emotional and behavioural problems (Hoare & Mann, 1994).

According to the buffer hypothesis (see Baumeister et al., 2003), low self-esteem might contribute to emotional problems because individuals with low self-esteem lack the coping resources that buffer the deleterious consequences of chronic or acute stressors whereas individuals with higher self-esteem are assumed to have better coping resources. For instance, social comparison research has found that persons with low self-esteem are less capable of making effective use of self-protection strategies to reduce the threat of unfavorable but unavoidable social comparisons, like ignoring the presumed superiority of the comparison standard, or lowering its importance or relevance (e.g., Mussweiler et al., 2000). In addition, low self-esteem has been associated with a reduced ability to abandon an unattainable goal or standard by substituting it with positive affirmations on another aspect of self, making it harder to disengage from unconstructive repetitive thoughts about negative self-discrepancies (Watkins, 2008). Self-regulation theory states that maladaptive perseveration on irreducible negative self-discrepancies due to chronic conditions implicating a threat, a loss, a failure or interpersonal difficulties is associated with emotional problems and disorder (Pyszczynski & Greenberg, 1987).

Based on this theory, it may be hypothesized that adoption of hearing-related standards by deaf adolescents will elicit recurrent maladaptive perseveration on irreducible negative self-discrepancies between having restricted hearing or feeling handicapped otherwise as one's actual state, and being hearing or healthy as one's desired but unattainable standard. Consequently, specific deafness-related and contextual variables that contribute to the salience of hearing-related standards,

will induce chronic stress. As deaf adolescents with high self-esteem are assumed to have better coping resources than those with low self-esteem, we expected that the association between self-esteem and emotional problems would be especially strong where these stress-inducing variables are present, i.e. these variables would moderate the relationship between self-esteem and emotional problems.

Firstly, in line with the suggestion that the profitable use of residual hearing makes it more difficult to accept deafness (Polat, 2003), the deafness characteristics, a lesser degree of deafness or having a cochlear implant (CI) may contribute to the salience of health-related standards. This may be illustrated by the finding that deaf students with more hearing residuals hide their deafness, i.e. by pretending to understand everything when interacting with hearing people (Jambor et al., 2005). Secondly, neurological disorders and other physical disorders which co-occur much more often with acquired and syndromal deafness than with uncomplicated deafness of genetic origin, may provoke a deaf child to perceive himself as handicapped in a primarily hearing and healthy world. Moreover, acquired deafness may contribute to the perception of being handicapped, especially when this perception is reinforced by hearing parents and other family members. Thirdly, the environmental context of having contacts mainly with hearing significant others, as indicated by living with hearing parents, and attending a mainstream school, may contribute to the salience of hearing-related standards. This is supported by findings that a greater amount of contacts with hearing people is associated with less identification with the Deaf community (Jambor et al., 2005) and a more hearing oriented acculturation style (Hintermair, 2008).

Self-concept, peer rejection and behavioural mental health problems

Harter (2006) proposed that behavioural problems are associated with low self-esteem because negative self-evaluation, humiliating rejection and negative affect are associated with both. In support of this 'low self-esteem' hypothesis a small to moderate correlation between low self-esteem and behavioural problems has been found in the majority of the studies reviewed by Walker and Bright (2009). Baumeister, Smart and Boden (1996), however, proposed that behavioural

problems are associated with highly favourable views of the self that are threatened or disputed by others. In support of the 'disputed self' hypothesis, studies among children and adolescents have found strong associations between behavioural problems and overestimation of self-perceived social acceptance, i.e. exaggerated self-appraisal of social acceptance relative to the appraisals by others (eg., David & Kistner, 2000,). The association between overestimation of social acceptance and behavioural problems appeared to be particularly strong in children or adolescents who were rejected by others (Diamantopoulou, Rydell, & Henricsson, 2008).

This study

The present study examined associations of self-esteem and self-perceived social acceptance with emotional and behavioural problems and disorders in a representative sample of deaf adolescents of normal intelligence (i.e. $IQ > 80$). In line with the results of studies in hearing samples, we expected to find negative associations of self-esteem with measures of emotional problems.

Furthermore, this study examined the associations of emotional problems with the deafness characteristics lesser degree of deafness and acquired or otherwise complicated deafness, and with the contextual variable routine contact with hearing people, and the associations of emotional and behavioural problems with peer rejection. We expected to find positive associations.

Most importantly, this study examined whether both the deafness characteristics and the contextual variable moderate the associations between self-esteem and emotional mental health problems, and whether peer rejection moderates the associations between social acceptance and behavioural problems.

Method

Participants

Participants of the study were recruited from a year cohort of the total secondary school population ($N = 94$) of one of the three large organizations in the Netherlands offering education in special school settings and residential facilities as well as educational counselling for deaf children and adolescents in mainstream schools. Details of the sampling and data collection procedure and the non-response

analysis are described by Van Gent et al. (2007). We obtained informed consent from 70 (74%) of the 94 students and their parents. Because of missing measures (due to scheduling problems) 2 of the 70 participants were excluded. We obtained permission from 18 of the 24 non-responders and their parents to use their school records for non-response analysis. The non-responders were significantly older, showed a lower mean IQ and were more likely to have psychosocial stressors (e.g., family conflicts, penal violation, sexual abuse). Table 1 shows descriptive statistics of the demographic, deafness and physical disorder variables.

Measures

Self-Perception Profile for Adolescents. Self-esteem and self-perceived social acceptance were operationalized by means of the Global Self-worth (GSW) and Social Acceptance (SA) subscales of the Dutch version of Harter's Self-Perception Profile for Adolescents (SPPA; Harter, 1988; Treffers et al., 2002). Treffers et al. (2002) reported Cronbach's α of .76 for both scales and 3-5 week test-retest correlations of .72 (GS-w) and .67 (SA). A team of deaf and hearing professionals, all fluently signing and experienced in working with deaf adolescents, adapted the instrument by minimizing metaphoric language and difficult words. In the present sample, the internal consistencies were .73 (GSW) and .72 (SA).

Emotional and behavioural problems. The internalizing and externalizing problem scales of the Dutch versions of the well-known Child Behaviour Checklist (CBCL; Achenbach, 1991a; Verhulst, Van der Ende & Koot, 1997a) and Teacher's Report Form (TRF; Achenbach, 1991b; Verhulst, Van der Ende & Koot, 1997b) were used to assess emotional and behavioural problems as reported by parents and teachers respectively. The subscale of Aggressive Behaviour in the Dutch version of the Semi-structured Clinical Interview for Children and Adolescents (SCICA; McConaughy & Achenbach, 1994; Kasius, 1997) was used as a self-report measure of behavioural problems; the sum of the standardized scores on the SCICA-subscale Anxious and Lonely was used as self-report measure of emotional problems. All instruments were adapted for use with deaf adolescents, and good inter-rater agreement was reported, as described by van Gent et al. (2007).

Table 1.
Demographic, deafness and physical disorder variables

Characteristics	N	%	Variables	N	%
<i>Gender</i>			<i>Degree of deafness^{a,b}</i>		
Male	31	46	Severe: 73-95 dB	13	20
Female	37	54	Profound: ≥ 96 dB	52	80
<i>Age</i>			<i>Cochlear Implant (CI):</i>		
Mean 16.5 yrs; s.d. 1.8; range 13-21 yr			Without CI	65	96
<i>Ethnicity</i>			With CI	3	4
Dutch	50	73	<i>Cause of deafness</i>		
Other ^c	18	26	Hereditary, non-syndromal	19	28
<i>Highest educational level parents</i>			Hereditary, syndromal	5	7
Low	21	31	Acquired, pre-, peri- or postnatal	22	32
Medium	18	26	Unknown	22	32
High	21	31	<i>Primary communication mode</i>		
Unknown	8	12	Spoken language	36	53
<i>Family with:</i>			Signing	32	47
Two biological parents	49	72	<i>Type of school</i>		
Other	19	28	Special school for the deaf	50	74
<i>Parental hearing status</i>			Ordinary school	18	26
Hearing impaired parents	3	4	<i>History of 3 or more physical disorders^{a,c}</i>		
Hearing parent(s)	65	96	0-2 different disorders	40	60
<i>Place of residence</i>			3 or more different disorders	27	40
Residential setting	26	38	<i>History of neurological disorders^d</i>		
Parental home	42	62	None	44	65
			One or more	24	35

Note: ^a Missing data with 1-3 cases. ^b Deafness is quantified as the unaided average hearing impairment for the better ear. ^c Cases for which specialist medical care had been provided in the past. ^d Cases with nervous system disorders for which specialist medical care had been provided in the past. ^e The group "Other ethnicity" is very heterogeneous, the highest frequency was found for Moroccan parents (6), followed by Turkish (2) and Surinam (2) parents.

Psychiatric disorder. The procedure to determine the dossier DSM-IV diagnoses using (1) semi-structured interviews with parents and adolescents about the psychological impact of deafness, (2) CBCL, TRF, and SCICA questionnaires without scale scores and (3) school records (demographic, deafness-related, medical and audiological data and IQ), is presented in detail by Van Gent et al. (2007). All primary and concomitant DSM-IV diagnoses with the participants were grouped into (1) emotional disorders, including anxiety and mood disorders, (2) behavioural disorders, including attention-deficit, oppositional defiant disorder and disruptive behaviour disorders, and (3) other disorders (e.g., psychosis, somatoform disorder, and pain disorder).

Peer Rejection (PR). A measure of peer rejection was created by combining the CBCL- and TRF-items 25 ('Not get along'), 34 ('Feels persecuted'), 38 ('Teased') and 48 ('Not liked') of the Social Problems scale (these items are not used in the externalizing or internalizing scales). We imputed CBCL scores if TRF was missing (N=2) and TRF scores if CBCL was missing (N=12). Coefficient alpha of the PR, computed on cases without missing values, was 0.85.

Contacts with Hearing People (CHP) This indicator for daily interaction with meaningful hearing others (parents, peers, teachers; e.g., Harter, 2006) was created by combining place of residence and type of school: 0= living in a residential setting for deaf children and adolescents and attending a special school for the deaf (n=26); 1= living at home with hearing parent(s) and attending a special school for the deaf (n=24); 2= living with hearing parent(s) and attending an ordinary school (n=18).

Stress Inducing Deafness Characteristics (SID). This indicator was created by combining less severe deafness or having a CI and acquired or syndromal deafness, i.e. deafness characteristics that may contribute to the salience of hearing self-standards. Less severe deafness indicating the profitable use of hearing residuals was defined as severe deafness (70-95dB hearing loss, as opposed to profound deafness of more than 95dB loss), or having a CI. In addition to acquired or syndromal deafness, both indicating otherwise complicated deafness, the combination of unknown cause of deafness and present or past neurological disorder was used, as (past) neurological disorder was present in most adolescents

with acquired (64%) or syndromal hereditary deafness (60%) and in a minority (16%) of adolescents with non-syndromal hereditary deafness: χ^2 (2df)= 10.12, $p < 0.01$. We defined SID as: 1 (high)= severe deafness *or* with CI *and/or* acquired deafness *or* syndromal hereditary deafness *or* unknown cause of deafness with [past] neurological disorder (n=40); 0 (low)= remaining cases (n=28).

IQ. : In line with contemporary practice in testing the intelligence of deaf adolescents in The Netherlands, Wechsler performance scales were used.

Procedures

Participants were administered the SPPA individually following the SCICA interview. At the start of each individual assessment session, the participants were consulted to determine their preferred mode of communication with the interviewer, i.e. signing or spoken language, and to decide on the assistance of a sign-language interpreter during the session. Parents were asked to complete the CBCL at home. Due to practical reasons 12 parental couples did not complete the CBCL. TRF's were gathered for 66 of the participating adolescents.

Statistical Methods

Bivariate Spearman correlations were calculated to analyse univariate associations between the measures of mental health problems and the remaining study variables. In examining moderator effects, we used the three conditions for moderators proposed by Kraemer, Stice, Kazdin, Offord and Kupfer (2001), where A moderates B if (1) A precedes B, (2) A and B are not correlated, and (3) A and B co-dominate in the prediction of the dependent variable. Spearman correlations were used to examine the second condition. The third moderator condition was examined by testing improvement in the prediction of the dependent variable after entering the interaction term A*B as second step in hierarchical regression analysis. In the first step of the hierarchical regression analyses we entered the focal predictor (i.e. Global Self-worth or Social Acceptance), the potential moderator variable(s) and control variables (i.e. study variables that showed a significant correlation with one of the measures of emotional or behavioural problems respectively). The improvement in the prediction of the dependent variable after entering one of

the interaction terms was tested using the $\Delta\chi^2$ -test with logistic regression and the F-test for the significance of ΔR^2 with multiple regression. Global Self-worth, Social Acceptance and Peer Rejection were standardized prior to the regression analyses.

Results

Univariate analyses.

Spearman correlations showed the expected negative correlations between Global Self-worth and the measures of emotional problems except TRF internalizing (see Table 2). Social Acceptance was not associated with any measure of emotional problems but showed positive correlations with the DSM diagnosis behavioural disorder and TRF externalizing. It may be noted that Global Self-worth and Social Acceptance were not associated.

Stress Inducing Deafness Characteristics and Contacts with Hearing People were not associated with Global Self-worth, and Peer Rejection was not associated with Social Acceptance, i.e. these measures fulfilled the second moderator condition proposed by Kraemer et al. (2002). From the variables presented in Table 1, only gender, IQ and history of three or more physical disorders showed correlations with measures of emotional or behavioural problems. Stress Inducing Deafness Characteristics, Contacts with Hearing People and Peer Rejection were added to the control variables in the prediction of behavioural and emotional problems respectively, as they showed significant associations with these measures (see Table 2).

Predicting emotional problems.

The results of moderated logistic and multiple regression analyses with measures of emotional problems as dependent variables are presented in Table 3. Contrary to our hypothesis, the interaction between Global Self-worth and Contacts with Hearing People did not improve the prediction of any measure of emotional problems. The interaction term Global Self-worth x Stress Inducing Deafness Characteristics was significant in the prediction of emotional disorder and the combined anxious/lonely scale of the SCICA. We probed the nature of the

Table 2.

Means and standard deviations or percentage of cases in the specified category and bivariate Spearman correlations of study variables.

Study variables	Mean (SD)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Gender (%female)	54%	---														
2. Performance IQ	109.9 (13.0)	-.15	---													
3. History of 3(+) phys.dis. ¹ (% present)	40%	.09	-.12	---												
4. SID ²	59% ²	.01	-.07	.08	---											
5. CHP ³	38/36/26% ³	.24*	.24*	-.20	.07	---										
6. PR ⁴	2.3 (3.1)	-.07	-.06	.19	.03	-.18	---									
7. Global Self-worth	14.5 (3.3)	-.22	.23	-.03	.02	.03	-.09	---								
8. Social Acceptance	13.6 (3.1)	.09	-.21	.07	-.17	-.28*	-.17	.08	---							
9. DSM Emotional Disorder ^a (% present)	26%	.22	-.09	.39**	.03	-.07	.33*	-.34**	-.21	---						
10. CBCL Internalizing (n=56) T-scores	55.2 (14.4)	.05	-.21	.12	.10	-.29*	.67**	-.29*	-.14	.41**	---					
11. TRF Internalizing (n=66) T-scores	55.4 (13.9)	.07	-.13	.15	-.28*	-.18	.55**	.02	.07	.09	.34*	---				
12. SCICA Anx./Lonely ⁵ (sum z-scores)	0.0 (1.8)	.41**	-.12	.10	-.12	.08	.23	-.28*	-.23	.63**	.33*	.18	---			
13. DSM Behavioural Disorder ^a (% present)	15%	-.12	-.29*	-.01	-.16	-.30*	.40**	-.05	.41**	-.06	.42**	.42**	-.19	---		
14. CBCL Externalizing (n=56) T-scores	51.9 (13.1)	-.03	-.21	.01	.10	-.28*	.38**	-.22	.14	.19	.61**	.02	.00	.47**	---	
15. TRF Externalizing (n=66) T-scores	54.0 (14.0)	.03	-.45**	.15	-.26*	-.48**	.21	-.10	.38**	.09	.32*	.44**	-.02	.55**	.45**	---
16. SCICA Aggression	4.2 (4.2)	-.01	-.26*	.21	.08	-.32**	.25*	-.12	.15	.01	.21	.09	.03	.39**	.27*	.40**

Notes. ¹ History of 3(+) phys. dys.= History of 3 or more physical disorders; ² SID= Stress Inducing Deafness Characteristics: % cases with severe deafness or CI and/or acquired deafness or syndromal hereditary deafness or (past) neurological disorder present in cases of unknown cause of deafness; ³ CHP=Contacts with Hearing People: % low, medium and high; ⁴ PR = Peer Rejection; ⁵ SCICA Anx./Lonely= SCICA Anxious and Lonely. ^a: Including 2 cases with both emotional and behavioural disorder. *: p<0.05; **: p<0.01.

interaction effects by estimating the conditional effect of Global Self-worth at the two values of Stress Inducing Deafness Characteristics (Hayes & Matthes, 2009). Global Self-worth was not associated with emotional problems in the absence of Stress Inducing Deafness Characteristics. In the presence of Stress Inducing Deafness Characteristics, lower scores on Global Self-worth were associated with a significantly higher risk of emotional disorder: OR=0.11 ($p < 0.005$; 95%CI 0.02-0.50), and with higher scores on the combined anxious and lonely scales of the SCICA: $b = -0.70$, $se = .24$, $p < 0.005$.

We further explored this result by computing Spearman correlations of Global Self-worth with emotional disorder and the combined SCICA anxious/lonely scale for the presence and absence of each component of Stress Inducing Deafness Characteristics separately. Strong negative correlations ($r < -0.50$) were found in the presence of (1) severe deafness *or* with CI, (2) acquired deafness *or* syndromal hereditary deafness and (3) (past) neurological disorder. No significant correlations were found in the absence of each component. These findings indicated that each component modifies the associations of Global Self-worth with emotional disorder and self-reported emotional problems.

Predicting behavioural mental health problems.

Table 4 presents the results of the moderated regressions on behavioural mental health problems. In support of our hypotheses, the interaction term Social Acceptance x Peer Rejection was significant in the prediction of all measures of behavioural problems except SCICA aggression.

The nature of each Social Acceptance x Peer Rejection interaction effect was probed using the Johnson–Neyman technique (Hayes & Matthes, 2009). This technique identifies regions of Peer Rejection where the association between Social Acceptance and measures of behavioural mental health problems is statistically significant and non significant, respectively. For behavioural disorder, non-significant associations with Social Acceptance were found up to Peer Rejection = 1.6 (i.e. < 2), while significant associations were found at all higher levels for Peer Rejection. For CBCL and TRF externalizing, non-significant associations with Social Acceptance were found for Peer Rejection < 5 and < 2 respectively, while

Table 3.
Hierarchical moderated regressions on measures of emotional problems.

	DSM-diagnosis Emotional Disorder		SCICA Anxious/ Lonely		CBCL Internalizing		TRF Internalizing	
	OR (95% CI)	$\Delta\chi^2(df) / \text{Nagelk. } R^2_a$	β	ΔR^2	β	ΔR^2	β	ΔR^2
<i>Step 1</i>		27.95 (1)*** / .50		.31**		.35**		.45***
Gender	2.49 (0.51 – 12.05)		0.30*	-0.03	-0.03		0.15	
History of 3 or more physical disorders	10.48** (2.13 – 51.57)		0.09	0.03	0.03		0.03	
PR ¹	2.49* (1.20 – 5.16)		0.31**	0.50***	0.53***			
Global Self-worth	0.37* (0.17 – 0.82)		-0.20	-0.16	0.10			
SID ²	1.09 (0.26 – 4.55)		-0.14	0.05	-0.33**			
CHP ³	0.96 (0.33 – 2.82)		-0.09	-0.13	-0.13			
<i>Step 2a</i>		8.85(1)** / .61		.06*		.00		.00
Global Self-worth x SID ²	0.07** (0.01 – 0.48)		-0.44*	-0.03	-0.07			
<i>Step 2b</i>		1.03 (1) / .51		.02	.02		.02	
Global Self-worth x CHP ³	0.61 (0.23 – 1.66)		-0.23	0.23	0.22			

Note: ^a Nagelk. R²; ¹ PR = Peer Rejection; ² SID=Stress Inducing Deafness Characteristics; ³ CHP=Contacts with Hearing People.

*; p<0.05; **, p<0.01; ***, p<0.001; Global Self-worth and Peer Rejection are standardized.

significant positive associations were found at all higher levels. These findings indicate that positively biased Social Acceptance, i.e. the combination of high levels of Social Acceptance and peer rejection and humiliation according to parent and teacher reports is associated with behavioural problems in deaf adolescents .

Table 4.

Hierarchical moderated regressions on measures of behavioural problems.

	DSM-diagnosis Behavioural Disorder	SCICA Aggression		CBCL Externalizing		TRF Externalizing		
		OR (95% CI)	$\Delta\chi^2(df) /$ Nagelk. R ^{2 a}	β	ΔR^2	β	ΔR^2	β
<i>Step 1</i>								
		31.99(5)***/.66	.21*	.30**		.47***		
Perfomal IQ	0.92 (0.84–1.02)		-0.19	-0.05		-0.28**		
CHP ¹	0.42 (0.05–3.73)		-0.16	-0.17		-0.02		
SID ²	0.29 (0.03–2.70)		.13	-.10		-.27**		
Social Acceptance	10.77**(1.82–63.68)		0.22	0.20		0.34**		
PR ³	5.83**(1.63–20.91)		0.16	0.42**		0.43***		
<i>Step 2</i>								
		7.21(1)**/.77	.01	.06*		.08**		
Social Acceptance x PR ³	15.82 [†] (0.98–279.79)		0.10	0.28*		0.30**		

Note: ^a Nagelk. R²: Nagelkerke R²; ¹ CHP=Contacts with Hearing People; ² SID=Stress Inducing Deafness Characteristics; ³ PR = Peer Rejection.

[†]: p<0.10; *: p<0.05; **: p<0.01; ***: p<0.001; Social Acceptance and Peer Rejection are standardized.

Discussion

Some major findings emerge from this study. Similar to previous studies in samples of hearing adolescents (e.g., Harter, 2006), moderate negative correlations were found between Global Self-worth and DSM-IV emotional disorder and the combined SCICA anxious and lonely scales. Stress inducing deafness characteristics were shown to moderate these correlations. Specifically: Global

Self-worth appeared to be a risk factor for an emotional disorder in adolescents with severe deafness or acquired or syndromal deafness or (a history of) one or more neurological disorders, but not in profoundly deaf adolescents with an uncomplicated genetic cause of deafness and no (history of) neurological disorder. Peer Rejection moderated the positive associations of Social Acceptance with behavioural disorder and the CBCL and TRF externalizing scales.

The finding that the *combination* of low self-esteem and Stress Inducing Deafness Characteristics is associated with a high risk of emotional disorder, extends the view that being deaf does not in itself contribute to psychopathology (Van Gent et al, 2007). The stress inducing deafness characteristics identified in this study may contribute to unconstructive repetitive thought on negative discrepancies with hearing and healthy people in several ways. Firstly, adolescents with CI or lesser severe deafness may be challenged more intensively to adapt to communicative and cultural values in the hearing oriented world, and perceive their limited capacities in spoken language as an “incorrigible” personal shortcoming. Secondly, deaf adolescents with acquired deafness usually grow up in a hearing family unfamiliar with deafness, and, like deaf children with a syndromal cause of deafness or a history of neurological disorder, they often have to cope with additional physical handicap or illness and its interpersonal consequences. Thirdly, deaf adolescents with a history of neurological disorder are at risk of experiencing disabilities in motor function, coordination, cognition or executive functioning, all of which may affect visual communication and social interaction. Moreover, the invisible and hidden character of many of such minor disabilities may contribute to significant interactional misunderstandings, emotional insecurity, and negative self-evaluations (Miyahara & Piek, 2006).

Contrary to our expectations, the amount of contact with significant hearing people did not affect the association between Global Self-worth and measures of emotional problems. This may suggest that even deaf adolescents with low self-esteem have the capacity to protect the self from threatening social comparisons and unattainable hearing-related standards. This hypothesis may be supported by the finding that a higher level of contacts with hearing people was associated with lower Social Acceptance but not with lower Global Self-worth, which might

indicate a discounting of social acceptance in hearing contexts, i.e. degrading the importance of the social domain with higher levels of contacts with hearing people.

The finding that Peer Rejection moderated the positive associations of Social Acceptance with behavioural disorder and the CBCL and TRF externalizing scales, adds to the evidence of a link between positively biased self-perceptions and aggression. As suggested by Diamantopoulou et al. (2008), this connection may be explained by poor social information processing that is shown in positively biased self-perceptions and is characteristic of aggressive youth. Deaf children may be at a greater risk of misinterpreting important social information such as nuances in behaviour or beliefs, which is normally learned through passive exposure to events witnessed or overheard in the process of incidental learning (Calderon et al., 2003).

A strength of this study is the use of multiple informants of problems and the expert diagnosis of psychiatric disorder integrating reports from these informants plus additional information. Use of multiple informants provides information on contextual aspects of disorder and informer related perspectives. Clinical expert ratings synthesizing multi-source information is probably the most reliable estimate of disorder in deaf adolescents, while adolescents and teachers may be the most reliable single informants of emotional and behavioural problems respectively (van Gent et al., 2007). The majority of hearing parents and teachers may have problems in recognizing emotions of deaf children and discussing these with them. As a result they may be less capable of judging their self-esteem.

There are some limitations that must be considered. Firstly, as there are no Dutch multidimensional self-concept measures specifically developed for using with deaf children and adolescents, existing instruments were adapted for this specific population. However, the possible matter of limited understanding of the language used in the self-report questionnaires was addressed by encouraging the participants to seek assistance in their preferred mode of communication. Secondly, due to the small sample size, the analysis of this study should be replicated before firm conclusions can be drawn. Thirdly, the cross-sectional nature of this study does not allow for strong causal conclusions. Longitudinal studies with larger

samples are needed to further examine relations between protective intrapersonal characteristics, such as self-concept and socio-cognitive maturity, and stress-inducing conditions like restricted language abilities irrespective of modality (e.g., Dammeyer, 2009) with mental health problems within deaf populations.

The findings from this study increase our knowledge of specific intrapersonal and environmental factors that might be a significant focus for preventive and therapeutic strategies with deaf children and adolescents. For instance, the moderating effects found in this study indicate that low self-esteem is only a risk factor for emotional problems among deaf adolescents when combined with specific deafness- and physical illness related attributes.

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Key Points

- Previous research in deaf adolescents has found increased rates of psychopathology, but effects of self-concept, deafness- and context- related factors on emotional and behavioural disorders are unknown.
- The present study indicates that (1) self-esteem buffers the negative influence of a lesser degree of deafness, acquired or syndromal deafness and (past) neurological disorders on the vulnerability for emotional disorders, (2) peer rejection moderates the positive associations of self-perceived social acceptance with behavioural disorder, and (3) the amount of contact with hearing people does not have a comparable moderator effect.
- These findings emphasise the importance of considering self-concept dimensions and factors related to degree and cause of deafness and physical disorder when assessing and treating deaf adolescents.

Chapter 5

Self-concept and ego development in deaf adolescents: A comparative study

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Abstract

Self-concept and ego development, two intertwined aspects of self indicating well-being and social-cognitive maturation respectively, were examined in a representative sample of deaf adolescents of normal intelligence (N=68), using translated and adapted versions of Harter's (1988) multidimensional measure of self-concept and Loevinger's (1998) measure of ego development. Compared to hearing norm groups, deaf adolescents showed lower levels of self-perceived social acceptance, close friendships and ego development and higher physical appearance.

Hierarchical multiple regression analyses controlling for socio-demographic variables showed positive associations of global self-worth with support for signing during childhood and quality of parent-child communication and of ego development with attending a regular school. Cluster analysis identified three social competence profiles: uniformly low competence, uniformly high competence, and low social acceptance with high physical appearance. Cluster membership was associated with school type, ego development, and (past) neurological disorder.

The results are discussed in reference to interventions aimed at the well-being of deaf youth.

Introduction

There is considerable interest in the self-concept of deaf children and adolescents (e.g., Bat-Chava, 1993; Obrzut, Maddock & Lee, 1999; Kluwin, Stinson & Colarossi, 2002; Hintermair, 2008). Positive self-concept is associated with higher levels of positive adjustment and lower levels of psychosocial problems, especially internalizing problems (e.g., Crocker, & Wolfe, 2001; Harter, 1999; Owens, Stryker, & Goodman, 2001). The majority of the work in this field has focussed on the unique challenges that deaf youth face in developing a positive self-concept amid the demands of communicative challenges and the minority status in the predominantly hearing environment. About 90-95% of deaf children are born into hearing families and most deaf children are educated by hearing teachers (e.g., see Hindley & van Gent, 2002). Communication problems may originate from a number of - at least partly related - sources. Deaf children are more dependent on vision and visual orientation than hearing peers, and they are more likely to miss or to misunderstand parts of information (Marschark & Hauser, 2008). In general, the ability of deaf children to learn spoken language remains limited despite the development of advanced amplification devices (Marschark, 2007). Moreover, most hearing individuals use more restricted communication discourse patterns with deaf children than deaf-to-deaf individuals do (Hauser, Lukomski, & Hillman, 2008). As a result of such circumstances, deaf children are at risk of suffering from less diversity in early experience (Marschark, 2007), less incidental learning (Calderon & Greenberg, 2003), and less exposure to a variety of cause-effect relationships (Marschark et al., 2008) than their hearing peers. The lasting communicative deprivation, misunderstandings and sometimes even isolation, may be particularly troublesome during adolescence when belonging to a social network and intimate attachments with parents and peers are especially important for the development of a sense of competence and for identity or ego development (Calderon & Greenberg, 2003; Schlesinger, 2000; Traci & Koester, 2003).

Self-concept and identity or ego development reflect the two intertwined aspects of self that were distinguished by William James in 1890: self as object

of one's knowledge and evaluation (Me-self) and self as actor or knower (I-self). The concept of Me-self underlies models of self-concept capable of being tested empirically; the concept of I-self underlies models of mental processes that characterize the social-cognitive structures of the knower, such as Loevinger's model of ego development (McAdams, 1998). To the best of our knowledge, no attention has been given to ego development in deaf adolescents to date. The primary aim of this study is to investigate the effects of social context and deafness-related variables on both aspects of the self in deaf adolescents.

The Me-self

Traditionally the Me-self has been studied from a one-dimensional perspective, emphasizing self-esteem or global self-worth (these labels are interchangeably used throughout the text) as an accurate, overarching evaluation of one's self in the various facets of life. But since 1980 there is a growing interest in the multi-dimensionality of the self-concept (Byrne, 1996; Butler & Gasson, 2005), referring to the construct of multiple, relatively distinct domain-specific self-concepts or self-perceived competencies related to significant aspects of life, and a separate facet of global self-worth that refers to how much one likes oneself as a person (e.g., Byrne, 1996; Harter, 1998).

Harter (2006) cites considerable literature revealing that it is one of the critical developmental tasks in adolescence to construct a proliferation of context-specific selves which emerge under the influence of cognitive-developmental advances and socialization pressures. These selves vary across social roles and relationships and include selves developed through contact with meaningful adults, primarily the parents but also others such as teachers, and selves developed through contact with male and female peers. Evidence suggests that support especially from peers in the public domain, such as classmates, is predictive of global self-worth, i.e. far more predictive than support from close friends. According to Harter (1999) the former better represents approval from a more objective, generalized Other than the approval from close friends, which is more subjective. Harter, Marold and Whitesell (1992) have revealed the existence of two clusters of self-perceived competence and support that impact global self-worth. One cluster which

comprises self-perceived physical appearance and social acceptance in particular but also athletic competence is more strongly related to peer support than to parental support. The other comprises scholastic competence and behavioural conduct and is more strongly related to parental approval. Perceived inadequacies in both the peer-salient and the parent-salient cluster have been found to be particularly powerful predictors of low global self-worth, negative affect and depressive reactions (Harter & Whitesell, 1996).

Like adolescents of other minority groups, deaf young people are confronted with the challenge of coping with multiple worlds and of moving between multiple socio-cultural contexts (e.g., see Harter, 2006). In addition, communication problems may hinder them in developing a firm social network outside their family, which is regarded as one of the key resources for support and coping with stress for deaf adolescents (Calderon & Greenberg, 2003). Consequently one would expect that the development of a sense of competence in the peer-salient social domains which may affect global self-worth is particularly complicated for deaf adolescents in the process of individuation.

However, findings from research comparing self-concept in deaf children and hearing peers are ambiguous. Some studies reported lower levels of self-esteem in hearing-impaired children and young people than in their hearing peers (Loeb & Sarigiani, 1986; Tambs, 2004; Weisel & Kamara, 2005), but other studies did not (Koelle & Convey, 1982; Cates, 1991; Kluwin, 1999). The divergent results may reflect differences between samples of deaf children with regard to deafness and context related factors that are associated with self-esteem. These associations have been the subject of much research.

Associations between contextual or deafness-related variables and self-concept.

To date, most studies on self-concept among deaf children and adolescents have focused on associations of self-esteem with the deafness-related factors and contextual factors such as a preference for a deaf or hearing acculturation style, communication with parents and regular versus special school for deaf students. Associations with multidimensional aspects of self-concept have barely been addressed.

Conflicting results have been reported in regard to the deafness-related factors degree of deafness (Beck, 1988; Jambor & Elliot, 2005; Van Gurp, 2001; Weisel & Kamara, 2005), and time of onset (Loeb & Sarigiani, 1986; Warren & Hasenstab, 1986; Weisel & Kamara, 2005). While non-syndromal genetic deafness has been associated with a better psycho-social adaptation and communicative attunement between parents and child (e.g., Marschark, 1993; Bat-Chava, 1993; Hindley & Van Gent, 2002) than other causes of deafness, i.e. acquired (viral infections, prematurity, rhesus antagonism, meningitis etc.) or syndromal genetic (hereditary deafness accompanied by other physical abnormalities), we could not find any study on the association between self-concept and cause of deafness. More consistent findings have been reported on the association between the contextual factors deaf or hearing acculturation style and communication with parents and self-esteem. As deaf people participate in both the deaf minority culture and the hearing majority culture around them, a certain amount of identification with and acculturation into each culture will result. Two studies found positive associations between aspects of identification with the Deaf community (e.g., preference for sign language, having primarily deaf friends, involvement with the community) and self-esteem (Bat-Chava, 2000; Jambor & Elliot, 2005). Hintermair (2008) and Maxwell-McCaw (2001) and found that a marginal acculturation style, i.e. lacking the anchor of a positive preference for either a deaf, a hearing or a bicultural way of life, was linked to lower self-esteem. In accordance with the premise that signing better fulfills basic visual needs and the visual-spatial experience of deaf children, good parental signing proficiency has been associated with higher levels of self-esteem in the child, regardless of parental hearing status (Bat-Chava, 1993; Desselle, 1994). In line with these findings, satisfaction with home communication has been positively associated with both self-perceived scholastic and social competence, and marginally to global self-esteem (Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2009). Studies of the association between the contextual factor type of school and self-esteem have yielded more inconsistent findings. A number of researchers (e.g., Farrugia & Austin, 1989; Musselman, Mootilal, & MacKay, 1996; Weisel & Kamara, 2005) have addressed the hypothesis that attending regular school settings is associated with the experience of insecurity

and loneliness, social rejection and low self-esteem in deaf students as compared to attending a special school for the deaf. Indeed, in one multidimensional study higher levels of global self-esteem and more positive self-perceptions in the domains of physical appearance and peer relations were found in moderately to profoundly hearing-impaired adolescents of normal intelligence who attended a special, i.e. a segregated, residential school setting, as compared to peers in more integrated school settings (Van Gorp, 2001). However, other studies reported reverse findings: higher levels of global and domain specific self-perceptions were observed in samples of mainstreamed deaf adolescents irrespective of the use of a cochlear implant (Leigh et al., 2009), mainstreamed hard-of-hearing students (Mejstad, Heiling, & Svedin, 2009), or in younger hearing-impaired children (Keilman, Limberger, & Mann, 2007). Yet another group of studies could not confirm an association between the type of school setting and self-esteem (Bat-Chava, 1993; Kluwin et al., 2002; Jambor & Elliot, 2005).

The I-self

McAdams (1998) argued that the I-self may be viewed as the process of synthesizing subjective experience, conceptualized as the ego in Loevinger's model of ego development (Loevinger, 1976). Ego development may be portrayed as a series of changes in social-cognitive maturation along lines of impulse control, complexity of self reflection, interpersonal relations and conscious preoccupations (Recklitis & Noam, 2004). The level of ego development has proved to be relevant to a wide variety of psychological issues in the adolescent period (see Westenberg, Blasi, & Cohn, 1998).

On the basis of their study of ego development in a representative sample of over 2500 children and adolescents, Westenberg, Jonckheer, Treffers and Drewes (1998) provided descriptions of the first four ego levels that represent the stages of ego development found between late childhood and late adolescence: the impulsive, self-protective, conformist and self-aware ego levels. The *Impulsive* level is characterized as a combination of impulsivity, vulnerability, and dependency. Impulsive individuals are very dependent on direct care, guidance and protection by their caretakers, and attach importance to physical strength,

both within themselves and in their caretakers. The keyword at the *Self-protective* level is 'control'. Manipulation of one's own feelings (e.g., denial of pain or hurt feelings or of problems in general) is typical as an interpersonal style characterized by manipulative, opportunistic or hostile qualities. In contrast, *Conformist* individuals are socially attuned and will try to meet the demands of their reference group, in terms of the right opinions, correct behaviour, desired appearance, and expected level of performance. The dominant characteristic of the fourth stage, *Self-Aware*, is that the person has begun to recognize that not everyone, including possibly him/herself, conforms to the previously simple role-related stereotypes. Alternative possibilities are discovered and explored that were previously out of bounds for the Conformist.

There are substantial individual differences in the speed and timing of the developmental steps, partly related to differences in genetic and socialization factors, parental support, events such as exposure to a different or widening social context, and cognitive abilities (e.g., Dubow, Huesmann, & Eron, 1987; Newman, Tellegen & Bouchard, 1998). We are not aware of studies that have examined ego development levels and their correlates in a deaf population. We would expect to find a lower mean level of ego development in deaf adolescents as it is rather likely that they have had difficulties with socialization and with obtaining support from their parents because of a limited shared communication mode with hearing significant others (e.g., Vaccari & Marschark, 1997; Wallis, Musselman & MacKay, 2004).

Moreover, the challenge of getting access to a broader social context might be hindered due to either restricted opportunities of getting access to outside activities in the case of segregated, residential placement (Musselman et al., 1996) or considerable communicative differences with less familiar and predominantly hearing others in new socio-cultural environments. Therefore, one might expect to find lower levels of ego development in subgroups of deaf adolescents as compared to hearing peers of the same age.

The current study

The current study compares domain-specific self-perceptions and global self-

worth in deaf adolescents with those of hearing peers. We expected discrepancies between deaf and hearing adolescents to occur primarily in the social domains of self-perception. Novel in this field is the study of ego development in deaf adolescents, both as a related aspect of self and as an index of psychosocial maturity. Levels of ego development in deaf adolescents are compared to those in hearing peers. We expected to find a preponderance of lower ego levels in the deaf sample based on the assumption that most deaf children and adolescents are still growing up under often less favourable environmental conditions which may hinder social, emotional and cognitive development (e.g., Calderon & Greenberg, 2003; Hauser & Marschark, 2008).

In addition, we examined deafness-related variables including degree and cause of deafness and (past) neurological disorders, and the contextual variables place of residence, type of school, parental support for signing during childhood, quality of communication between parents and child as currently experienced by both, and preferential aspects of identification with deaf people. We explored whether these are associated with self-esteem or ego development. We also considered whether one or more of these variables incrementally predict self-esteem or ego development, beyond the variance accounted for by socio-demographic variables (i.e. age, gender, IQ and parental SES).

Finally, this is the first study on deaf adolescents to explore profiles of self-concept in the peer-salient social domains of physical appearance, social acceptance and athletic competence, and associations of these profiles with global self-worth, ego development, deafness- and contextual variables.

Method

Participants

Participants in the study were recruited from the total secondary school population of a large organization for deaf children and adolescents in the Netherlands which offers both special education with or without residential facilities, and educational counselling facilities for deaf children and adolescents who are integrated into ordinary schools (for details of the sampling and data collection procedure see Van Gent, Goedhart, Hindley & Treffers, 2007).

Table 1.
Socio-Demographic and Deafness Related Characteristics

Socio-Demographic Characteristic	N	%	Deafness Related Characteristic	N	%
<i>Age</i>			<i>Degree of deafness^{a b}</i>		
Mean 16.5 years; SD 1,8			73-95 dB or Cochlear Implant (N=3)	16	25
Range 13-21 years			≥96 dB	49	75
<i>Gender</i>			<i>Cause of deafness</i>		
Boy	31	46	Hereditary, non-syndromal	19	28
Girl	37	54	Acquired or syndromal	27	39
<i>Performance IQ^b</i>			Unknown	22	32
Mean 109.8; SD 13.2			<i>History of neurological disorders^c</i>		
<i>Ethnicity</i>			None	44	65
Dutch	50	73	One or more	24	35
Other (Turkish/Moroccan/other)	18	26	<i>Place of residence</i>		
<i>Highest educational level parents</i>			Residential setting	26	38
Low	21	31	Parental home	42	62
Middle	18	26	<i>Type of school</i>		
High	21	31	Special school for the deaf	50	74
Unknown	8	12	Ordinary school	18	26
<i>Family Composition</i>					
Two biological parents	49	72			
Other	19	28			

Note. ^a Deafness can be functionally defined as the permanent bilateral severe to profound lack of hearing speech and other sounds, and quantified as the unaided average hearing impairment for the better ear of more than 70 decibels (dB) according to the available audiological information. ^b Missing quantitative data with 1-3 cases.. ^c Cases for which specialist medical care had been provided in the past. The first category of all categorical variables is coded as 0, the next as 1, etc.

The content of educational programs is much the same throughout The Netherlands, the only difference being their location. The sample (N=94) may be regarded as representative of the population of deaf adolescents of normal intelligence in the Netherlands. We obtained informed consent from 70 of the 94 students (74%) and their parents. The final sample consists of 68 students because the self-concept measure was missing for two of the students due to scheduling problems. Permission to use information from their school file was obtained from 18 of the 24 non-respondents. The non-respondents were significantly older, showed a lower mean IQ and were more likely to have psychosocial stressors (e.g., family conflicts, penal violation, or sexual abuse). Table 1 shows descriptive statistics of demographic and deafness-related characteristics of the participants.

Measures

Self-concept. Self-concept was assessed with the Dutch language version (Treffers et al., 2002) of the Self-Perception Profile for Adolescents (SPPA; Harter, 1988). Because of socio-cultural differences between the United States and the Netherlands/Flemish Belgium, the Dutch language version measures self-perceived competence on six specific domains of life, i.e. Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Behavioural Conduct, and Close Friendships as well as self-perceived general competence, i.e. Global Self-worth. Each subscale contains 5 items. Each item comprises descriptions of two different kinds of teenagers. The adolescent is first asked to decide which of the two is most like him- or herself, for example (from the adapted Dutch deaf version): 'Some young people have many friends' BUT 'Other young people do not have many friends' (Social Acceptance) and 'Some teenagers are happy with themselves most of the time' BUT 'Other teenagers are not very happy with themselves' (Global Self-worth). The adolescent is then asked to indicate the degree to which he or she is like the chosen description by choosing one of the following options: 'Is completely like me' OR 'Is a little like me'. Answers are scored from 1 to 4, with 4 representing higher self-concept, according to the choices the adolescent has made. For example, the score 1 is assigned when 'Some teenagers have many friends' and 'Is completely like me' were chosen. The score 2 is assigned

when 'Other teenagers have many friends' and 'Is a little like me' were chosen, and so forth.

The internal consistency of the scales in the Dutch norm group ranged from $\alpha=.65$ (Scholastic Competence) to $\alpha=.88$ (Athletic Competence); the 3-5 week test-retest correlations ranged from .72 (Global Self-worth) to .87 (Athletic Competence). A team of deaf and hearing professionals, all fluently signing and experienced in working with deaf adolescents, adapted the Dutch version of the tool by minimizing metaphoric language and difficult words. In the current sample, we found internal consistencies below 0.70 with the subscales Scholastic Competence ($\alpha=.58$) and Behavioral Conduct ($\alpha=.64$); the highest internal consistency ($\alpha=.73$) was found with Physical Appearance and Global Self-Worth; for Social Acceptance .72 was found, and for both Athletic Competence and Close Friendships .71. The inter-correlations of the SPPA-scales were comparable with the inter-correlations found in the Dutch norm group, except for Social Acceptance and Close Friendship that showed lower correlations with the remaining scales. Physical Appearance showed the strongest correlation with Global Self-worth, as was also found in the Dutch norm group. With respect to the validity of the SPPA competence scales, we examined correlations of these scales with competence items from the Child Behaviour Checklist (CBCL; Achenbach, 1991a; Verhulst, Van der Ende & Koot, 1997a) that were reported by 47 parents. Significant Spearman correlations were found between Social Acceptance and competence item 'number of friends' ($r=.36$, $n=47$, $p<0.05$), and between Close Friendship and 'contacts with friends' ($r=.33$, $n=47$, $p<0.05$). In addition, we found significant correlations of Scholastic Competence with the sum of the items assessing current academic performance ($r=.38$, $n=41$, $p<0.05$) and with the adaptive functioning item 'how much is he/she learning?' ($r=.29$, $n=66$, $p<0.05$) from the Teacher's Report Form (TRF; Achenbach, 1991b; Verhulst, Van der Ende & Koot, 1997b). The Lonely scale of the Semi-structured Clinical Interview for Children and Adolescents (SCICA; McConaughy & Achenbach, 1994; Kasius, 1997), showed negative correlations with Close Friendship ($r=-.26$, $n=68$, $p<0.05$) and Physical Appearance ($r=-.23$, $n=68$, $p<0.05$). Negative Spearman correlations were also found between Athletic Competence and total number of (past) physical disorders ($r=-.24$, $p<0.05$) and history of neurological disorders ($r=-.30$, $p<0.05$).

Ego Development. The level of ego development was assessed using the Sentence Completion Test for Children and Youths (SCT-Y; Westenberg et al., 2000). The SCT-Y is the Dutch version of the Washington University Sentence Completion Test (WUSCT; Hy & Loevinger, 1996; Loevinger, 1998), specifically constructed for use with children over 8 years of age and adolescents. The SCT-Y consists of 32 sentence stems, for example 'School...', 'My biggest problem is...', and 'A good father...'. The respondent is instructed to 'complete the following sentences in any way that you wish'. Responses to sentence items are scored for ego level, i.e. from 2 (impulsive) to 5 (self-aware), using the published manual. Item scores were used to compute the Total Protocol Rating (TPR) and the Ego Level Score (ELS). The TPR reflects the respondent's core ego level, e.g., impulsive, self-protective, conformist, or self-aware. This rating was obtained by matching the respondent frequency distribution of ratings for each item with the prototypical frequency distribution described in the manual. The ELS is computed as the sum of the scores of the 32 items. Consistent with the requirement that the SCT-Y should tap a one-dimensional construct, the items of the SCT-Y represent a 1-factor structure (Westenberg et al., 2000). In the current study two psychologists who were trained in scoring the SCT-Y, scored the ego levels of 18 randomly selected participants independently. The interrater-agreement on TPR was excellent ($\kappa = 1.0$), which is in line with findings in other studies (e.g., Westenberg, Drewes, Goedhart, Siebelink, & Treffers, 2004). The remaining 52 participants were scored by one of them.

In support of the validity of the SCT-Y in the present study, the product-moment correlation between performance IQ and ELS ($r = .28$, $p < 0.05$) was nearly equal to the corresponding average correlation ($r = .29$) found in the meta-analysis of Cohen & Westenberg (2004). As in previous studies (see Westenberg et al., 2000), we found a higher ELS score for girls ($t(66df) = 2.14$, $p < 0.05$) and a positive Spearman correlation with the level of parental education (available for 60 participants: $r = .33$, $p < 0.05$).

IQ. In accordance with contemporary practice in testing the intelligence of deaf adolescents in the Netherlands, Wechsler performance scales from the Dutch version of the WISC-R (De Bruyn, Vander Steene, & Van Haasen, 1986) were used with most participants in this study.

Support for Signing, Parent-Child Communication and Identification with Deaf People. Items from the Deaf Young People's Guided Interview Schedule and the Parents' Guided Interview Schedule (Gregory, Bishop & Sheldon, 1995) were used to measure the constructs *Support for Signing in Childhood (SSC)*, *Quality of Parent-Child Communication as currently perceived by both parents and adolescents (QPCC)*, and *Identification with the Deaf People (IDP)*. Responses on the selected questions were coded 1 if indicative or 0 if not indicative. See Appendix for the indicative responses of Support for Signing during Childhood (5 items), Quality of Parent-Child Communication (6 items) and preferential aspects of Identification with Deaf People (5 items). Missing items (answers such as 'don't know', or 'other') were replaced by the rounded mean score of the non-missing items of the scale. As at most two missing values were allowed, Support for Signing in Childhood and Quality of Parent-Child Communication were missing from one participant, Identification with Deaf People from two participants. Coefficient alpha of the scales were Support for Signing in Childhood: .74; Quality of Parent-Child Communication: .64; Identification with Deaf People: .66.

We found positive Spearman correlations of SSC with QPCC and IDP and a negative correlation between QPCC and IDP (see Table 3). In addition, we found a positive correlation of Quality of Parent-Child Communication (QPCC) with two variables that are negatively related to IDP, type of school and communication mode, indicating that a higher level of QPCC was found with adolescents attending a regular school and with adolescents using spoken language. The negative correlation of QPCC with family composition indicates a lower level of QPCC for adolescents growing up in one-parent families. Multiple regression analysis revealed unique contributions of SSC, IDP and family composition to the prediction of QPCC. These findings lend support to the validity of these measures because they are in line with results of previous studies indicating that (1) early adaptation to visual communicative needs of a deaf child promotes parent-child communication and social interaction (e.g., Marshark, 2007), (2) deaf cultural preferences are negatively associated with the quality of parent-child communication (Leigh et al., 2009), and (3) parental distress, such as the experience of a lack of social support, is a significant source of negative parent-

child interaction (e.g., Calderon & Greenberg, 1999). Finally it may be noted that Identification with Deaf People was more likely with adolescents at special schools or in a residential setting than among those attending ordinary schools or living with their parents.

Procedures

At the start of the each individual assessment session, the participants were consulted to determine their preferred mode of communication with the interviewer, i.e. sign language (Nederlandse GebarenTaal, NGT), sign supported Dutch (Nederlands ondersteund Met Gebaren, NMG) or spoken Dutch, and to decide on the assistance of a professional interpreter (in NGT or NMG). The Gregory's interviews with parents and with adolescents were conducted by a child psychologist. The intelligence of the participants was tested by a psychologist. The preferred mode of communication was recorded as oral communication or signing + (i.e. use of signing and/or speech and speech reading depending on their conversation partners).

The psychologist or the psychiatrist who also conducted a diagnostic interview with the participants assisted with the completion of both the SPPA and the SCT-Y. The participants had ample opportunity to receive instructions on completing the SPPA and the SCT-Y. They were urged to get additional clarification in their preferred mode of communication and in line with the instructions of the manual before completing the questionnaires.

Data analysis

Statistical analyses were performed using SPSS Version 18.0 for Windows. To test the independent contribution of deafness-related or context variables to the prediction of Global Self-worth and Ego Level Score, we performed hierarchical multiple regression, entering first a block of social-demographic characteristics (age, gender, IQ, ethnicity and parental SES), followed by those deafness-related and context variables that showed significant associations with Global Self-worth and Ego Level Score, respectively. Predictors were standardized to remove any collinearity that involves the intercept. All models were evaluated for multivariate

outliers, using the SPSS default value for standardized residuals as cut-off for removing them.

Cluster analysis with the SPPA-scales Social Acceptance, Athletic Competence and Physical Appearance, was performed using the two-step procedure as suggested by Clatworthy, Hankins, Buick, Weinman, & Horne (2007). In the first step, Ward's hierarchical clustering procedure was applied based on squared Euclidian distances between cases on each clustering variable. A relative large increase in the cluster agglomeration coefficient was used as a criterion to select a solution (this procedure is equivalent to the inspection of the plot of eigenvalues in factor analysis). In the second step, a non-hierarchical K-means cluster analysis was conducted with the centroids from Ward's method solution used as the seed points. The K-means procedure was done as an independent check on the stability of the cluster structure and as a way of optimizing cluster membership.

Results

Differences in self-concept and ego development with Hearing Adolescents

As gender and educational level were associated with most SPPA-scales in the Dutch norm group (Treffers et al., 2002), boys (N=219) and girls (N=380) with a comparable educational level who were part of the Dutch norm group were selected for the hearing comparison group. We used the means and standard deviations on the SPPA-scales of the boys and girls of the comparison group to compute T-scores for boys and girls separately (for the boys and girls of the comparison group, the mean T-score is 50, standard deviation is 10). Means and standard deviations of the T-scores on the SPPA-scales of the deaf adolescents are presented in Table 2. One-sample t-tests showed that the mean T-scores in our study sample were significantly lower than 50 for Social Acceptance and Close Friendship and significantly higher than 50 for Physical Appearance. It may be noted that the mean score on the three social competence scales (Social Acceptance, Physical Appearance and Athletic Competence) is 49.9, i.e. about the same as the mean of hearing adolescents. The mean T-score of Global Self-worth and the remaining competence scales were not different from 50.

The observed prevalence of the stages in the current sample was compared to the prevalence of the corresponding stages in hearing boys and girls between the ages of 13 and 15 years, as documented in the Dutch manual (Westenberg et al., 2000). Using the chi-square test we found a significant difference between the distributions of the levels of ego development, i.e. the observed prevalence of the impulsive and self-protective stages in the current sample of deaf adolescents was higher than the expected prevalence (i.e. the prevalence with hearing young adolescents), the observed prevalence of the conformist and self-aware stages was lower (see Table 2).

Table 2.

Mean (SD) T-Scores of Perceived Competence Scales (SPPA-scales) and Observed and Expected Prevalence (Percentage) of Stages of Ego Development (TPR)

	SPPA-scales		Ego Development (TPR)		
	Mean T-score (SD)	t (67 df) ^a	Observed (%)	Expected (%)	χ^2 (3 df) ^b
SPPA-scales					
Scholastic Competence	51.7 (9.2)	1.53			
Social Acceptance	45.1 (10.7)	-3.75***			
Athletic Competence	52.2 (9.5)	1.88			
Physical Appearance	52.3 (8.8)	2.16*			
Behavioral Conduct	49.9 (9.9)	-0.06			
Close Friendships	45.9 (13.0)	-2.62 *			
Global Self-Worth	48.0 (9.6)	-1.75			
Stages Ego Development					58.64***
Impulsive			16 (24%)	3.4 (5%)	
Self-protective			31 (46%)	27.2 (40%)	
Conformist			20 (29%)	34.0 (50%)	
Self-aware			1 (1%)	3.4 (5%)	

Note. TPR=Total Protocol Rating. ^a One-sample t-test of mean=50; . ^b One-sample chi-square test of difference between observed and expected prevalence of the stages of ego development; *, p<0.05; **, p<0.01; ***, p<0.001.

Table 3.
Intercorrelations Among Study Variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	
1. Gender	-																			
2. Age	-.12	-																		
3. Performance IQ	-.15	.04	-																	
4. Ethnicity	-.12	.11	-.28 ¹	-																
5. Parental Educ. Level	.08	-.10	.06	-.32 ¹	-															
6. Family Composition	.11	.02	-.29 ¹	.07	.18	-														
7. Degree of deafness	.12	-.01	.05	-.21	-.13	-.10	-													
8. Cause of deafness	-.02	.12	-.08	.12	.26	.10	-.02	-												
9. History of neur. dis.	.06	.00	-.15	-.16	.08	.09	.05	.47 ²	-											
10. Place of residence	-.25 ¹	.36 ²	-.07	.21	-.25	-.02	-.08	.03	-.07	-										
11. Type of school	.15	-.20	.39 ³	-.28 ¹	.35 ²	-.23	.06	-.07	-.03	-.48 ³	-									
12. SSC	-.03	.13	-.12	-.03	-.07	-.08	.01	-.13	.05	-.01	-.07	-								
13. QPCC	-.12	-.04	.14	-.16	.19	-.29 ¹	.06	.08	.04	-.11	.43 ³	.32 ¹	-							
14. IDP	.03	.38 ²	-.15	.20	-.33 ¹	.03	.04	-.07	-.09	.40 ³	-.66 ³	.33 ¹	-.27 ¹	-						
15. Social Acceptance	.01	-.07	-.20	.25 ¹	.05	.22	.06	-.24	-.12	.25 ¹	-.28 ¹	.22	-.09	.25 ¹	-					
16. Athletic Competence	.24 ¹	-.12	-.02	.08	.01	-.21	-.17	-.25	-.30 ¹	-.05	.07	.11	-.05	-.07	-.01	-				
17. Physical Appearance	.05	-.03	.14	-.02	.06	.04	-.07	.05	-.10	.14	.26 ³	.19	.20	-.01	.20	-.28	-			
18. Global Self-worth	.03	-.10	.21	-.19	-.14	-.15	.02	-.06	.04	.05	.22	.32 ¹	.27 ¹	.07	.08	.20	.54 ²	-		
19. Ego Level Score	.24 ¹	.02	.28 ¹	-.13	.33 ¹	.04	-.09	.20	.06	-.29	.65 ³	-.17	.23	-.43 ²	-.18	-.22	.17	-.02	-	

Note. SSC=Support for Signing in Childhood; QPCC=Quality of Parent-Child Communication; IDP=Identification with Deaf People. ¹: p<0.05; ²: p<0.01; ³: p<0.001 (2-tailed significance levels).

Inter-correlations of study variables

Spearman correlations of demographic, deafness-related and contextual variables, the SPPA social competence scales, Global Self-worth and Ego Level Score are presented in Table 3. It may be noted that no association was found between Global Self-worth and Ego Level Score, and that both variables were associated with different contextual variables. A higher level of Global Self-worth was associated with more Support for Signing in Childhood (SSC) and a better Quality of Parent-Child Communication (QPCC). Higher levels of Ego Level Scores were found among girls, among participants with a higher IQ, with parents of a higher educational level, among participants attending an ordinary school and among participants having a lower Identification with Deaf People. In addition, we explored the associations of respondent's actual preference for signing with Global Self-Worth, SSC and QPCC. These associations were not significant. Instead, the actual preference for signing was negatively associated with type of school (i.e. preference for speech when attending regular school) and Ego Level Scores (Spearman's $r = -.57$ and $-.41$ respectively).

Unique contributions of contextual variables in predicting Global Self-worth and Ego Level Score

Hierarchical multiple regression analyses were used to examine whether contextual variables that were significantly associated with Global Self-worth and Ego Level Score respectively, predicted these variables, over and above the socio-demographic characteristics age, gender, IQ, and parental educational level as a measure of socio-economic status (SES). The results of these analyses indicated that Support for Signing in Childhood and Quality of Parent-Child Communication significantly increased the prediction of Global Self-worth, while type of school significantly increased the prediction of Ego Level Score (see Table 4).

Table 4.

Standardized Regression Coefficients for Hierarchical Regression Analyses Predicting Global Self-worth and Ego Level Score.

Predictors	Global Self-worth ¹		Ego Level Score ²	
	Step 1 β	Step 2 β	Step 1 β	Step 2 β
Step 1				
Gender	.12	.18	.30*	.21*
Age	-.16	-.16	.05	.16
IQ	.31*	.27*	.27*	.02
Parental Educational Level	-.20	-.24*	.27*	.06
Step 2				
SSC		.24*		
QPCC		.32*		
IDP				-.12
Type of school#				.62***
R ²	.15	.36	.25	.59
R ² Δ	.15	.21	.25	.34
F Δ	2.56*	9.21***	4.84**	23.51***
Df	4.59	2.57	4.59	2.57

Note. β = standardized beta reflects association of dependent variable with predictor, with simultaneous control of all predictors in the same step. ¹: three outliers were removed from the model; ²: two outliers were removed from the model. SSC=Support for Signing in Childhood; QPCC= Quality of Parent-Child Communication; IDP= Identification with Deaf People. #: codes: 0=special school for the deaf, 1=regular school. *: p<0.05; **: p<0.01; ***: p<0.001.

Social Competence Profiles

Cluster analysis was conducted on the three SPPA-scales indicating social competence (see Harter et al., 1992), i.e. Social Acceptance, Physical Appearance and Athletic Competence, to find groups with similar social competence profiles. In the first step, the clustering agglomeration coefficient indicated three-cluster solutions as rather large increases were found in going from three clusters to two, whereas the increase from four to three clusters was essentially the same as the increase from five to four clusters (the 5 largest coefficients were 201, 148, 112, 95, and 80). In the second step, the centroids of the three-cluster solution were used as seed points for the K-means procedure.

The first cluster consisted of 30 adolescents, who scored high on the three social competence scales (see Table 5). This profile was labelled 'high' social competence. In the second cluster there were 25 adolescents, whose scores on the social competence scales were uniformly low. This profile was labelled 'low' social competence. The third cluster consisted of 13 adolescents who reported a particularly low level of Social Acceptance, a mean level of Athletic Competence and a relatively high level of Physical Appearance. This profile was labelled 'mixed' social competence. Girls and boys were evenly distributed in the clusters; the mean age of the clusters was about the same.

Analyses of variance with social competence profile as the independent measure and the continuous study variables as the dependent measure were used to examine linear and quadratic trends. Chi-square tests were used to investigate the association of the clusters with the categorical variables history of neurological disorder(s) and type of school that were found to be associated with one of the three social competence domains (see Table 3).

As shown in Table 5, adolescents with high or low social competence profiles reported higher or lower levels, respectively, on all remaining SPPA scales, except Scholastic Competence. Adolescents with a mixed profile reported a very low level of Close Friendship, but a high level of Behavioural Conduct and a relatively normal level of Global Self-worth.

Table 5.

Means and Standard Deviations of Continuous Study Variables and Frequencies and Percentage of Categorical Study Variables for Social Competence Clusters, and Associations of Study Variables with Social Competence Clusters.

	Mean (SD) or Number (row %)			Trend Analysis		
	Low SC (n=25)	Mixed SC ^a (n=13)	High SC (n=30)	Limear F(1,65)	Quadratic F(1,65)	χ^2 (2df)
Scholastic Competence	50.8 (8.9)	48.9 (8.7)	53.6 (9.4)	1.41	1.36	
Social Acceptance	44.4 (8.1)	30.5 (7.6)	52.1 (6.2)	18.14***	62.95***	
Athletic Competence	46.5 (6.0)	51.8 (11.4)	57.1 (8.6)	21.98***	0.00	
Physical Appearance	44.0 (4.7)	55.6 (6.0)	57.7 (7.0)	68.12***	6.38*	
Behavioral Conduct	46.8 (11.3)	56.0 (9.3)	49.9 (7.7)	1.26	6.93*	
Close Friendships	42.7 (12.5)	37.6 (17.3)	52.1 (7.6)	9.29**	7.34**	
Global Self-Worth	43.8 (8.4)	49.8 (10.7)	50.7 (9.1)	7.86**	0.87	
Ego Level Score	103.1 (10.5)	115.9 (16.2)	100.8 (15.0)	0.56	10.75**	
SSC	1.9 (1.7)	1.8 (1.3)	2.8 (1.7)	4.35*	1.08	
QPCC	3.8 (1.8)	4.8 (1.4)	4.0 (1.8)	0.28	2.83	
IDP	2.8 (1.5)	1.7 (2.0)	3.1 (1.4)	0.42	5.90*	
History of neurological disorders						8.29*
- None	13 (30%)	6 (14%)	25 (57%)			
- One or more	12 (50%)	7 (29%)	5 (21%)			
Type of school						18.04**
- Special school for the deaf	21 (42%)	4 (8%)	25 (50%)			
- Ordinary school	4 (22%)	9 (50%)	5 (28%)			

Note: ^a: Mixed SC= Low Social Acceptance and High Physical Appearance; SSC=Support for Signing in Childhood; QPCC= Quality of Parent-Child Communication; IDP= Identification with Deaf People. *: p<0.05; **: p<0.01; *** p<0.001

The quadratic trends found with Ego Level Score and Identification with Deaf People indicated that the 'mixed' cluster showed higher mean scores on Ego Level Score and a lower mean score on Identification with Deaf People. As indicated by the significant linear trend, a higher level of Support for Signing in Childhood was associated with high social competence. The chi-square analyses showed significant associations of the social competence profiles with a history of neurological disorder(s) and type of school. More specifically: the percentage of adolescents with a history of neurological disorder(s) was lowest in the high social competence profile, and the percentage of adolescents attending an ordinary school was highest in the 'mixed' profile.

Discussion

The goal of this study was to examine self-concept and ego development in deaf adolescents by (1) comparing the levels of both aspects of self with the levels found in hearing norm groups, (2) identifying profiles of peer-related social competence in deaf adolescents, and (3) examining the associations of social competence profiles with global self-worth, ego development, deafness-related and contextual variables.

Deaf adolescents reported lower Social Acceptance and Close Friendship scores and higher Physical Appearance scores as compared to hearing peers from the norm group with a comparable educational level. These findings confirm and extend the evidence from the comparative and multidimensional study by Capelli et al. (1995) showing that younger deaf children primarily experience self-concept problems in the social domains. As no difference was found for Global Self-worth in the whole sample, it may be hypothesized - in line with the theory of Harter (1999) - that a number of adolescents in this sample were able to discount the importance of social acceptance and close friendships, i.e. they decreased the relevance of the domains they did not feel competent in, in order to maintain a positive sense of Global Self-worth. At the same time, discounting often accompanies the endorsement of those domains in which one feels most competent, even with the tendency to inflate one's sense of competence, particularly in young people with higher self-worth (Harter, 1986). The finding of a higher mean score for Physical

Appearance suggests that - at least in this sample - self-enhancement strategies operated especially within the domain of Physical Appearance, the domain most highly correlated with Global Self-worth across studies (Harter, 1999).

In line with our expectations, this study found a much higher percentage of deaf adolescents at lower, pre-conformist stages of ego development than the expected percentage of hearing peers. We suggest that lower levels of ego development must be expected because deaf youth today often grow up under less favourable environmental conditions which may hinder social, emotional and cognitive development. The finding of a strong association between ego development and type of school, even after taking gender, age, IQ and parental educational level into consideration, suggests that a special school for the deaf may offer less favourable environmental conditions. However, in this study we did not examine language ability in signed or spoken language. As language ability may be associated with both the type of school and with ego development it may partly explain the correlation found between type of school and ego development. Nevertheless, this finding corresponds to previous studies indicating that, besides genetic and socialization factors, cognitive abilities, parental support, exposure to a different or widening social context contribute to ego development (e.g., Dubow et al., 1987; Newman et al., 1998). The percentage of participants in the (post) conformist stages (89%) was even higher among the subgroup of deaf adolescents attending ordinary school than the corresponding percentage (75%) among hearing adolescents of the same age. In contrast, 90% of the adolescents attending a special school were in the pre-conformist stages. However, this large difference not only reflects the influence of the social context. The adolescents attending an ordinary school were significantly more often female, had a higher IQ, were less often immigrants, and more often had parents with a higher educational level (see Table 3). Given the importance of ego development, i.e. the importance of changes along lines of impulse control, complexity of self reflection and interpersonal style (Recklitis & Noam, 2004), further differentiated and longitudinal studies are needed to reveal those factors which may constitute a testable focus for interventions contributing to progression in ego development. For instance, the presence of behavioral problems could be one of the inhibiting factors. Deaf students with behavioral problems are more

likely to be referred to a special school (Lynas, 1995; Van Gent et al, 2007), and evidence suggests that behavioral problems occurring in early adolescence hinder the attainment of the conformist level of ego development in adolescents at pre-conformist ego levels (Krettenauer, Ulrich, Hofman, & Edelstein, 2003).

Support for Signing during Childhood (SSC) and Quality of Parent-Child Communication (QPCC) predicted Global Self-worth level beyond the variance explained by IQ and parental educational level in this sample. This finding fits with Harter's (1999) theory that positive self-worth is strongly dependent on the level of support from meaningful others, and corroborates previous studies which showed that both visual linguistic support (Bat-Chava, 1993; Desselle, 1994) and satisfactory communication at home (Leigh et al., 2009) are seen as predictors of self-esteem. Neither Global Self-worth nor satisfaction with communication at home was associated with the adolescents' communication mode. This is in line with the finding in other studies (Van Gurp, 2001; Weisel & Kamara, 2005) of no association between Global Self-worth and the preference for either signed or spoken language by deaf adolescents and young adults themselves.

Based on the broadly accepted view that communicative barriers in a hearing world especially affect social well-being and self-concept in social interactions (e.g., Calderon & Greenberg, 2003; Oblowitz, Green & Heyns, 1991; Schlesinger & Meadow, 1972), cluster analyses were performed on three competence domains indicating peer related social competence, i.e. Social Acceptance, Physical Appearance and Athletic Competence. Similar to results of other cluster analyses (i.e. Salmivalli, 1998), high and low social competence profiles were found, showing high and low scores in these three domains, respectively. Our cluster analysis also identified a mixed profile, characterized by a very low score on Social Acceptance and a high score on Physical Appearance.

Membership of the low social competence cluster was associated with low self-perceived competence in most other domains except the parent-related domain of Scholastic Competence. This suggests not only that the adolescents in this cluster feel inadequate in these domains, but also that they cannot discount the importance of these domains, and that they cannot escape from their unfavourable circumstances. This might put them at an increased risk of developing depressed

affect and anger as suggested by Harter (1999), and indicates the need for support from parents and others. Many adolescents in this cluster had a history of neurological disease, which in itself may add to the threat of unfavorable but unavoidable social comparisons (e.g., Mussweiler, Gabriel & Bodenhausen, 2000; Van Gent et al., 2011).

Inclusion in the mixed cluster (low Social Acceptance and high Physical Appearance) was associated with a normal level of Global Self-worth, the highest mean Ego Level Score, a hearing acculturation style and a hearing social context. Apparently adolescents in this cluster were able to maintain an average level of Global Self-worth roughly equal to the mean of hearing norm peers, by discounting the importance of the social domains in which they were experiencing less competence or support (Social Acceptance and Close Friendships). At the same time, they endorsed the importance of domains in which they experienced competence or support, i.e. the peer-related domains of Physical Appearance and Athletic Competence and the parent-related domain of Behavioral Conduct (with mean levels of competence in the scholastic domain). Most adolescents in this cluster lived with their parents and attended ordinary schools, which in itself was also positively associated with ego development. The finding of the lowest level of Social Acceptance in this cluster, containing the majority of adolescents attending an ordinary school, supports the view that those adolescents who are included in mainstreaming, have a particularly hard time socially and lack support from the majority of hearing peers. In our sample, most students attended education in larger hearing schools with no or very few other deaf students as class peers, i.e. on the basis of individual inclusion. Therefore they had fewest opportunities to socialize, on a day-to-day basis with other deaf people, who can validate who one is as a person (Harter, 2006). But, taking into account the average level of Global Self-worth of the adolescents in this cluster, it would seem that they have accepted the experience of little peer support as a social condition that has little to do with their personal values. Our finding of greater differentiation in self-perceptions among social self-concept domains in this mixed cluster is in line with a more mature cognitive-developmental level, as compared to a simpler pattern in the other clusters (Harter, 1986; 2006). As with previous research showing that higher

ego levels are associated with more complexity of self-reflection and interpersonal relations (Recklitis & Noam, 2004; Westenberg, Siebelink, Warmenhoven, & Treffers, 1999), we found that 9 (70%) of the 13 adolescents with a mixed social competence profile were in the (post) conformist stage. In contrast, more than 75% of the adolescents with either a high or a low social competence profile were in a pre-conformist stage.

Adolescents in the high social competence cluster also showed relatively high scores on Close Friendships and Scholastic Competence, but mean scores on Behavioral Conduct and Global Self-worth. Such a profile probably indicates a combination of intrapersonal self-enhancement strategies, i.e. the tendency to endorse the importance of the domains one feels competent in, the tendency to take more responsibility for success than for failure, as well as the tendency to overrate one's competence, all of which might reflect the impact of a younger mental age, and a more idealized and less differentiated self-concept (e.g., Harter, 2006).

This assumption is supported by the finding of significantly lower socio-cognitive maturity among adolescents in this cluster than among adolescents in the mixed cluster. Inclusion in the high social competence cluster was also associated with the absence of neurological disorders, which in itself is significantly associated with non complicated familial deafness (Van Gent et al., 2011), and the highest rates of support for signing and preferential aspects of identification with deaf people and type of school. This adds support to the view that pre-existing familiarity with deafness, parental support and an otherwise positive engagement in a primarily deaf environment correlates with a high sense of social acceptance. The three children of deaf parents (see Table 1) typically belonged to this cluster; this is in line with Crowe (2003), who found that deaf respondents with deaf parents scored higher on self-esteem compared to those with hearing parents, regardless of signing ability.

Limitations

There are several limitations to this study. Firstly, as there are neither measures for socio-cognitive maturity nor multidimensional self-concept measures with firmly

established psychometric properties specifically developed for using with Dutch deaf children and adolescents, standard instruments were used and adapted for using with deaf subjects. The possible issue of limited understanding of language used in the self-report questionnaires was addressed by communicating in the participants' preferred mode of communication and by encouraging them to seek assistance when needed. Moreover, research has demonstrated that the SCT-Y is fairly robust regarding modified administration procedures (e.g., Drewes & Westenberg, 2001). Secondly, as with all cross-sectional studies, findings do not allow for strong causal conclusions. Finally, another limitation of this study is the relatively small sample size and the substantial number (26%) of non-respondents. In view of the characteristics of the non-respondents (lower IQ and higher rates of psychological stressors) it might be hypothesized that the levels of Global Self-worth and ego development in the participating sample are not underestimated.

Implications for interventions and future research

Findings from this study extend our understanding of the dynamics of self-concept, i.e. on how facets of self-concept may be differentially related to a set of intrapersonal and contextual characteristics (including [past] neurological disorders) in samples of deaf adolescents. They may help to identify more specific directions for preventive and socio- and psychotherapeutic interventions with deaf children and adolescents. For example, it may prove especially relevant to mobilize sources of social approval and promote acceptance and validation of personal competences by significant others, particularly peers and parents, for those members of the low social competence cluster who seem unable to discount the importance of specific domains.

For members of the mixed social competence cluster, approval and acceptance by peers may be an important intervention target in order to prevent or diminish the risk of social isolation. Members of both clusters may be at even greater risk of developing a depressed affect if they suffer from additional physical distress through a history of neurological disorder, which may add to the risk of unavoidable negative self-evaluation (see Harter, 1986; 1999) and loss of self-esteem (Pyszczynski & Greenberg, 1987). Associations between ego development,

the three social competence profiles and these contextual factors may point at other points of intervention. For instance, the finding of a high rate of lower levels of ego development among adolescents in the high social competence cluster suggests that many adolescents from this cluster in particular are inclined to intrapersonal self-enhancement and overestimating one's own competence. Excessive overestimation has a negative impact on social relations (Harter, 2006) and is associated with behavioral problems which indeed were found more often among adolescents at special schools (Van Gent et al., 2011).

Finally, findings indicate directions for further research in longitudinal studies to determine causal relations. Such studies should include a range of putative predictors of multidimensional aspects of self-concept and social-cognitive maturity, including language ability, which in itself is reciprocally related to socio-emotional and cognitive development (Marschark, 2007), and should also make use of observational measures (e.g., Wauters & Knoors, 2008; Wolters, Knoors, Cillesen, & Verhoeven, in press) in addition to the previously mentioned variables under scrutiny. It is recommended that further research be directed at adolescents with cochlear implants which are changing the face of deafness in many ways and at great pace (e.g., see Marschark, 2007). In The Netherlands about 90% of deaf pre-schoolers now have implants, and in the near future larger groups of adolescents may profit from the positive effects of early implantation on hearing, speech perception and spoken language skills, communication and socialization, academic achievement, and in other areas of functioning. Despite the many reported benefits of CI, data on associations of CI with self-esteem and psycho-social adjustment are still few and findings as well as conclusions vary substantially (e.g., see Leigh et al., 2009; Martin, Bat-Chava, Lalwani, & Waltzman, 2010; Nicolas & Geers, 2003). As the development of children with and without implants may be different in many domains, it is very important to include the effects of CI in future studies.

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Appendix

Responses to selected items from the Deaf Young People's Guided Interview Schedule and the Parents' Guided Interview Schedule (Gregory, Bishop, and Sheldon, 1995) that were used as indicators for Support for Signing in Childhood (SSC, e.g., 'Was signing encouraged at home?' [A45c]), Quality of Parent-Child communication (QPCC, e.g., 'Was it ever difficult to explain something to your mother or father?' [A23]; 'Do you feel that because [sometimes] communication is a problem there are parts of his/her life you know nothing about?' [P161]), and Identification with Deaf People (IDP, e.g., 'If you had a very deaf child how would you communicate with him or her?' [A48], 'Are his/her friends mostly deaf or hearing?' [P177]). The number of the interview question is noted between brackets, with A and P denoting the interview schedules for adolescent and parents respectively.

Responses on the selected questions were coded 1 if indicative or 0 if not indicative, i.e. the total number of indicative responses is used as scale score.

Indicative responses of SSC.

1. Parents showed a positive attitude towards sign language (A44).
2. Signing in class was allowed or encouraged in childhood (A45a).
3. Signing in playground was allowed or encouraged in childhood (A45b).
4. Signing at home was allowed or encouraged in childhood (A45c).
5. At least one of the parents used sign or a combination of sign and spoken language in childhood (P130).

Indicative responses of QPCC.

1. Feels well understood by parents (A13).
2. Has not experienced any difficulties to explain something to parents (A23).
3. Has the opportunity to talk things over in depth with family (A25).
4. Has not been treated differently by family because of deafness (A27).

5. Parents report no particular situations which present difficulties in communicating with their deaf son/daughter (P144).
6. Parents don't feel that there are parts of their deaf child's life that they don't know because of communication difficulties (P161).

Indicative responses of IDP.

1. Manages in following conversations with a group of deaf friends reasonably to good. ^a
2. Knows people close to him/her using sign language (A46).
3. Would use signing if parent of a deaf child (A48).
4. Most or all close friends are deaf (A66c).
5. Parents report that most or all friends are deaf (P177).

Note: ^a In the Dutch translation of the interview with young people, a question about following conversations with a group of deaf friends was added to the question about following conversations with a group of hearing friends in the original interview (A38)

Chapter 6

Characteristics of children and adolescents in the Dutch national in- and outpatient mental health service for deaf and hard of hearing youth over a period of 15 years.

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Abstract

In this study socio-demographic, deafness-related and diagnostic characteristics of hearing impaired children and adolescents referred to a national mental health service for deaf and hard of hearing children and adolescents were examined, as well as differences with characteristics of hearing referred peers with identified mental health problems. A total of 389 deaf and hard of hearing and 3361 hearing children and adolescents were derived from a database, all first referrals of patients of a centre for child and adolescent psychiatry over a 15 year period of time. With deaf and hard of hearing patients we found higher rates of environmental stress, as indicated by conditions such as more one parent families (38.6% versus 25.8%), and more parents with a low educational level (44.2% versus 31.1%). Moreover, deaf and hard of hearing patients were older at their first referral (10.8 versus 9.4 years) and had higher rates of pervasive developmental disorders (23.7% versus 12.3%) and mental retardation (20.3% versus 3.9%). Within the target group of deaf and hard of hearing patients, most patients were deaf (68.9%; 22.3% was severely hard of hearing), relatively few (13.7%) had a non-syndromal hereditary hearing impairment, and with relatively many (21.3%) a disabling physical health condition was found, especially among those with a pervasive developmental disorder (42.6%). These findings illustrate both the complexity of the problems of deaf and hard of hearing children and adolescents referred to specialist mental health services, and the need for preventive interventions such as aimed at early recognition.

Keywords: hearing loss, mental health, multiple disabilities, pervasive developmental disorders, mental retardation, environmental stress.

Highlights

- 389 hearing impaired and 3361 hearing children with psychiatric disorder were studied
- Age at first referral is higher with hearing impaired than with hearing referrals
- Clinical pictures of hearing impaired youth are often more complex
- Much distress, and high rates of physical and autistic spectrum disorders are found
- Those with low IQ or disabling physical health conditions are very vulnerable

1. Introduction

Specialist mental health service provision for deaf and hard of hearing children and adolescents occurs in a low incidence, highly specialized area of cure and care. Probably more than 1 in 1000 children in European countries have permanent, bilateral congenital hearing impairment (HI)¹ of moderate or greater severity (e.g., Davis & Parving, 1994; Fortnum & Davis, 1997), rising to another 50-90% among children 9 years of age and older, mainly due to late onset or progressive inherited HI, and, to a lesser extent, by acquired HI (approximately 4-9% of overall prevalence) and delayed confirmation of congenital HI (Fortnum et al., 2001).

Since the 1960s there has been an increasing recognition of the need for specialist mental health services for deaf and severely hard of hearing people in order to meet the visual-spatial and communicative needs of this small minority group with mental health problems more adequately than in generic mental health services (e.g., Rainer & Altshuler, 1966; Altshuler, 1971; Denmark & Warren, 1972; Schlesinger & Meadow, 1972). Specialist mental health services for HI children and their families bundle expertise in Psychiatry, medical and audiological aspects of HI, the influence of deafness and loss of hearing on development, as well as linguistic-communicative, systemic and socio-cultural aspects of deafness and other hearing impairments (e.g., Roberts & Hindley, 1999; Mathos & Broussard, 2005). Hearing staff-members need to be trained in sign language. Referral to specialist services should be guided by two considerations: the communication needs of the HI child and/or his HI family members and the complexity of the case (Hindley & Van Gent, 2002).

1.1. Added complexities of mental health problems in deaf and hard of hearing youth

As a group, deaf and hard of hearing children and adolescents are exposed to a number of factors that may add to the complexity of their mental health problems. Firstly, especially children with syndromal and acquired HI are particularly at risk of central nervous system disorders, other concomitant physical health disorders or concomitant intellectual impairment (Evans & Elliott, 1987; Hindley, 1997).

Secondly, m.i. linguistic-communicative problems (e.g., low language skills) may contribute to social deprivation and negatively affect psychological development and the sense of self (e.g., Calderon & Greenberg, 2003). Thirdly, deaf youth may more often experience environmental risk factors such as distress within the family, particularly in hearing families (e.g., Gregory, Bishop, & Sheldon, 1995; Hindley, 1999), the experience of traumatic life events such as bullying, especially in mainstream schooling (Smith & Sharp, 1994), and maltreatment and abuse, which might occur more often frequently in residential settings (Sullivan, Brookhouser, & Scanlan, 2000).

Besides the challenge of dealing with the complexity of cases (Heller, 1987), the scarce specialist mental health services must also actively deal with difficulties in reaching deaf youth with mental health problems and promoting accessibility of services. Communication problems between the deaf child and the hearing environment as well as diagnostic shadowing, i.e. the unwarranted assumption that deafness explains all problems in deaf children (Kitson & Thacker, 2000), may impede both the sharing of problems by HI children and adolescents and the exploration and recognition of their psychological problems by hearing key figures, thus contributing to lower service use. Findings from community surveys suggest that only about 25 % of hearing children and adults with serious mental health problems contact mental health services (e.g., Ford, Hamilton, Meltzer, & Goodman, 2007). The proportion of deaf adolescents with serious problems in contact with mental health services may be much smaller (less than 10%; Van Gent et al., 2007), indicating substantially lower mental health service utilization.

1.2. Present study

The present study is the first to examine a large number of characteristics in clinical samples of both hearing impaired and hearing children and adolescents over a longer period of time, i.e. 15 years. Comparing characteristics of hearing and HI children and adolescents who are referred to mental health services will help to identify specify factors that may add to the complexity of the mental health problems of deaf youth and factors that may impede contact with specialist mental health care services. We found only two studies of clinical samples of HI children

that made use of a hearing sample with mental health problems as comparison group (Van Gent & Hendriks, 1994; Willis & Vernon, 2002). Both studies reported higher rates of concomitant neurological, visual and other physical disorders, intellectual impairment and environmental distress, as indicated by increased rates of parental divorce and one-parent families. The greater prevalence of physical disorder in clinical samples may be largely explained by a relative underrepresentation of a non-syndromal genetic cause of HI combined with an overrepresentation of syndromal and acquired aetiologies of deafness (e.g., pre-, peri- or postnatal infection, prematurity or rhesus-antagonism) found in clinical samples (Goldberg, Lobb, & Kroll, 1975; Van Gent & Hendriks, 1994; Willis & Vernon, 2002). However, we found no study that examined the way physical disorders and mental retardation may add to the complexities of mental health problems of HI youth.

The first aim of the current study is to compare the socio-demographic, psychological and diagnostic characteristics of referred hearing impaired (HI) children and adolescents to corresponding characteristics of referred hearing youth. We expected to find increased rates of identified risk factors and additional factors complicating the clinical picture in the HI sample as compared to the clinical picture in the hearing patients. In addition we expected a higher mean age at first referral for deaf youth because due to deafness-related factors that may impede contact with specialist mental health care services. We also explored whether there are different shifts in (some of the) diagnoses of the referred HI patients as compared to referred hearing patients. We expected to encounter a shift in referrals with HI patients, from relatively more behavioural disorders to relatively more emotional disorders compared to the referral pattern with hearing patients, in line with the assumption that referral patterns differ over time, when the first need to cope with the most serious and disturbing behaviour problems is met. In addition we examined the influence of the parental hearing status on socio-demographic and diagnostic differences between referred HI and hearing children and adolescents. We expected more concomitant central nervous system disorders and other physical disorders due to an acquired cause, as well as developmental disadvantages related to the risk of a possibly less optimal

adaptation to deafness with referred HI patients of hearing parents in comparison with HI patients with one or two deaf parents (e.g., see Hindley & Van Gent, 2002; Marschark, 2007). We also examined the socio-demographic characteristics and psychiatric diagnosis of hearing children of HI parents, as growing up hearing in a family with profoundly or severely HI parents has been associated with the risk of communication problems between parents and their child, problems of the child to cope with a role of spokesperson or interpreter for its parents, which may lead to parentification at an early age (Singleton & Tittle, 2000), or the risk of social and emotional problems (Charlson, 2004). Therefore we expected to find a preponderance of emotional disorders in this specific subgroup.

The second aim is to better understand the way mental retardation and a disabling physical health condition may add to the complexities of diagnosis and treatment of mental health problems of deaf youth. To this end we examined the correlates of mental retardation and a disabling physical health condition with deafness-related and socio-demographic variables and with the psychiatric diagnosis. In a preliminary analyses we operationalized a disabling physical health condition by creating a combination of physical health problems that strongly differentiated referred HI youth attending special schools for deaf students with multiple disabilities from other referred HI youth. Research on HI children with multiple disabilities is scarce. The co-occurrence of multiple, i.e. physical or cognitive, disabilities and severe to profound HI has consequences for communication, education, mobility, living skills and learning (Knoors & Vervloed, 2011), and an increased risk of mental health problems (Sinkkonen, 1994).

2. Method

2.1. Participants

This study relies on archival data available within an Academic Centre for Child and Adolescent Psychiatry which delivers in- and outpatient services for hearing children and adolescents in a large, socio-demographically diverse region in the mid-western part of The Netherlands. An outpatient and outreaching consultation

service for deaf and hard of hearing children and adolescents and children of severely hearing impaired parents started as a department of the larger Academic Centre in 1987. Between 1993 and 2008 this specialized mental health service was the only centre in The Netherlands with a specialized inpatient, outpatient and outreaching consultation mental health service for deaf and hard of hearing patients from all over the country. The patients of this specialist department may be regarded as representative for the total clinical population of deaf and (severely) hard of hearing children and young people with serious mental health problems in The Netherlands. Deaf and -generally severely- hard of hearing individuals are characterised by the shared need for visual or otherwise adapted communication and special facilities which make communication and social interaction accessible, and which cannot be sufficiently met in regular local mental health services. The national specialist mental health department worked intensively together with the special educational organisations for the deaf and severely hard of hearing students, with the ambulatory specialist mental health services for the deaf and the hard of hearing and with other care organisations in the country to cover a countrywide network of educational, care and mental health services for this population. In addition the mental health service for the deaf and hard of hearing was sufficiently well-known in the country to get referrals from regular health and mental health services.

Socio-demographic and diagnostic data on all referred patients are registered in an electronic patient database in the Academic Centre, which is described by Treffers, Goedhart, Waltz, and Koudijs (1990). Specific data on (past) physical disorders and significant characteristics related to hearing impairment of 286 deaf or hard of hearing patients who completed the psychiatric assessment of their first admission at the Department for the Deaf and Hard of Hearing between January 1990 and January 2002, are registered in an additional database of patients referred to the specialist department. For the purpose of this study we used all records of the additional database. From the general patient database we selected all the records of first admissions who underwent a complete diagnostic assessment of the outpatients admitted between January 1990 and January 2005. 3750 Cases from the patient database were selected. 3339 cases were hearing

control patients of hearing parents (HOH) assessed in the regular mental health service. Assessments from the specialist mental health service included 362 deaf or hard of hearing children of hearing parents (DOH), 27 deaf or hard of hearing children of one (N=11) or two (N=16) deaf or hard of hearing parents (DOD) and 22 hearing children of one (N=3) or two (N=19) deaf or hard of hearing parents (HOD). Informed consent from participants was not required because data which could lead to identification were removed

2.2. Measures

The routine assessment procedures of the regular and the specialist centre were comparable, and based on a multi-informant approach and were performed by multidisciplinary teams of professionals. The standard procedure included, generally, two separate interviews with the parents in order to obtain information about the development and actual functioning of the child, at least two psychiatric interviews with the child, in many cases a family interview, a psychological assessment of significant cognitive, educational, neuropsychological and personality aspects, parental and teachers questionnaires, as well as self-reports with young people, a physical examination by an expert pediatrician in the field, and -upon parental or patient consent- information by others, such as school, primary care physician, social agencies, medical and paramedical professionals involved. The final diagnosis and treatment planning were decided upon at a diagnostic conference with the multidisciplinary team members involved and chaired by a child- and adolescent psychiatrist. All professionals of the specialist mental health service were experienced in working with deaf and hard of hearing children and adults and were expected to achieve high levels of sign language proficiency. If required, professional interpreters in sign language, in sign supported Dutch, in four-hand signing with deaf-blind individuals, or in other languages were involved.

2.2.1. Diagnosis

In this study, we used the broad diagnostic categories of (a) emotional disorder (DSM codes 296.00 to 296.70, 300.4, 311, 300.00-300.02, 300.20-300.29, 309.21,

309.81, 309.89, 313.00 and 313,21); (b) behavioral disorder (DSM codes 313.81, 313.82, 313.89, 312.00 - 312.90, 314.00, 304.01, 304.9); (c) pervasive developmental disorder (DSM codes 299.00, 299.10, 299.80); (d) mental retardation (DSM codes 317.00 – 318.20, 319); and (5) other diagnoses, for inter-diagnosis comparison of hearing and deaf groups of patients.

The DSM versions used with hearing and hearing impaired patients over time concerned DSM-III R (till 1994), DSM- IV (1994-2000) and DSM-IV R (from 2000).

2.2.2. *Intelligence Quotient (IQ)*

IQ was generally assessed using total, i.e. performance and verbal, IQ tests from the Wechsler series (WISC) with hearing patients. With most HI patients the performance scales of the Snijders-Oomen non-verbal intelligence test (SON) were used instead of the performance scales of the WISC tests (with 55% and 24% of the HI patients respectively; other tests were used with 8%, IQ was not assessed with 13%). In order to increase comparability, hearing norms were used for HI and hearing patients.

2.3. *Data analyses*

Firstly, we described the socio-demographic and psychiatric characteristics of hearing children of hearing parents (HOH), hearing children of deaf or hard of hearing parents (HOD) and deaf and hard of hearing children of hearing (DOH) or deaf or hard of hearing parents (DOD). Secondly, we examined whether the hearing status of the patients, i.e. hearing versus deaf or hard of hearing, had a unique contribution to the prediction of psychiatric diagnoses, over and above the contributions of socio-demographic variables. Thirdly, we used the additional database to demonstrate the associations of mental retardation and a disabling physical health condition with socio-demographic, deafness-related and psychiatric characteristics.

Analyses of Variance (ANOVA's) were used to compare continuous characteristics and χ^2 tests were used to compare categorical characteristics. In addition to the χ^2 tests, we identified cells that offer a substantial contribution

to the χ^2 statistic by using the $|\text{standardized residual}| > 2$ criterion suggested by Haberman (1973). Multivariate logistic regression analyses were used to examine the unique contributions of independent variables to the prediction of psychiatric diagnoses. All analyses were conducted using the statistical package SPSS 18.0; α was set at 0.05.

3. Results

3.1. Socio-demographic and psychiatric differences between patient groups

Substantial differences were found in the distributions of the socio-demographic variables age, performal IQ, family composition, parental country of origin and highest parental educational level, across the HOH, HOD, DOH and DOD patient groups. As shown in Table 1, less favorable family compositions, i.e. child not living with two biological parents, parents with low levels of education and one or both parents being foreign-born, were more often found with DOH patients (Standardized Residuals were -2.7, 2.9 and 13.8 respectively) and, to a lesser extent with DOD patients. In addition, we found that only 1% of the HOH patient's lives in a residential setting most of the time compared to 44% of the DOH, 30% of the DOD and 14% of the HOD patients.

HOH patients showed a higher mean level of performal IQ as compared to DOH patients and DOD patients. This finding reflects the relatively high percentage of deaf and hard of hearing patients with mental retardation (see Table 2). The difference between the mean IQ's of HOH and DOH patients decreased from 18.9 to 10.7 after removal of all patients with mental retardation, but the differences between the groups remained significant ($F(3,1945) = 21.29, p < 0.0001$). Mean IQ difference between HOH and DOD patients decreased in a comparable way, from 16.4 to 9.8.

Fewer emotional disorders were found in DOH patients as compared to the remaining three patient groups ($|\text{standardized residual}| > 2$, see Table 2). More specifically, we found a significantly lower percentage of anxiety disorders with DOH patients (18.0% versus 27-33%; $\chi^2_{(3,3670)} = 14.15, p < 0.005$) and a higher percentage of depressive disorders with HOD patients (36.4% versus 14 - 17.1%;

Table 1.
Socio-demographic Characteristics

	HOH N= 3339	HOD N=22	DOH N= 362	DOD N=27	χ^2 or F
Girls, %/SR	30.8/-0.5	45.5/1.2	34.5/1.1	33.3/0.2	$\chi^2_{(3,3670)} = 4.18$
Age, mean (SD)	9.4 (3.6) ¹	9.4 (3.7)	10.8 (4.4) ²	11.1 (4.1) ²	$F(3,3746)=19.22^{***}$
Performal IQ ^a , mean (SD)	102.5 (16.8) ¹	93.5 (22.3)	83.6 (26.3) ²	86.1 (24.0) ²	$F(3,2075)=73.19^{***}$
Lives with both biological parents, %/SR	74.2/1.0	59.1/-0.8	60.8/-2.7	70.4/-0.1	$\chi^2_{(3,3670)} = 31.82^{***}$
One or both parents foreign-born, %/SR	8.4/-4.9	18.2/1.0	35.6/13.8	33.3/3.4	$\chi^2_{(3,3670)} = 256.11^{***}$
Highest parental education ^b %/SR					$\chi^2_{(6,3108)} = 32.62^{***}$
<i>Low</i>	31.1/-1.2	60.0/2.2	43.0/2.9	61.1/2.1	
<i>middle</i>	38.7/0.4	35.0/-0.2	34.1/-1.0	16.7/-1.5	
<i>High</i>	30.2/0.8	5.0/-2.0	22.9/-1.9	22.2/-0.6	

Note: HOH: hearing patients of hearing parents; HOD: hearing patients of deaf or hard-of-hearing parents; DOH: deaf and hard of hearing patients of hearing parents; DOD: deaf and hard of hearing patients of deaf or hard of hearing parents; SR: Standardized Residual. ^{***}; $p < 0.001$. ^{1,2}: different superscripts indicated different means using the Ryan-Einot-Gabriel-Welsh Range ($p < 0.05$); [‡]: due to missing data number of cases are: HOH: 1836, HOD: 14, DOH: 205, DOD: 24; ^b: due to missing data number of cases are: HOH: 2862, HOD: 20, DOH: 249, DOD: 18.

$\chi^2_{(3,3670)} = 8.46, p < 0.05$). After removal of all patients with mental retardation, we found higher percentages of both emotional disorders (32.6% instead of 27.6%) and behavioral disorders (38.2% instead of 35.4%) and lower percentages of pervasive developmental disorder (20.8% instead of 24.3%) for DOH patients selectively.

A remarkable difference was found for the trend of referrals for behavioral disorders over 5 periods of 3 year each only. Nearly equal rates of behavioral disorder in each of the 5 periods were found in the HOH group, but a strong decline of the rates was found in the group of hearing impaired patients. A one sample chi-square test indicated a significant declining rate of behavioral disorders in the DOH group compared to the expected equal frequencies (as found in the HOH group): $\chi^2_{(4)} = 9.53, p < 0.05$. No differences between the HOH en DOH patient groups were found in the referral trends for the remaining disorders.

Table 2.

Broad diagnostic categories of study groups

Diagnostic Category	Percentage with Diagnosis / Standardized Residual				$\chi^2_{(3,3750)}$
	HOH N= 3339	HOD N=22	DOH N= 362	DOD N=27	
Emotional disorder	37.7/0.9	50.0/1.3	27.6/-2.9	37.0/0.0	16.01***
Behavioral disorder	28.7/-0.7	22.7/-0.6	35.4/2.1	29.6/0.0	7.41 n.s.
Pervasive developmental disorder	12.3/-1.8	9.1/-0.6	24.3/5.6	14.8/0.2	40.50***
Mental retardation	3.9/4.2	9.1/0.7	20.4/11.9	18.5/2.8	117.47***

Note: HOH: hearing patients of hearing parents; HOD: hearing patients of deaf or hard-of-hearing parents; DOH: deaf and hard of hearing patients of hearing parents; DOD: deaf and hard of hearing patients of deaf or hard of hearing parents. n.s.: not significant; ***: $p < 0.001$.

Table 3.

Mental Retardation, Cause of Deafness and Physical Health Problems by Type of School of Deaf and Hard of Hearing Patients.

Characteristic	Type of school		Total n (%)	$\chi^2_{(df, n)}$
	S. Mult. Hand. ^a n (%) / SR	Other n (%) / SR		
Mental Retardation	28 (37.3)/ 3.4	30 (13.9)/ -2.0	58 (19.9)	$\chi^2_{(1,286)}=19.17^{***}$
Cause of hearing impairment				$\chi^2_{(5,286)}=29.01^{***}$
Hereditary, non-syndromal	7 (9.3)/ -1.0	33 (15.3)/ 0.6	40 (13.7)	
Syndromal	8 (10.7)/ -0.2	25 (11.6)/ 0.1	33 (11.3)	
Rubella	24 (32.0)/ 4.0	18 (8.3)/ -2.4	42 (14.4)	
Meningitis	6 (8.0)/ -0.5	23 (10.6)/ 0.3	29 (10.0)	
Otherwise acquired	9 (12.0)/ -0.9	17 (7.9)/ -0.5	26 (8.9)	
Unknown	21 (28.0)/ -1.8	100 (46.3)/ 1.1	121 (41.6)	
Past Physical disorders ^b				
Ear and mastoid	38 (50.7)/ -1.0	130 (62.2)/ 0.6	168 (59.2)	$\chi^2_{(1,286)}=3.04$
Eye	39 (52.0)/ 3.3	48 (23.0)/ -2.0	87 (30.6)	$\chi^2_{(1,286)}=21.90^{***}$
Neurological motor disorder	41 (54.7)/ 2.7	61 (29.2)/ -1.6	102 (35.9)	$\chi^2_{(1,286)}=15.57^{***}$
Epilepsy	9 (12.2)/ 3.0	4 (2.0)/ -1.8	13 (4.6)	$\chi^2_{(1,286)}=12.76^{***}$
Respiratory system	11 (14.7)/ -1.2	49 (23.4)/ 0.7	60 (21.1)	$\chi^2_{(1,286)}=2.55$
Circulatory system	20 (26.7)/ 2.2	27 (12.9)/ -1.3	47 (16.5)	$\chi^2_{(1,286)}=7.55^{**}$
Peri- or neo-natal	34 (45.3)/ 0.7	80 (38.3)/ -0.4	114 (40.1)	$\chi^2_{(1,286)}=1.14$
Other	32 (42.7)/ 0.2	86 (41.1)/ -0.1	118 (41.5)	$\chi^2_{(1,286)}=0.05$
Four or more past phys. disorders	36 (48.8)/ 2.5	54 (25.8)/ -1.5	90 (31.7)	$\chi^2_{(1,286)}=12.52^{***}$
Three or more actual phys. disorders	19 (25.7)/ 1.9	27 (13.2)/ -1.2	46 (16.5)	$\chi^2_{(1,286)}=6.18^*$
Four or more hospital admissions	21 (28.0)/ 1.7	34 (16.1)/ -1.0	55 (19.2)	$\chi^2_{(1,286)}=5.03^*$

Note: ^a: S. Mult. Dis. = Special school for deaf youth with multiple handicaps; ^b: A past physical disorder is defined as a disorder for which specialist medical care has been provided in the past. SR = Standardized Residual; *: p<0.05; **: p<0.01; ***: p<0.001.

Multivariate logistic regression analyses were used to examine the associations of hearing status (i.e. HOH patients versus all deaf and hard of hearing patients) with each of the four diagnostic categories after controlling for gender, age, family composition, parental country of origin and highest parental educational level. We found that even after controlling for the other socio-demographic variables, hearing patients were more likely to have an emotional disorder than deaf and hard of hearing patients (OR= 0.68, $p < 0.001$, 95% CI: 0.51 – 0.90), while deaf and hard of hearing patients were far more likely than hearing patients to have a pervasive developmental disorder (OR= 3.01, $p < 0.001$, 95% CI: 2.14 – 4.26) or mental retardation (OR= 4.08, $p < 0.001$, 95% CI: 2.65 – 6.29). After removal of all patients with mental retardation, hearing status was no longer a significant predictor of emotional disorder while the OR of hearing status dropped to 2.55 (95% CI: 1.74 – 3.74) for the prediction of pervasive developmental disorder.

3.2. Preliminary analysis: operationalisation of disabling physical health condition

As shown in Table 3, higher rates of mental retardation (MR), past physical disorders and rubella-induced deafness were found in patients attending a school for deaf children and adolescents with multiple handicaps (the MH group) compared with other deaf and hard of hearing children and adolescents (the non-MH group). It may be noted that there was a high rate of acquired causes in both groups, and this was more pronounced for the MH group than for the non-MH group. In line with this finding and the notion that acquired causes of HI coincide more often than a non-syndromal genetic HI with other physical disorders, histories of serious eye disorder, neurological motor disorder, epilepsy or circulatory system disorder were found significantly more often among MH patients than among non-MH patients. The presence of a more complicated physical health condition for many patients from the MH group in particular is illustrated by a more serious history of physical disorders, the presence of more actual physical disorders and a history of more hospital admissions for physical disorders in the group of MH patients than in the group of non-MH patients.

Receiver Operating Characteristic (ROC) analysis was used to create a combination of past physical disorders and rubella-induced deafness that best

discriminated between MH and non-MH patients. First, we found that the area under curve (AUC) of the sum score of the four best predictors (rubella-induced deafness, histories of serious eye disorder, neurological motor disorder and epilepsy) was higher than the AUC of all five significant predictors (i.e. including a history of circulatory system disorder): .733 (S.E. .036) versus .722 (S.E. .036). The ROC curve indicated 2 as cut-off point for the sum score of the four best predictors. Consequently, disabling physical health condition (DPHC) was defined by the presence of two or more of the following characteristics: rubella-induced deafness, a history of specialist medical care for visual problems, for neurological motor disorder(s) or for epilepsy. A substantial association was found between DPHC and the distinction between MH and non-MH patients: kappa= 0.38, $p < .0001$.

As DPHC was not associated with mental retardation we decided to combine DPHC and mental retardation in the Multiple Disabilities Index (MDI) defined as: 0= no MR and no DPHC, 1= MR without DPHC, 2 = DPHC with or without MR. The Multiple Disabilities Index was strongly associated with the MH/non-MH distinction: OR=3.98, $p < 0.0001$ (95% CI: 2.72 – 5.83), a score of 0 on this index was found in 78.7% of the non-MH group and 28.0% of the MH-group.

3.3. Deafness-related Characteristics and the Multiple Disabilities Index

In table 4 characteristics of deafness are shown of the total HI sample, the subgroup with mental retardation (MR) and the subgroup with a disabling physical health condition (DPHC), i.e. the two subgroups which largely describe the population with significant multiple disabilities, and the subgroup without multiple disabilities. Irrespective of the presence or absence of multiple disabilities, most patients in the total sample were deaf (69%; according to one of the classification criteria used in the Netherlands) and had two hearing parents (90.3%). Nearly all deaf and hard of hearing patients had a perceptive HI (90.7%), were prelingually HI (HI at birth or before 19 months of age: 95.3%), and had no Cochlear Implant (97.9%). A large majority (83.6%) had no HI relatives.

With respect to the distribution of etiologies of hearing impairments of more than 40dB, especially more rubella with referred patients (14.4%) were found as

compared to rubella as a cause of HI in a general population of moderately to profoundly HI children (4.1% for all prenatal causes including infections in the UK population; Fortnum et al., 2001), as were fewer referrals with non-syndromal genetic HI (13.7% versus > 20% in the same population of HI children; Fortnum et al., 2001) which co-occurs less frequently with multiple organic dysfunctions (Evans & Elliott, 1987; Walch, Anderhuber, Köle, & Berghold, 2000).

Primary communication modes between child with parents and parents with child were associated with the degree of HI ($\chi^2_{(6,271)}=51.75$, $p<0.001$ and $\chi^2_{(8,271)}=42.58$, $p<0.001$, respectively), especially because of differences in the use of speech. In the child-parent communication speech was used by 9% of the deaf, by 21% of the severely HI patients and by 58% of the mildly to moderately HI patients.

A Disabling Physical Health Condition (DPHC) was present in 61 (21%) of the HI patients. Patients with a DPHC were more severely to profoundly hearing impaired than other patients from the other groups; patients with DPHC were on average older at the time of referral than patients with mental retardation (MR), who in turn were older than others without multiple disabilities. The great majority of parents of children with either DPHC or MR were found to be hearing. The modes of both child-parent and parent-child communication were also strongly associated with the multiple disabilities index (see Table 4): Especially HI patients with DPHC but also patients with MR used speech only significantly less often than other patients, and significantly more often than basic communication other than sign or speech. Finally, a much larger number of patients with multiple disabilities stayed in a residential setting than without multiple disabilities: DPHC patients were admitted more often (67.2%) than MR patients (46.3%) and other patients (35.3%)

Emotional disorder was found significantly more often in patients without mental retardation and DPHC, pervasive developmental disorder was found significantly more often in patients with DPHC (see Table 5). Multivariate logistic regression showed that the Multiple Disabilities Index remained associated with emotional disorder and pervasive developmental disorder after controlling for the socio-demographic variables gender, age, family composition, parental country

Table 4.
Deafness-related Characteristics by Multiple Disabilities Index

	Multiple disabilities Index			Total n (%)	$\chi^2_{(df;n)}$
	None n (%) / SR	MR ^a n (%) / SR	DPHC ^b n (%) / SR		
Degree of hearing impairment ^c					$\chi^2_{(4;273)} = 11.30^*$
Deaf (>89 dB)	126 (72.0)/ 0.5	22 (57.9)/ -0.8	40 (66.7)/ -0.2	188 (68.9)	
Severely HH (60-89 dB)	30 (17.1)/ -1.5	12 (31.6)/ 1.2	19 (31.7)/ 1.5	61 (22.3)	
Mild. to mod. HH (20-59 dB)	19 (10.9)/ 0.9	4 (10.5)/ 0.4	1 (1.7)/ -1.9	24 (8.8)	
One/ both parents hearing impaired	22 (12.3)/ 1.2	4 (10.5)/ 0.2	0 / -2.3	26 (9.5)	$\chi^2_{(2;273)} = 7.53^*$
Lives (partly) in residential setting	65 (35.3)/ -1.7	19 (46.3)/ 0.3	41 (67.2)/ 2.8	125 (43.7)	$\chi^2_{(2;286)} = 19.07^{***}$
Type of school					n.e.
Special school for deaf/HH	128 (69.6)/ 2.5	16 (39.0)/ -1.4	16 (26.2)/ -3.1	160 (55.9)	
Special school mult. hand. ^c	20 (10.9)/ -4.1	19 (46.3)/ 2.5	36 (59.0)/ 5.0	75 (26.2)	
Ordinary school	19 (10.3)/ 1.7	1 (2.4)/ -1.1	0 / -2.1	20 (7.0)	
No school ^d	17 (9.2)/ -0.7	5 (12.2)/ 0.3	9 (14.8)/ 0.9	31 (10.8)	
Parent(s)-child communication					$\chi^2_{(8;286)} = 36.11^{***}$
Speech only	54 (29.3)/ 1.3	9 (22.0)/ -0.3	7 (11.5)/ -2.1	70 (24.5)	
Speech with signing	66 (35.9)/ 1.4	9 (22.0)/ -0.9	11 (18.0)/ -1.7	86 (30.1)	
Signing	28 (15.2)/ 0.2	5 (12.2)/ -0.4	9 (14.8)/ 0.0	42 (14.7)	
Other (e.g., gestures, writing)	18 (9.8)/ -2.1	9 (19.5)/ 0.5	20 (32.8)/ 3.3	46 (16.1)	
Unknown	18 (9.8)/ -1.7	10 (24.4)/ 1.6	14 (23.0)/ 1.7	42 (14.7)	

Child-parent(s) communication						$\chi^2_{(6,286)} = 38.65^{***}$
Speech only	38 (20.7)/ 1.4	4 (9.8)/ -1.1	5 (8.2)/ -1.6	47 (16.4)		
Speech with signing	76 (41.3)/ 1.0	17 (41.5)/ 0.5	12 (19.7)/ -2.2	105 (36.7)		
Signing	39 (21.2)/ 0.6	6 (14.6)/ -0.7	10 (16.4)/ -0.5	55 (19.2)		
Other (e.g., gestures, writing)	31 (16.8)/ -2.8	14 (34.1)/ 0.8	34 (55.7)/ 4.2	79 (27.6)		

Notes. ^a: MR = mental retardation; ^b: DPHC = Disabling Physical Health Condition. ^c: Degree of hearing impairment is quantified as the unaided average hearing loss for the better ear; mild. = mildly, mod. = moderately, HH = hard of hearing; ^d: no school includes children who are too young (7) or adolescents who finished school (7). ^e: Special school mult. hand. = special school for the multiple handicapped.; SR = Standardized Residual; ^{*}: p<0.05; ^{**}: p<0.01; ^{***}: p<0.001; n.e. = not examined because part of the criteria of the multiple disabilities index.

Table 5.
Socio-demographic Characteristics and Psychiatric Diagnosis by Multiple Disabilities Index

	Multiple disabilities index			Total n (%) or mean(sd)	χ^2 _(df,N) or F(df1,df2)
	None n (%) / SR	MR ^a n (%) / SR	DPHC ^b n (%) / SR		
Gender: girl	56 (30.4)/ -0.6	16 (39.0)/ 0.7	22 (36.1)/ 0.4	94 (32.9)	χ^2 _(2,286) = 1.48
Age, mean (SD)/ n	10.4 (4.4)/ 177	11.7 (3.7)/ 39	13.0 (4.1)/ 70	11.2 (4.4)	F(2,283) = 10.27***
IQ, mean (SD)/ n	94.5 (15.3)/ 147	62.9 (10.0)/ 34	81.5 (19.9)/ 37	87.4 (19.3)	n.e.
Lives with both biol. parents	118 (64.1)/ 0.4	20 (48.8)/ -1.1	39 (63.9)/ 0.2	177 (61.9)	χ^2 _(2,286) = 3.49
One/both parents foreign-born	76 (41.3)/ 0.8	20 (48.8)/ 0.3	34 (55.7)/ 1.2	130 (45.5)	χ^2 _(2,286) = 4.06
Highest parental education					χ^2 _(4,211) = 8.26
Low	57 (39.9)/ -0.8	17 (65.4)/ 1.6	20 (47.6)/ 0.3	94 (44.5)	
Middle	52 (36.4)/ 0.7	3 (11.5)/ -1.9	15 (35.7)/ 0.3	70 (33.2)	
High	34 (23.8)/ 0.4	6 (23.1)/ 0.1	7 (16.7)/ -0.8	47 (22.3)	
Emotional disorder	57 (31.0)/ 1.9	5 (12.2)/ -1.6	7 (11.5)/ -2.0	69 (24.1)	χ^2 _(2,286) = 13.24***
Behavioral disorder	75 (40.8)/ 0.9	13 (3.7)/ -0.5	17 (27.9)/ -1.1	105 (36.7)	χ^2 _(2,286) = 3.79
Pervasive developmental dis.	36 (19.6)/ -3.6	12 (29.3)/ 0.4	26 (42.6)/ 2.6	74 (25.6)	χ^2 _(2,286) = 12.99**
Mental Retardation	0 / -6.1	41 (100)/ 11.3	17 (27.9)/ 1.3	58 (20.3)	n.e.
Sexual abuse in clinical diagn.	4 (11.1)/ 0.8	4 (11.1)/ 0.8	4 (7.3)/ 0.0	19 (7.3)	χ^2 _(2,259) = 0.91
Other disorders ^c	63 (34.2)/ -0.9	16 (39.0)/ 0.1	30 (49.2)/ 1.4	109 (38.1)	χ^2 _(2,286) = 4.35

Notes. ^a: MR=mental retardation; ^b: DPHC: Disabling Physical Health Condition with or without MR; ^c: Other disorders include impulse control disorders not elsewhere classified (10.0%), sleep disorders (9.0%), elimination disorders (7.2%), tic disorders (5.2%) and specific development disorders (axis II, 6.9%); SR= Standardized Residual; *: p<0.05; **: p<0.005; ***: p<0.001; n.e.= not examined because IQ and the presence of MR are implied in the conditions of the multiple disabilities index.

of origin and highest parental educational level. Additionally, highly probable or proven sexual abuse was diagnosed in more than 11% of cases irrespective of the presence of MR and in more than 7% of cases with DPHC.

4. Discussion

This study on referrals to the national specialist mental health service for deaf and hard of hearing children and adolescents in The Netherlands during a period of 15 years concerns the largest hearing impaired (HI) clinical sample of children and adolescents studied to date. The first main aim was to compare socio-demographic characteristics and rates of mental health problems in the HI and a hearing clinical sample. The second main aim was to examine the prevalence and correlates of serious, possibly deafness-related, disabilities in the HI sample.

A number of differences were found between the HI and the hearing clinical samples. First, HI referrals were on average older than hearing referrals, irrespective of the hearing status of their parents. Second, a higher rate of environmental distress was found in the HI referrals, as suggested by increased rates of parental divorce and one-parent families, of immigrant parents, and of parents with a lower educational level. Third, the HI sample showed higher rates of pervasive developmental disorder and mental retardation and lower rates of emotional disorders. Fourth, a lower mean IQ was found in the HI sample; this difference remained after removal of all patients with mental retardation.

With regard to the second aim, we first defined a disabling physical health condition (DPHC) by the presence of two or more of the following characteristics: rubella-induced deafness, a history of specialist medical care for visual problems, for neurological motor disorder(s) and for epilepsy. We found indications that this disabling physical health condition (DPHC) is associated with added complexity of mental health problems, even more so than mental retardation. Patients with DPHC were on average older at the time of referral than patients with MR, who were in turn older than the remaining patients. In addition patients with DPHC more often used other modes of communication than speech and/or signing with their parents (and vice versa) and all DPHC patients had hearing parents. DPHC

patients were also more often diagnosed with a pervasive developmental disorder than patients with MR who in turn had a pervasive developmental disorder more often than patients from the group without disabilities. DPHC patients were found to live more often in a residential setting than MR patients who in turn were admitted more often than non-MR-non DPHC patients. These findings illustrate that patients with multiple disabilities, especially patients with DPHC, but also patients with MR, are much more dependent on intensive professional help, education and support as compared to members of the non-MR-non-DPHC group.

4.1 Age

A number of factors may contribute to the older mean age of the HI sample. First, linguistic communication problems between hearing environment and a HI child may impede sharing of problems by the child and recognition of problems by hearing parents, hearing teachers or inexperienced hearing professionals (Van Gent et al., 2007). In addition, serious communication problems between child and parent and vice versa are to be expected with the oldest subgroups of HI patients, i.e. the patients with mental retardation or a disabling physical health condition (DPHC), because their mode of communication was characterised by more simple and primitive modes of communicating far more often than speech, signing or a combination of both, as compared to their non DPHC non MR hearing impaired peers. Second, lack of agreement on the significance of problems, their impact and the preferred interventions between parents, teachers and others may postpone referral to mental health services, part of which may reflect cultural differences between deaf and hearing individuals (e.g., Hindley, Hill, & Bond, 1993), as well as different perceptions of problem behaviour according to the different perspectives of people involved (Fombonne, 2002). Third, the coexistence of HI and mental health problems may lead caregivers to assume prematurely that HI explains all, the phenomenon of diagnostic shadowing (Kitson & Thacker, 2000). Especially in the case of pervasive developmental disorder, which prevailed especially in the HI patients with DPHC, it may have been difficult to differentiate developmental delays due to physical interferences or a cognitive impairment in a HI child

from a developmental disorder characterised by restricted or abnormal social involvement and often occurring atypical sensory responses (Rogers & Ozonoff, 2005). Finally, the accessibility of the few specialist mental health services for HI children and young people throughout the country is restricted due to a long travel distance to such services for families with HI children, combined with a limited opportunity to deliver outreaching services closer to home and schools of potential referrals, due to economic reasons. This may have contributed to the undesirable prolongation of seeking help with and service provision by dedicated professionals in the large educational organisations, who - however- are not specifically trained in the recognition and assessment of psychiatric disorders.

4.2 IQ

The difference of about 18 points in average performal IQ of HI and hearing control-patients is much larger than the 4 points difference between larger non-clinical populations of hearing and deaf children (Meadow, 1980). The larger difference found in this study can be explained by the high prevalence of HI patients with mental retardation referred to the specialist service for HI children. A higher prevalence of low IQs in populations of HI children and adolescents than in hearing populations is to be expected as brain damage is a common underlying cause of both HI and cognitive impairment (e.g., Vernon, 1968/2005). Brain damage in itself is one of the main known risk factors to mental health disorders, as is cognitive impairment (e.g., Friedman & Chase-Lansdale, 2002). In this study we found a particularly low mean IQ (81.5) in HI patients with a disabling physical health condition (DPHC), while a higher mean IQ (94.5, approaching the mean of the hearing sample) was found with the other HI patients, i.e. when the patients with MR were excluded. In addition, the considerable difference in rates of mental retardation between the HI and the hearing populations in this study may be partly explained by the not unusual practice of referring hearing children or adolescents with MR and mental health problems to services for the multiple handicapped, while all HI children and youth including children with MR were primarily referred to the new national mental health service for deaf and hard of hearing children and young people.

4.3 *Environmental adversity*

A number of findings may indicate higher levels of environmental adversity in the referred HI population. Firstly, hearing children of HI parents and HI children of hearing parents lived in one-parent families more often than hearing children of hearing parents and HI children of HI parents. This may suggest that aural and concomitant communicative and socio-cultural differences between a child and its parents may be associated with an increased prevalence of parental divorce and a broken home. Both a communicative mismatch and the absence of satisfying communication between the child and his parents (e.g., Wallis, Musselman, & MacKay, 2004), parental distress, and divorce (e.g., Goodman, 2002) may all contribute to mental health problems in children. Secondly, significantly more HI patients from non-Caucasian or Mediterranean origin were found among the HI referrals than among the hearing referrals. It may be hypothesized that accumulation of health-related and aversive socio-economic risk factors in families from this minority (e.g., see Stacey, Fortnum, Barton, & Summerfield, 2002) has rendered HI children more vulnerable to mental health problems (e.g., see Friedman & Chase-Lansdale, 2002). Alternatively, better educational and mental health care facilities in The Netherlands may have attracted parents from abroad to present their HI child for assessment and treatment in one of the scarce mental health centres for the deaf and the hard of hearing in Europe. Thirdly, the educational level of HI parents differed significantly from hearing parents of referred children, either HI or hearing. This is consistent with the finding of lower educational (Traxler, 2000, Antia, Jones, Reed, & Kreimeyer, 2009) and employment (Winn, 2007) outcome among deaf school leavers and adults, both of which are recognized as cumulative risk factors that may add to the vulnerability of the child (e.g., Friedman & Chase-Lansdale, 2002).

4.4 *Diagnostic groups*

Prevalences of emotional disorder, pervasive developmental disorder and mental retardation were found to vary significantly between the four patient groups: hearing patients of hearing parents (HOH), hearing patients of one or two deaf or hard of hearing parents (HOD), deaf or hard of hearing patients of hearing parents

(DOH) and deaf or hard of hearing patients of one or two deaf or hard of hearing parents (DOD). The highest prevalence of emotional disorders was found in HOD patients. Upon further analysis we found an especially high rate of depression in this group (36.4% versus a mean prevalence of 17.3% in the other groups). Whether this reflects high emotional distress as a consequence of psychological problems balancing between two cultures and recurrent problems between parents and child (e.g., Singleton & Tittle, 2000) needs to be studied further. With regard to the broad category of behavioral disorders more disorders were found in HI children of hearing parents than in either HI children of HI parents or hearing children of hearing parents from the control group but the difference did not prove significant. The difference became significant when omitting all referrals with mental retardation. However, the rate of behavioral disorders in the HI referrals declined over the 15 years of study. A gradual decline of the initially raised rate could indicate that the most urgent demand for assessment and treatment of serious disturbing problem behaviour has been dealt with in the first phase of the new mental health service. Given the often very complex diagnostic presentations in HI patients (Heller, 1987) it might also be hypothesized that psychiatric diagnoses made in the new service have become more differentiated through the experience and gained - differential diagnostic- insights over time. It may take considerable time to differentiate between symptoms, to interpret behavior, and to understand how moods and affect may be displayed in HI patients (Evans & Elliott, 1987). For instance, feelings of impotence, anxiety, sadness or frustration with difficulties of communication may lead to opposition (Kelly et al., 1993) particularly in HI children and young people who have difficulty expressing him or herself in a hearing world. Finally, it is tempting to speculate that the increased attention for better communication with HI and recognition of special communicative needs in education over the years has contributed to a gradual decline of behavioral disorder, as has been proposed in a Swedish study by Sinkkonen (1994). The finding of a preponderance of pervasive developmental disorder (PDD) in the HI group is consistent with findings in other studies (Juré et al., 1991; Rosenhall et al., 1999), and has been associated with a common cause for both. Particularly brain dysfunction or damage of prenatal origin has been thought to play a role in the

aetiology of the combination of HI and PDD (e.g., Juré et al., 1991). In this study we found that PDD was associated with a disabling physical health condition (DPHC), indicating the presence of a neurological or visual disorder or rubella-induced deafness: PDD was found in 42.6% of the patients with a DPHC.

4.5 *Other findings*

Other findings are worth mentioning. The finding of a rate of 7-11% of highly likely or proven sexual abuse illustrates the considerable risk of abuse in children and young people with disabilities in general (Sullivan et al., 2000) including children and young people with limited speech and language skills (Sobsey & Varnhagen, 1988) and hearing impairments (Sullivan et al., 2000) which warrants for specific attention at assessments and prevention programs, as many cases may be missed. Secondly, and not surprisingly, the communication mode at home was related to degree of hearing loss with gradually more use of speech only in conjunction with a declining degree of hearing impairment. Thirdly, we expected that the main characteristic of the children attending special schools for students with multiple disabilities (MD) would be an IQ below 70 according to the main formal criterion for admission to those schools. However, mental retardation was found in only 37.3% of the patients attending this type of school, the majority of referred MD students belonged to a category that had been admitted on the basis of a so-called “rational departure of the rule”, indicating the need for intensified educational attention for other children and young people with problems with learning, social interaction or behavior. In this study children and adolescents with a complex physical health condition were identified as the majority of patients with multiple disabilities, many of whom attend special school programs for multiply handicapped students. Findings from this study support the evidence of a preponderance of acquired causes among children and adolescents with multiple disabilities, albeit predominantly of prenatal origin rather than perinatal origin as found by Admiraal and Huygen (1999) in deaf people with intellectual disabilities. The high rate of physical co-morbidity in this clinical population, and especially with patients with multiple disabilities, may also reflect the significance of neurological and other physical disorders as potential risk factors

to psychopathology. Moreover, the findings support the view that HI children with multiple disabilities are challenged in many domains of functioning (Knoors & Vervloed, 2011) which may cumulatively add to the risk of mental health disorder. Fourth, as during this study the number of implanted and referred children was only small, this sample may be viewed as representative of the majority of Dutch non-implanted HI children and adolescents with serious mental health problems in the “pre-implant period”. Research is needed to measure the effect of CI on the prevalence of psychopathology, as to date no relation with psychiatric diagnosis was found in a population based study of children and adolescents, using diagnostic parental interviews and parental and teachers’ questionnaires (Fellinger, Holzinger, Sattel, Laucht, & Goldberg, 2009). Similarly, the degree of hearing loss and CI use were not related to the increased level of self-reported depression in HI children as compared to the level of self-reported depression in hearing control children (Theunissen, Rieffe, Kouwenberg, Soede, Briaire, & Frijns, 2011).

Finally, degree of hearing impairment was not related to psychiatric diagnosis. In addition, the subgroup of mildly to moderately hard of hearing children and adolescents (8.8 % of the total HI sample) did not differ from the more severely HI majority in socio-demographic and cognitive characteristics.

4.6 Limitations

Firstly, the diagnostic data were only partly obtained by a combined approach of standardized diagnostic interviews and questionnaires. However, one could take the position that the validity of the diagnostic classifications used in this study is even higher than the validity of standardized diagnostic measures as our diagnoses result from an extensive - multi-disciplinary and multi-informant- approach to psychiatric diagnosis, based on clinical diagnostic interviews with the child and with the parents, a medical assessment, a psychological assessment using standardized measurements bringing together information from all informants and integrating the contributions from patient, parents, teacher and the professionals involved. Secondly, findings from this study may not be generalized to whole populations as they only reflect problems and characteristics of a referred population with

severe mental health problems. However, it seems likely that these findings reflect the problems and characteristics of the majority of HI children and adolescent with serious mental health disorders, albeit specifically within the mental health system in The Netherlands. Thirdly, no data was obtained on children and young people with psychiatric problems who did not make use of their referral to the specialist service or those who had serious but not recognized psychiatric problems. In general populations the proportion of children with a psychiatric disorder not using mental health services may be about 75% (e.g., Ford, Hamilton, Meltzer, & Goodman, 2007), but preliminary data with deaf adolescents suggests that underconsumption may be even more substantial in deaf populations (Van Gent et al., 2007). Whether the non-users tend to have milder or more serious problems, remains to be clarified.

5. Conclusions

Deafness does not produce any specific psychiatric syndrome (Goldberg et al., 1975), but specific factors related to deafness (e.g., degree, aetiology, physical comorbidity), cognition (IQ), communication (e.g., quality) and demographic circumstances (e.g., parental distress, ethnic background, residential setting) may help to identify characteristics of specific clinical subgroups and to specify risk factors to varying mental health disorders which may be cumulative. This data demonstrates that differential diagnosis in HI children and young people warrants a high degree of combined expertise in medical-audiological aspects of HI, the influence of deafness on development and social interactions, socio-cultural and communicative aspects. It highlights factors which may be the focus of more specific preventive interventions, such as those aimed at the early recognition and treatment of known risk factors and early screening for psychological problems. These findings also support the notion that a multi-informant approach by a multi-disciplinary team of specialized mental health professional, trained in communicating with HI individuals and their families, is warranted in order to meet the mental health needs of the children and adolescents with and without cognitive or other comorbidity and to deal with the high prevalence of disorders in this heterogeneous minority population.

¹ Note

For practical reasons the abbreviation HI is used for the terms hearing impairment or hearing impaired to indicate deaf and hard of hearing children and adolescents throughout the text of this article.

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Chapter

General discussion

Introduction

The main aim of this thesis is to expand the knowledge of mental health problems with deaf and severely hard of hearing children and adolescents in the following domains:

- The prevalence of mental health problems in this population and a comparison with the prevalence in the general population
- Specific intra- and inter-personal aspects of pathogenesis
- Characteristics of the clinically hearing impaired population with severe mental health problems.

The increase of knowledge in these domains may contribute to improvements in prevention, early recognition, assessment- and treatment strategies of mental health problems. It may also lead to a more specific focus for future service provision, and to formulate points of departure for future research.

In The Netherlands, there are approximately 3,000 deaf and severely hard of hearing children and young people, based on a prevalence rate of 0.74/1000 (De Graaf, Knippers & Bijl, 1997) in a population of about four million children and young people aged from 0-20 years (CBS Statline 2010). The rate of mental health problems in deaf and severely hard of hearing children and young people is increased compared to the rate in the general population combined with a reported underuse of services (see chapter 3). In a representative sample of severely to profoundly hearing impaired adolescents of average intelligence, 49% fulfilled the criteria for psychiatric caseness as defined by Goodman and co-workers (Goodman, Yude, Richards & Taylor, 1996) and 46% has a DSM-IV disorder. This is in line with findings of increased rates of problems and disorder in other studies (Hindley & Van Gent, 2002). We calculated post hoc that half of the disorders fulfilled the caseness-criteria for a disorder with significant or severe social impairment (23% of the sample), while the other half fulfilled criteria for a disorder without significant social impairment (23%). Novel in this field of study is the use of a diagnostic interview with all the participating adolescents instead of screened positive participants only, and the use of consensus expert ratings of

both caseness and DSM-IV disorder, bringing together information from parents, teachers, the adolescents, mental health professionals and available medical files. The findings in this prevalence study highlight the importance of the used multi-informant approach as a reliable and well-founded estimate of caseness and disorder, compared to the single ratings of caseness and problems. This strategy also highlights strengths and weaknesses of different informants, as for instance adolescents appeared to be better informants on emotional problems than parents and even far more better than teachers, while teachers were especially important for reporting behavioural problems (with parents second best). Comparable trends have been found in studies in general (see Fombonne, 2002) and in hearing impaired populations (Hindley, Hill, McGuigan & Kitson, 1994). These findings suggest that the multi-informant assessment approach which was used in this study, is a suitable method to investigate emotional and behavioural mental health problems in deaf and hard of hearing populations in the near future. In addition this approach may add to knowledge on specific contributions and shared variance of diverse informants to the measurement of psychopathology as well as on how to combine data from varying informants and from different settings (Fombonne, 2002). Marschark and Spencer (2010) urge the necessity of continuation of research in this field.

Studying deafness related variables

An overview of developmental and mental health issues (see Chapter 2) reveals the heterogeneity of the population of deaf and hard of hearing children and young people. This heterogeneity may be expressed by several deafness-related variables. Functional descriptions of audiological defined groups of hearing impaired people may strongly differ in their capacity to hear sounds or voices and to profit from hearing devices. For example unaided severely hearing impaired people will usually hear some words when shouted into the better ear, and they will benefit from strong hearing aids, whereas unaided profoundly impaired people are unable to hear a shouted voice at all and may profit less from hearing aids (World Health Organization, 2011). Several other factors of divergent nature may contribute to heterogeneity. Most children born deaf or becoming deaf during

infancy develop a spatial –visual orientation towards the world, while children becoming deaf later in life may develop a more aural-oral orientation. The preference of severely and profoundly hearing impaired children to use primarily signed language, spoken language or both will depend upon a variety of factors. Examples thereof include the linguistic-socio-cultural background of their parents, their own language abilities and the language abilities of the children themselves irrespective of modality, the degree and age of onset of deafness, the functional hearing residuals, and the experience with either signed or spoken language. In addition, the quality of parental involvement is an important factor determining linguistic, communicative, cognitive and socio-emotional development of a deaf or severely hard of hearing child. This involvement may include the capacity to adapt to the deafness of the child, their social-emotional relationship with the child and their linguistic adaptation to its needs. Broadly speaking, there will always be diversities in communication preferences and group identities within the population of deaf and hard of hearing people, and there will always be more than one method of communication to be appropriate for all. (Marschark & Spencer, 2011). Still other examples of factors contributing to heterogeneity are the cause of the hearing impairment; these may be more or less strongly related to the presence of additional physical and intellectual impairments with a great impact on mental well-being, and the use of advanced hearing aids and cochlear implants which enhance the accessibility to sounds and spoken language in many but not all deaf and severely hard of hearing children and adolescents.

The heterogeneous characteristics of the population of deaf and severely hard of hearing children and adolescents and their families complicate the clinical picture and differential diagnoses of mental health problems considerably. The findings on correlates in the study described in chapter 3 support the view that it is not deafness alone which contributes to mental health problems but rather deafness in conjunction with additional factors as communication problems, physical health problems, adverse living conditions and probably others.

The prevalence of mental health problems and its correlates, including deafness-related, intra- and interpersonal variables, was investigated in a sample of 70 deaf and hard of hearing adolescents of normal intelligence. The prevalence of any

psychiatric diagnosis (46%) and any emotional disorder (27%) among adolescents in our study were more than 3.5 times and 3 times respectively greater than the prevalence of these in a general population sample of adolescents in the United States (Costello, Mustillo, Erkanli, Keeler & Costello, 2003). The prevalence of behavioural disorder (11%) was about equal to that found in the same community sample of adolescents (Costello et al., 2003). The presence of behavioural disorders in this deaf adolescent sample appeared to be positively associated with high self-perceived social acceptance and peer rejection as reported by parents or teachers, and negatively with IQ and the opportunity of daily interaction with meaningful hearing others (parents, teachers, peers) (see Chapter 4). Peer rejection appeared to moderate the association of self-perceived social acceptance and behavioural disorder. Examining ego development in the same sample (see Chapter 5), it was shown that, compared to students in mainstream schooling, most special school students exhibited lower, i.e. pre-conformist ego levels, indicating a younger mental age and an increased risk of behavioural disorder rather than of simple emotional disorder.

Fellinger and co-workers suggest that the presence of behavioural disorder in our special sample (Chapter 3) could be explained by limited sign language proficiency in many deaf students attending a special school as a result of essentially restricted educational attention to teaching sign language in those schools (Fellinger, Holzinger, Beitel, Laucht & Goldberg, 2009a). Consequently, these students would suffer from substantial communicative deprivation which is associated with self-reported mental health difficulties and peer problems (Fellinger et al., 2009a). Limited language proficiency in the dominant mode of communication at school (i.e. in signed or spoken language) and communicative deprivation is certainly one of the risk factors related to mental health problems. However, we suggest that intrapersonal characteristics, deafness related and environmental factors interact with each other to influence the occurrence of psychopathology. Significant intrapersonal factors in this respect may be: ego development and self-perceived self-worth and competence (this thesis); emotion regulation skills, such as awareness, expression and communication of emotions, coping, empathy, and theory of mind, studied by Rieffe and co-workers (e.g., Rieffe,

2010; Kouwenberg, Rieffe & Theunissen, 2011); as well as cognitive abilities and language proficiency. Deafness related factors with an impact on mental health may be those related to aetiology, additional physical comorbidity, and degree of hearing loss and its interpersonal consequences (this thesis). Factors primarily related to interaction with the environment include quality of communication, acceptance, popularity, peer rejection and others, which may vary across social settings, such as the educational setting, as studied by Knoors and co-workers (e.g., Wauters & Knoors, 2007; Wolters, Knoors, Cillesen & Verhoeven, 2011).

In contrast, with regard to emotional disorders no significant differences between signing and speaking deaf adolescents were found, nor between students attending a special school for the Deaf or a regular school. In our analyses of self-perceived competence in the peer salient social domains of physical appearance, social acceptance and athletic competence, we distinguished three self-concept clusters (see Chapter 5): A *low social competence cluster* of adolescents with a low level of competence on all domains, associated with a low level of Global Self-worth, a *mixed cluster* of adolescents with a low level of social competence, a mean level of athletic competence and a relatively high level of physical appearance, associated with a relatively normal level of Global Self-worth, and a *high social competence cluster* of adolescents who scored high on all three social competence scales, associated with a relatively high level of Global Self-worth.

Interestingly in a post hoc analysis of the rate of emotional disorder in the subgroups of adolescents from these three self-concept clusters, the highest rate of emotional disorder was found among the adolescents from the mixed social competence cluster, i.e. those with a normal Global Self-worth. Emotional disorders were present in 46.2% of the adolescents in the mixed cluster versus 36% in the adolescents in the low social competence cluster and 10% of the adolescents in the high social competence cluster¹.

¹ Other differences between clusters: mean self-reported SCICA lonely scale scores mixed cluster 12.8 (sd 2.2), low and high cluster 7.9 (sd 5.3) $t(66df)=2.73$, $p<0.01$; mean self-reported SCICA anxious scale scores mixed cluster 9.3 (sd 5.0), low and high cluster 5.1 (4.7), $t(66df)=2.88$, $p<0.005$; self-reported SCICA aggression scale scores mixed cluster 2.5(sd 2.2), low and high cluster 4.6 (sd 4.5), $t(37.9df)=2.42$, $p<0.05$).

Inclusion in the mixed social competence cluster was associated with the highest mean ego level scores (in the conformist range), a hearing acculturation style and a hearing social context. Most students from this cluster attended normal education in larger hearing schools with no or very few other deaf classmates, and they thus had very few opportunities to socialise on a day to day basis with other deaf people. This may support the finding that a socially isolated position, being deaf amongst a large majority of hearing peers, is an important risk factor related to emotional mental health problems, as suggested in other studies (Farrugia & Austin, 1989; Van Gorp, 2001; Weisel & Kamara, 2005). Social isolation in general is regarded one of the interpersonal chronic risk factors that may predict emotional disorder (Hammen, 2005), and this may be independent from the level of self-esteem (e.g., Orth, Robins & Meier, 2009).

We would have expected that membership of the low self-concept cluster (i.e. among those with low self-perceived social acceptance, low physical appearance and low Global Self-worth) was associated with the highest risk related to emotional disorder. Inclusion in this cluster was associated with low mean ego level scores and a history of neurological disorder. Harter (1999) suggests that the combination of feeling inadequate in most domains of self-functioning, the inability to discount the importance of these domains and to escape from apparently unfavourable circumstances might have put them at an increased risk of developing depressed affect and anger. In this study we found support for the hypothesis that the association between low Global Self-worth and emotional disorder is moderated by circumstances that contribute to repetitive thought on inescapable negative discrepancies in a hearing world, such as having limited spoken language skills, feeling negatively different towards hearing family members, or towards physically healthy people whilst having to cope with additional physical handicaps and its interpersonal consequences (see Chapter 4). The finding that the amount of contact with hearing people did not have a moderating effect suggests that even deaf adolescents with low Global Self-worth may be capable of protecting the Self from negative social comparisons and standards, or that not all comparisons are negative and inescapable. In fact, further research with larger samples of deaf and hard of hearing children and adolescents, with well defined chronic stressors, and

moderating and mediating variables (e.g., Grant et al., 2003) is needed to confirm such findings in a relatively new field of research on intrapersonal and social dimensions in this population.

In Chapter 6 a clinical sample of referred deaf and hard of hearing children and adolescents, which may be regarded as representative for the population of deaf and severely hard of hearing children and adolescents with serious mental health problems in The Netherlands is described. No difference in the rate of emotional disorders was found between hearing impaired (HI) referrals and hearing controls when the HI children and adolescents with IQ's <71 were removed from the HI sample. No association with degree of HI or other deafness- or communication related variables was found. In contrast, more behavioural disorders were found in the HI children and adolescents when referrals with low IQ were left out.

Interestingly, a declining rate of behavioural disorder was observed over the 15 years of the study. Hypothetically a number of factors may have worked together to cause this trend. Firstly, any urgent cases with serious behavioural disorder may have been dealt with in the first few years of the new service, and over the years diagnoses may have become more differentiated, as suggested by Evans and Elliot (1987). Secondly, psychiatric consultation services and the development of expertise in orthopedagogical care, i.e. ambulatory and residential support for social and educational learning difficulties, may have had a positive effect on local treatment potential. Thirdly, increased recognition of special communicative needs and increased attention for the quality of communication with HI children and adolescents may have contributed to the decline in referrals for behavioural disorder (e.g., see Sinnkonen, 1994).

Limitations

One general limitation of all studies described in this thesis is the cross-sectional nature which does not allow for causal conclusions. In addition, correlational findings such as an association between communication mode and psychopathology should not be generalised as to reflect a general association between mental health problems and signing. Hypothetically, these associations may reflect the presence of still other, intermediating or moderating variables. For

instance, the finding of a selective association between behavioural disorder and signing may reflect referral bias: students with behavioural problems are more likely to be admitted to the more protective environment of a special school where signing is usually the primary mode of communication between students.

Other general limitations of the three studies in the sample of adolescents (Chapters 3, 4 and 5) include small sample size, a 26% refusal rate, and a relatively high rate of oral communication. Taking into account the characteristics of the non-responders such as lower IQ and the presence of relatively more psychosocial stressors in their lives, and the lower prevalence of caseness and behavioural disorder among orally communicating participants, it seems unlikely that these studies overestimate the prevalence of disorder (Chapters 3), or problems in self-perception or low levels of ego development (Chapters 4 and 5) in this population. A second limitation of these studies is that there are neither Dutch multidimensional self-concept measures nor ego development measures specifically developed for using with deaf individuals (Chapters 4 and 5). However, the possible issue of limited understanding of written Dutch in the questionnaires we used (the Dutch version of Harter's Self-Perception Profile for Adolescents [SPPA; Harter, 1988; Treffers et al., 2002] and the Sentence Completion Test for Children and Youth [SCT-Y; Westenberg et al., 2000]) was addressed by pro-actively consulting and encouraging the adolescents to seek assistance in their preferred mode of communication. This took into account a possibly more example-bound and -dependent approach to problem definition and problem solving (see Marschark, 2007). In addition, research has demonstrated that the ego development questionnaire is fairly robust regarding modified administration procedures (Drewes & Westenberg, 2001).

One of the limitations of the clinical study (Chapter 6) is that the data found in the relatively large clinical population may not be generalised to whole populations as they only reflect problems and characteristics of a referred population with severe mental health problems. However, as the mental health service involved had a national function within a network of educational and other services to cover the mental health needs of all deaf and severely hard of hearing children and young people nationwide, these findings probably reflect problems and characteristics of

the majority of HI children and adolescents with serious mental health problems, albeit within the Dutch mental health system. Another limitation with regard to the clinical study is that no data was obtained on children and young people with psychiatric problems who were referred to the specialist service but did not show up or those with serious but not recognised psychiatric problems. We do not know the nature and the severity of the problems of these non-users.

A final limitation concerns the representativeness of the two samples. Both samples included few children and adolescents with a cochlear implant, and thus may be regarded to represent only populations from the time period when CI was uncommon. As about 90% of deaf pre-schoolers in The Netherlands now have implants, much larger groups of older children and adolescents may soon benefit from the effects of cochlear implants on hearing, speech perception and spoken language skills, academic achievement, as well as in other areas of functioning. There is now a growing body of research examining the effects of CI on mental health functioning. Findings and conclusions from reports comparing CI recipients with non CI-users on different aspects of functioning vary substantially. Without purporting to be exhaustive, some examples may be given: a higher level of psychosocial adjustment in CI-users was found by some (e.g., Bat-Shava, Martin & Kosciw, 2005), but not by others (e.g., Dammeyer, 2009). Likewise, a positive impact of CI on self-concept (Martin, Bat-Shava, Lalwani & Waltzman, 2010) and Theory of Mind (Rommel & Peters, 2011) were suggested in some studies, whilst other studies did not observe differences between CI users and non-users, neither with regard to self-concept (Leigh, Maxwell-McCaw, Bat-Shava & Christiansen, 2008) nor with regard to Theory of Mind (e.g., Wellman, Fang & Peterson, 2011). Moreover, to date no differences in executive function (Figueras, Edwards & Langdon, 2008; Hintermair, 2011) or the prevalence of mental health disorder between CI users and non-users were found (Theunissen, Rieffe, Kouwenberg, Soede, Briaire & Frijns, 2011; Fellingner, Holzinger, Sattel, Laucht & Goldberg, 2009b). Comparisons between samples of CI users and either hearing or non-using hearing impaired comparison groups may be complicated by the fact that failure to control for specific characteristics of CI users may lead to over- or underestimation of the effectiveness of cochlear implantation (Stacey, Fortnum,

Barton & Summerfield, 2006). Overestimation may result from a generally later onset of hearing impairment in children with implants, which usually co-occurs with better pre-implant speech production and language; the overrepresentation of girls with generally better early communication skills than boys; the prevalence of significantly fewer disabilities in children with implants (including central nervous system abnormalities, other physical disorders, cognitive problems, and psychosocial disabilities); and an overrepresentation of a more affluent family background in most children with implants. Underestimation of the effectiveness of CI use may arise from a greater severity of pre-implant hearing loss or a younger age of implanted children (Fortnum, Marshall & Summerfield, 2002; Stacey et al., 2006).

Nevertheless, data on non-implanted children and adolescents in the industrialised world will be of value as findings in a base-line population from a time period before CI which “changed the face of deafness” as described by Marschark (2007). Furthermore, technically advanced hearing equipment such as CI will be only available for very few people in less well-developed countries, and unavailable for the majority of the world’s population (Leigh, Newall & Newall, 2010; Marschark & Spencer, 2010).

Clinical relevance

The findings from the prevalence study and its correlates in a representative sample of adolescents (Chapters 3-5) as well as from the clinical study underline the need for specialist mental health services where the mental health needs of deaf and severely hard of hearing children and young people and their families can be adequately met. They stress that specific expertise must be bundled to deal with the needs of a small and heterogeneous minority population, as mental health service provision for this population concerns highly specialised care in a low incidence area, which can be insufficiently covered within regular mental health care.

In this thesis a number of factors have been identified which support literature on known risk factors related to psychopathology in deaf and hard of hearing children and adolescents (central nervous system involvement, other physical disorders, cognitive impairment, restricted language abilities, parental

distress, serious distress such as through bullying or maltreatment; see Chapter 2). Intrapersonal factors related to self-functioning and their interaction with possible chronic stressors were found to be associated with disorders. Knowledge of these factors could guide schools and related services who deliver care for their target population to detect and prevent risk factors, to screen for psychological problems in children and young people, and to develop programmes for screening, early recognition, assessment and even (short-term) treatment facilities. These programmes should be organised partly within their own service organisation, and partly in conjunction with mental health services as good partners and consultants in mental health care. With regard to pathogenesis a number of chronic stressors was found to moderate the association between facets of self-concept and emotional and behavioural disorder. This might indicate that exploring different facets of self-concept and the experience of chronic distress during assessments might more specifically guide our focus towards special targets for treatment. For instance low self-esteem may be a risk factor related to emotional disorder especially in adolescents who experience chronic distress due to specific deafness- or physical-illness related characteristics. High self-perceived social acceptance may be a risk factor related to behavioural disorder especially in adolescents who are considered by teachers or parents to be rejected by peers. In addition subgroups of adolescents with specific self-concept profiles were found to differ from each other in a number of circumstances, as well as in the level of ego development. This indicates among other things that educational and orthopedagogical interventions at school and in residential settings may have a greater chance of succeeding when they take into account the level of the ego development of individual children.

In summary, we advise exploring multi-dimensional facets of self-concept, the level of ego development, the presence of chronic adverse living conditions which may be experienced as threatening and inescapable in view of being different in a hearing world as standard themes during mental assessment procedures. We also advise paying special attention to the improvement in mental health service provision for children and adolescents with additional disabilities among which serious cognitive impairment and a history of serious physical comorbidity.

Relevance for quality improvement of specialised mental health services

The main goal for mental health services for deaf and hard of hearing people should remain the improved accessibility and quality of services over time. This becomes particularly difficult as most hearing professionals are not experienced in communicating with deaf people, and trained deaf and hard of hearing professionals are scarce. As indicated by the results of the studies presented in this thesis, mental health professionals need to gain expertise in the following domains at least: medical and audiological aspects of hearing impairments, the influence of hearing impairment on development, socio-cultural aspects, and complex presentations of problems in differential diagnosis and treatment. Moreover, they have to gain sufficient skills to communicate with deaf and hard of hearing people, and to interpret signed or otherwise non-verbal expressions of emotional and other mental health problems, either in sign language, sign supported spoken language, spoken language, a combination thereof, or still other modalities. They should also know when and how to integrate the use of professional interpreters within assessment and treatment approaches. Regularly, interpreters in more than one modality have to be brought in, for instance when interpreting in sign language and interpreting in another foreign spoken language are both needed at the same time, or when relay interpreting is warranted to interpret information into another form of the same language. Finally, professionals have to know how to adapt an environment to make it accessible for deaf and hard of hearing people in order to guarantee good communication between the professional and the child and his or her family. All these prerequisites are required to conduct proper assessments and treatments with deaf and hard of hearing children and adolescents and their families, in order to meet their mental health needs more effectively.

Future research

It is essential to continue studying deaf and hard of hearing populations with identified mental health problems in order to highlight the unchanged high level of mental health needs in a population which is still underserved.

First of all, scientifically sound, i.e. reliable and valid, diagnostic instruments adapted for using with deaf and hard of hearing people are needed in order to deal with a possibly limited understanding of written or complex language by a number of HI people with linguistic and cultural differences. The availability of more instruments that could be administered in the preferred mode of communication of the participant would be an important advance in this domain. Facets of self-concept, level of ego development, the possible presence of distress related to deafness-aetiology, physical comorbidity, or interaction with peers, the possibility of sexual abuse, and the presence or absence of satisfaction with communication with varying meaningful others, such as parents, teachers and peers, are all factors to be taken into account during assessment procedures, as they may have a significant impact on mental health.

Secondly, longitudinal studies are needed on the prevalence and pathogenesis of mental health problems and disorder and the correlates thereof in the population of deaf and severely hard of hearing children and adolescents, which include subpopulations with CI, cognitive impairments and physical disorder. With regard to prevention and early recognition we found an association between specific intrapersonal factors, i.e. facets of self-concept, and psychopathology, as well as moderating effects of specific deafness related characteristics. It is tempting to speculate that both low global self-worth and high self-perceived social acceptance are independent risk factors related to psychopathology. Moreover, it is tempting to speculate that the deafness related moderators may be viewed as independent chronic stressors and risk factors related to psychopathology, in addition to the already known risk factors described by Hindley and Van Gent (2002). Longitudinal studies are needed to examine the validity of these causal inferences. Replication of our findings in longitudinal research is important as the results may stimulate schools and educational care organisations to pay greater attention to these intrapersonal and deafness related factors which may indicate increased risk. This longitudinal research may assess the policy of integrating deaf and hard of hearing students into regular education, with follow-up research on the intra- and interpersonal consequences of types of placements of severely hearing impaired children and young people in the regular school system. Following a

proposal by Stinson and Kluwin (2011), a useful approach to gaining more insight into the consequences of specific school placements on personal characteristics could be to give detailed accounts on intrapersonal, social, deafness-related, communicative and demographic characteristics of students and the effects of interventions aimed at improving the educational experience.

Thirdly, studies on interventions aimed at treating specific psychiatric disorders are highly essential. For instance we do not know whether specific treatment techniques, such as Cognitive Behavioural Therapy or Interpersonal Therapy, are as effective in deaf children and adolescents as in hearing peers. We suggest that pedagogical or therapeutic interventions have to be adapted to the ego level of the individual child or adolescent, which portrays its socio-cognitive maturity along lines of impulse control, complexity of self-reflection, interpersonal relations and conscious preoccupations, as described by Recklitis and Noam (2004).

Concluding remarks

We began this study project with the aim of contributing to improvements in prevention, early recognition, assessment- and treatment strategies of mental health problems, a more specific focus for future service provision, and future research. The findings in this thesis and the recommendations for (ortho-) pedagogical and therapeutic intervention strategies following on from these findings must be implemented both inventively and economically. Although the development of early newborn hearing screening and intervention programmes in The Netherlands has contributed to more effective family support and the promotion of developmental progress in hearing impaired children (e.g., Oudesluys-Murphy, Van Straaten, Ens-Dokkum & Kauffman-de Boer, 2000), the major challenge for mental health service provision is the current scarcity of well-equipped specialised mental health services and trained mental health professionals. Consequently, the current mental health services deliver only some of the basic services that are required to cover the mental health needs of this small population nationwide. For instance, at present there is a scarcity of specialised psychiatrists, skilled psychotherapists and parent counsellors, as well as well-equipped outpatient- and inpatient services and outreaching consultation facilities. Economic planning

of services must start with the organisation of a balanced coordinated network to cover the field of mental health needs for deaf and hard of hearing people. These range from a highly specialised inpatient and outpatient service to more dispersed ambulatory services and outreaching consultation services which all work together with specialised educational and care organisations, audiology centres, other professional organisations in the field, and with local regular mental health services.

Collaboration between the combined special school and care organisations and specialist mental health services is essential for delivering co-ordinated services for special, complex and small populations near to where children and their parents live (e.g., see Salmon & Kirby, 2008). School based mental health services should preferably be integrated in the proposed nationwide network organisation with distinct locally accessible bases from where these and other services are delivered and co-ordinated on a regional and more local level. Integrated services may include family support and parent counselling, communication therapy, speech and language therapy, social skills training, pedagogic home counselling, short term interpersonal, cognitive behavioural, group or family therapy, health care provision based on general practitioner practices, psychiatric consultation and other ambulatory and outreaching mental health services, flexible crisis intervention services, etc. Group based training programmes at school may promote integrated social-emotional competence such as Promoting Alternative THinking Strategies (PATHS), developed by Greenberg and Kusché (1993), and anti-bullying programmes (e.g., Fellingner et al., 2009). A relatively small inpatient unit would be expected to be capable of dealing with the need for specialist inpatient assessment and treatment in The Netherlands.

At an organisational level it is important to give priority to the development of this collaborative chain of services which includes prevention, early recognition, assessment and stepped and matched care services, quick and smooth referrals, and effective treatment facilities. As it concerns a relatively small and complex population which requires highly specialised care, one nationwide organisation that integrates mental health care at all levels of complexity, and is capable of offering professional training and education, and research is recommended.

Preferred stakeholders in this organisation are the integrated specialist mental health services and the integrated school and care organisations, together with the responsible ministry, the health inspection, the insurance companies and certainly those interest organisations, who started a comparable initiative 27 years ago.

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Summary in Dutch

Samenvatting

Inleiding

Dit proefschrift beoogt een bijdrage te leveren aan kennis op het gebied van de geestelijke gezondheidszorg voor dove en ernstig slechthorende kinderen en adolescenten. In de eerste plaats is een kort overzicht geschetst van de doelgroep en de geschiedenis van de psychische hulpverlening aan doven en ernstig slechthorenden. In de tweede plaats is aan de hand van literatuuronderzoek een overzicht gegeven van relevante aspecten van psychische stoornissen bij kinderen en adolescenten uit deze heterogene doelgroep. In de derde plaats is onderzoek verricht naar epidemiologische, specifieke intra-persoonlijke en klinische aspecten van psychische stoornissen bij dove en slechthorende kinderen en adolescenten.

Beschrijving en bevindingen

Hoofdstuk 1 biedt een inleidende beschrijving van de kleine maar in een aantal opzichten zeer heterogene doelgroep van dove en ernstig slechthorende kinderen en adolescenten vanuit medisch-audiologisch en sociaal-cultureel perspectief. Daarnaast wordt een beschrijving gegeven van de korte geschiedenis van psychische hulpverlening in binnen- en buitenland evenals van het wetenschappelijk onderzoek op het gebied van de geestelijke gezondheidszorg voor de doelgroep in de 20^e eeuw. Tenslotte worden de doelstellingen van het proefschrift en de strekking van de hoofdstukken toegelicht.

Hoofdstuk 2 is een recent gereviseerde en uitgebreide versie van een hoofdstuk over psychische stoornissen bij dove kinderen en adolescenten, dat in 2002 werd gepubliceerd in het kinder- en jeugdpsychiatrisch handboek *Child and Adolescent Psychiatry, Fourth Edition* onder redactie van Sir Michael Rutter en Eric Taylor. In dit gereviseerde hoofdstuk wordt een overzicht gegeven van medisch-audiologische, aetiologische, culturele, linguïstische, interactieve en ontwikkelingspsychologische aspecten die van invloed zijn op de psychische gezondheid van auditief ernstig beperkte kinderen en adolescenten. Vervolgens wordt een overzicht gegeven van epidemiologische en klinische aspecten van

psychische stoornissen bij kinderen en jongeren uit de doelgroep. Tevens wordt kort stilgestaan bij belangrijke omstandigheden waarmee rekening moet worden gehouden in de geestelijke gezondheidszorg voor specifieke deelgroepen auditief beperkte kinderen en adolescenten, te weten die van kinderen met (recidiverende of chronische) middenoorontsteking, horende kinderen van ernstig auditief beperkte ouders, kinderen met meervoudige zintuiglijke - ernstige auditieve en visuele - beperkingen, en kinderen met een cochleair implantaat.

Het hoofdstuk benadrukt het belang van specifieke aandacht voor de geestelijke gezondheidszorgbehoefte van de doelgroep, en beoogt actuele kennis die aan de basis ligt van een goede geestelijke gezondheidszorg voor dove en slechthorende kinderen en jongeren en hun ouders en siblings samen te vatten.

Hoofdstuk 3 betreft een onderzoek naar de prevalentie van psychopathologie en naar demografische, psychologische en aan doofheid gerelateerde correlaten in een onderzoeksgroep van gemiddeld intelligente, dove, schoolgaande adolescenten. Het is het eerste onderzoek met ernstig auditief beperkte deelnemers dat gebruik maakt van semi-gestructureerde psychiatrische interviews om psychiatrische stoornissen vast te stellen. Het is tevens het eerste onderzoek dat gebruik maakt van een consensus beoordeling door ervaren kinder- en jeugdpsychiaters van psychiatrische "caseness" en DSM IV classificatie, op basis van informatie van ouders, leerkrachten, beoordelingen van de adolescenten zelf, beoordelingen van klinici, en informatie uit medische dossiers. Deze beoordeling van onbewerkte informatie van verschillende informanten door experts is vergeleken met beoordelingen op basis van de gestandaardiseerde informatie van de afzonderlijke informanten.

Bevindingen. In het verlengde van de meeste andere epidemiologische onderzoeken rapporteerden de verschillende informanten afzonderlijk (ouders, leraren, adolescenten zelf en klinici) hoge percentages psychische problemen in de onderzoeksgroep die representatief kan worden genoemd voor de populatie dove, gemiddeld intelligente, schoolgaande adolescenten in Nederland. Door de klinici werden ernstige psychische problemen ('psychiatric caseness') vastgesteld bij de helft (49%) van de dove adolescenten. Ouders en leerkrachten

rapporteerden ernstig probleemgedrag bij 28% respectievelijk 32% van de dove adolescenten. Dat is bijna twee keer vaker dan in de normgroepen van horende adolescenten. Uit de gestructureerde interviews van de adolescenten bleek bij 49% ernstig probleemgedrag aanwezig te zijn, dat is hetzelfde percentage als in eerder onderzoek werd gevonden in een polikliniek kinder- en jeugdpsychiatrie voor horende leeftijdgenoten. De hoge prevalentie van 'psychiatric caseness' bleek vooral voort te komen uit een hoge prevalentie van emotionele stoornissen. In de onderzoeksgroep werd bij 27% van de adolescenten de consensus diagnose emotionele stoornis en bij 11% de consensus diagnose gedragsstoornis vastgesteld. Ouders en leerkrachten rapporteerden bij 19% respectievelijk 25% een score in het klinisch gebied op de schaal Internaliserende problemen, hetgeen 2,1 respectievelijk 2,8 keer hoger is dan de overeenkomstige percentages bij ouders en leerkrachten van de normgroep. De overeenstemming in de beoordeling van psychische problemen tussen de afzonderlijke informanten (ouders, leerkrachten, adolescenten zelf en klinici), berekend op basis van gedichotomiseerde scores (wel/niet in het klinisch gebied) op de overeenkomstige gestandaardiseerde vragenlijsten, bleek matig (kappa gemiddeld 0.30). Dit is lager dan de redelijk goede overeenstemming tussen experts, die zich baseerden op ruwe, onbewerkte gegevens van verschillende informanten en medische dossiergegevens, en de afzonderlijke informanten (kappa gemiddeld 0.43). Dit resultaat laat zien dat verschillende informanten ieder vanuit eigen perspectief invulling geven aan de beoordeling van psychische problemen bij jongeren. Het ondersteunt ook - bij ontbreken van een gouden standaard voor een eenduidige diagnostische procedure - de veronderstelling dat een diagnostische benadering die bestaat uit het bijeen brengen en wegen van informatie uit verschillende invalshoeken door professionele experts waarschijnlijk de meest betrouwbare en valide manier is om psychiatrische casuïstiek te beoordelen. Tevens illustreert de hoge prevalentie psychische stoornissen (49%) in een representatieve onderzoeksgroep dove schoolgaande adolescenten in combinatie met een voorlopige aanwijzing voor een laag gebruik van GGZ voorzieningen door de doelgroep (minder dan 10%) de urgentie om ruimschoots aandacht te besteden aan de wenselijkheid te voorzien in toegankelijke geestelijke gezondheidszorg voor deze doelgroep. In dit onderzoek

gaven de adolescenten, en met name meisjes, zelf aan veel problemen te ervaren en bereid te zijn daarover te communiceren, mits de communicatie voldoende is afgestemd op hun behoeften. Het selectief voorkomen van gedragsproblemen bij jongeren in het speciale onderwijs kan doen vermoeden dat bij uitstek kinderen met verstorend gedrag naar een speciale schoolsetting worden verwezen. De hoge prevalentie van vooral emotionele stoornissen in de doelgroep, ongeacht communicatiemodus of schooltype, onderschrijft ook het belang van het ontwikkelen van initiatieven om psychische, en met name emotionele, problemen vroegtijdig op te sporen bij alle dove jongeren - in speciale en meer reguliere onderwijsprogramma's.

De in dit onderzoek gevonden verbanden van psychische stoornissen met IQ en lichamelijke aandoeningen liggen in het verlengde van bevindingen in epidemiologisch onderzoek met niet auditief beperkte populaties.

Hoofdstuk 4 is een onderzoek naar het modererend effect van chronische stressoren op (1) het verband tussen het globale gevoel van eigenwaarde en emotionele stoornissen en (2) het verband tussen de zelfwaardering op het gebied van sociale acceptatie en gedragsstoornissen. Als chronische stressoren in het leven van dove adolescenten is op basis van literatuuronderzoek gekozen voor inter-persoonlijke omstandigheden die in het bijzonder bij dove adolescenten die zich sterker vergelijken met *horende* leeftijdgenoten dan met dove leeftijdgenoten, terugkerende negatieve gedachten (ook wel omschreven als maladaptief persevereren) kunnen oproepen. Deze adolescenten beschouwen de eigen situatie als heel ongunstig en oncorrigeerbaar in het licht van de geïdealiseerde maar onbereikbare toestand van horend, gezond en sociaal geaccepteerd te zijn. De volgende inter-persoonlijke stressoren die zouden kunnen bijdragen tot het persevereren over deze discrepantie zijn onderzocht: (1) de aanwezigheid bij minder ernstig dove adolescenten van functionele hoorresten die naar verwachting leiden tot grotere acceptatieproblemen van de doofheid dan bij adolescenten zonder functionele hoorresten; of de aanwezigheid van een bijkomende lichamelijke handicap; of doof zijn in een horend gezin in het geval van verworven doofheid; (2) primair opgroeien in een horende omgeving, niet alleen thuis maar ook op school; (3) afwijzing door leeftijdgenoten.

Bevindingen. Net als in onderzoeken bij horende adolescenten vonden we bij dove adolescenten (dezelfde onderzoeksgroep als in hoofdstuk 3) een matig negatief verband tussen globaal gevoel van eigenwaarde en emotionele stoornissen. Zoals verwacht werd een dergelijk verband specifiek gevonden bij adolescenten die minder ernstig doof zijn, een verworven of syndromale oorzaak van doofheid hebben of een voorgeschiedenis van neurologische stoornissen in het geval van een onbekende doofheidsoorzaak. Het verband werd niet gevonden bij adolescenten die minder functioneel restgehoor hebben en ernstiger doof zijn (meer dan 95dB gehoorverlies; geen CI). Evenmin werd het verband gevonden bij adolescenten die doof zijn door een niet-syndromale, erfelijke oorzaak met minder kans op lichamelijke comorbiditeit, noch bij adolescenten bij wie de oorzaak van de doofheid onbekend is en bij wie geen sprake is van neurologische complicaties. Deze bevindingen zijn consistent met de veronderstelling dat men de genoemde omstandigheden kan beschouwen als chronische stressoren die aanleiding kunnen geven tot onontkoombare, negatieve en terugkerende gedachten over discrepanties tussen de eigen conditie en die van horende en gezonde mensen. Waarschijnlijk vergroot het hebben van meer functioneel restgehoor het perspectief om te horen en brengt het de wens om als horend te functioneren dichterbij. Daarnaast maakt dit restgehoor het besef auditief tekort te schieten ten opzichte van horenden en de onontkoombaarheid daarvan groter. Ook ondersteunen de bevindingen de veronderstelling dat neurologische en andere lichamelijke stoornissen - die veel vaker bij verworven en syndromale doofheid worden gezien dan bij niet-syndromale erfelijke doofheid - risicofactoren zijn voor psychopathologie. Stoornissen in motoriek of coördinatie en cognitieve en executieve disfuncties kunnen interfereren met de visuele communicatie en sociale interactie. Bovendien kan het verborgen karakter van vooral “kleine gebreken” (minor dysfunctions) bijdragen tot inter-persoonlijke misverstanden, emotionele onzekerheid en negatieve zelf-evaluaties. De kans hierop is groter bij mensen met een laag globaal gevoel van eigenwaarde omdat lichamelijke comorbiditeit vooral bij hen zou bijdragen tot een oncorrigeerbare negatieve evaluatie van zichzelf als zijnde gehandicapt in een wereld met vooral gezonde, horende mensen. Tenslotte ondersteunt de bevinding van een modererend effect van verworven doofheid de

opvatting dat verworven doofheid, die vooral voorkomt bij kinderen van horende ouders, in het bijzonder bij adolescenten met een laag globaal zelfgevoel bijdraagt tot een algemeen gevoel gehandicapt te zijn in een primair horende familie die onbekend is met doofheid. De mate van contact met betekenisvolle horende mensen in de directe omgeving (ouders, leeftijdgenoten en leerkrachten) bleek tegen de verwachting in geen invloed te hebben op het verband tussen globaal zelfgevoel en emotionele problemen. Deze bevinding lijkt er op te wijzen dat dove adolescenten die opgroeien in een voornamelijk horend milieu zichzelf kunnen beschermen tegen mogelijk negatieve sociale vergelijkingen, bijvoorbeeld door minder belang te hechten aan de eigen competentiebeleving in het domein van sociale acceptatie, zodat deze geen aanslag voor de globale zelfwaardering vormt. Dit is in overeenstemming met onze bevinding dat er geen verband bestaat tussen de mate van contact met horenden en globaal zelfgevoel, maar dat veel contact met horenden samengaat met een lager gevoel van sociale acceptatie. Tenslotte bleek de door ouders en leerkrachten gerapporteerde afwijzing door leeftijdgenoten een significante moderator van het verband tussen een hoog gevoel van zelfwaardering op het gebied van sociale acceptatie en gedragsstoornissen. Met andere woorden: in overeenstemming met literatuurbevindingen worden gedragsstoornissen vooral gerapporteerd bij adolescenten met een hoog gevoel van zelfwaardering op het gebied van sociale acceptatie die naar het oordeel van ouders en leerkrachten door leeftijdgenoten worden afgewezen. Hypothetisch zouden vooral adolescenten die tot deze subgroep behoren minder goed in staat zijn sociale informatie op waarde te schatten.

Hoofdstuk 5 betreft een onderzoek naar twee gerelateerde aspecten van het zelf, het zelfconcept en de ego-ontwikkeling, in dezelfde representatieve onderzoeksgroep gemiddeld intelligente dove adolescenten als in de twee voorgaande hoofdstukken. In dit hoofdstuk is het niveau van zelfconcept en ego-ontwikkeling in de doelgroep vergeleken met de corresponderende niveaus in de (horende) normpopulatie. Tevens is onderzoek verricht naar verbanden tussen enerzijds zelfconcept en ego-ontwikkeling en anderzijds doofheid- en context gerelateerde variabelen zoals ernst en oorzaak van doofheid, bijkomende neurologische stoornissen, verblijfplaats,

type onderwijs, ontvangen steun voor gebarentalige communicatie in de jeugd, actuele door ouders en kind ervaren kwaliteit van de onderlinge communicatie, en de mate van identificatie met doven. Het is het eerste onderzoek bij dove adolescenten waarin het niveau van ego-ontwikkeling is onderzocht, én het eerste onderzoek waarin exploratief onderzoek is verricht naar zelfconcept profielen in de sociale domeinen van fysieke verschijning, sociale acceptatie en sportieve vaardigheden. Ook is in subgroepen adolescenten het verband tussen enerzijds deze profielen en anderzijds het globaal gevoel van eigenwaarde, het niveau van ego-ontwikkeling, en doofheid- en context-gerelateerde variabelen onderzocht.

Bevindingen. In de eerste plaats bleek de groep dove adolescenten ten opzichte van horende leeftijdgenoten uit de Nederlandse normgroep gemiddeld een lager gevoel van zelfwaardering te hebben in de domeinen fysieke verschijning, sociale acceptatie en hechte vriendschap, maar niet in de andere specifieke domeinen, en evenmin wat betreft het globaal gevoel van eigenwaarde. Het niveau van het globale gevoel van eigenwaarde bleek samen te hangen met steun voor gebarentalige communicatie in de kindertijd en de kwaliteit van de communicatie tussen ouders en kind. Daarentegen hing noch het globale gevoel van eigenwaarde noch de kwaliteit van de communicatie tussen ouders en kind samen met de communicatie modus. Het globale gevoel van eigenwaarde hing ook niet samen met de mate van identificatie met andere doven. In de tweede plaats werd in de onderzoeksgroep een hoger percentage adolescenten met een lager, preconformistisch, niveau van ego-ontwikkeling gevonden dan verwacht mag worden op grond van de verdeling van niveaus van ego-ontwikkeling onder leeftijdgenoten uit een horende normgroep. Het niveau van ego-ontwikkeling bleek sterk samen te hangen met het schooltype, en dit effect hield stand als gecontroleerd werd voor de effecten van het geslacht, de leeftijd, het IQ van de participanten, en het opleidingsniveau van de ouders. Negentig procent van de adolescenten in het speciale onderwijs functioneerden op preconformistisch niveau, en 89% van de adolescenten in het reguliere onderwijs functioneerden op conformistisch niveau. Deze bevindingen wettigen nader onderzoek naar het effect van de sociale context van school, en andere variabelen zoals de invloed van taalvaardigheden en de aanwezigheid van gedragsproblemen op de ego-ontwikkeling bij dove adolescenten. In de

derde plaats voerden we - ervan uitgaande dat communicatieve barrières in de horende wereld bij adolescenten in de eerste plaats van invloed zullen zijn op het sociale welzijn en het zelf-concept in sociale contacten - een clusteranalyse uit met betrekking tot die domeinen van het zelf-concept die een indicatie geven voor de competentiebeleving in de omgang met leeftijdgenoten: Sociale Acceptatie, Fysieke Verschijning, en Sportieve Vaardigheden. Er konden drie clusterprofielen worden onderscheiden. Een lage zelfwaardering in alle drie sociale competentiegebieden was geassocieerd met een lage zelfwaardering op de meeste andere gebieden, inclusief globale zelfwaardering, maar met uitzondering van zelfwaardering op het gebied van schoolse vaardigheden. Lidmaatschap van dit lage sociale competentie cluster was geassocieerd met een laag niveau van ego-ontwikkeling. Veel van deze adolescenten hadden een voorgeschiedenis van neurologische stoornissen, en velen volgden speciaal onderwijs. Een hoog niveau van zelfwaardering in alle drie sociale domeinen was geassocieerd met gemiddeld tot hoge niveaus van zelfwaardering in de andere domeinen van zelfwaardering inclusief globale zelfwaardering. Lidmaatschap van dit hoge sociale competentie cluster was geassocieerd met een laag niveau van ego-ontwikkeling, het ontbreken van neurologische stoornissen, steun voor gebaren in de kindertijd, identificatie met andere doven, en het volgen van speciaal onderwijs. De combinatie van een lage zelfwaardering op het gebied van sociale acceptatie en een hoge zelfwaardering op het gebied van de fysieke verschijning was geassocieerd met een gemiddeld niveau van globale zelfwaardering, een relatief hoog, conformistisch, niveau van ego-ontwikkeling, het volgen van regulier onderwijs, een horende acculturatie stijl en een primair horende sociale context. Bovengenoemde bevindingen illustreren hoe gedifferentieerd de globale en domein-specifieke zelfwaardering geassocieerd zijn met intra-persoonlijke, contextuele en aan doofheid gerelateerde kenmerken bij dove adolescenten. De bevindingen kunnen bijdragen aan de identificatie van aangrijpingspunten voor preventieve en socio- en psychotherapeutische interventies bij dove kinderen en adolescenten met specifieke sociale competentie profielen.

Hoofdstuk 6 is een onderzoek naar socio-demografische, psychiatrisch diagnostische en aan de auditieve beperking gerelateerde kenmerken van kinderen en adolescenten die in de loop van vijftien jaar in verband met psychiatrische problemen voor de eerste maal werden verwezen naar de landelijke poliklinische en klinische GGZ-voorziening voor doven en slechthorenden verbonden aan een van de academische kinder- en jeugdpsychiatrisch centra in het land. Dit onderzoek betreft de grootste klinische populatie dove en slechthorende kinderen en jongeren waarover tot nu toe systematisch verzamelde data beschikbaar zijn. In de eerste plaats zijn verschillen en overeenkomsten in socio-demografische, diagnostische en doofheid gerelateerde kenmerken tussen onderscheiden subgroepen kinderen en jongeren die naar deze grote klinische en poliklinische voorziening – een van de eerste ter wereld voor deze doelgroep – zijn verwezen, onderzocht: dove en slechthorende kinderen van horende ouders (N=362), dove en slechthorende kinderen van (een of twee) ernstige auditief beperkte ouders (N=27), en horende kinderen van ernstig auditief beperkte ouders (N=22). In de tweede plaats zijn een aantal specifieke kenmerken van drie groepen auditief beperkte kinderen en jongeren in kaart gebracht en onderling vergeleken. De eerste van de drie groepen auditief beperkte kinderen bestaat uit jeugdigen met een cognitieve beperking, de tweede bestaat uit jeugdigen met complexe lichamelijke gezondheidsproblemen, de derde bestaat uit de overige verwezen jeugdigen. Tenslotte zijn socio-demografische en diagnostische kenmerken van de doelgroepkinderen vergeleken met overeenkomstige kenmerken van een grote vergelijkingsgroep horende kinderen en jongeren die in verband met psychiatrische problemen zijn verwezen naar het academische kinder- en jeugdpsychiatrische centrum (N=3339).

Bevindingen. De onderzoeksgroep dove en slechthorende kinderen en adolescenten die in een periode van 15 jaar in verband met psychische problemen naar een landelijke psychiatrische voorziening werden verwezen, onderscheidde zich op een aantal gebieden van de vergelijkingsgroep verwezen horende kinderen en jongeren. De gemiddelde leeftijd waarop verwezen werd, was hoger; significant vaker werden pervasieve ontwikkelingsstoornissen en mentale retardatie gediagnosticeerd; uiteenlopende chronische contextuele stressoren en mogelijke

risicofactoren waren significant vaker aanwezig: meer auditief beperkte kinderen groeiden op in een één-ouder gezin, hadden lager opgeleide ouders, en/of ouders met een niet-Kaukasische achtergrond.

Van de dove en slechthorende patiënten was de overgrote meerderheid doof, en minder dan 10% matig ernstig of licht slechthorend. Bij de verwezen patiënten werd minder vaak een niet-syndromale erfelijke oorzaak voor de doofheid gevonden dan op grond van bekende verdelingen van oorzaken in populatie onderzoek mocht worden verwacht. Daarentegen kwamen verworven oorzaken, met name een intra-uteriene rubella virusinfectie, juist vaker voor. Een relatief hoog percentage verwezen auditief beperkte patiënten (21.3%) had complexe lichamelijke gezondheidsproblemen (tenminste twee van de volgende: rubella-dooftheid, een visusstoornis, een neurologische motorische stoornis of epilepsie), met name patiënten met een pervasieve ontwikkelingsstoornis. De patiënten met complexe lichamelijke gezondheidsproblemen waren vaker (67.2%) aangewezen op een residentiële vorm van zorg dan de andere auditief beperkte patiënten, met (46.3%) of zonder (35.3%) mentale retardatie. Bij horende kinderen van een of twee ernstig auditief beperkte ouders werd vaker dan in de andere onderzochte subgroepen patiënten een depressieve stoornis gediagnosticeerd. De bewezen of waarschijnlijke aanwezigheid van seksueel misbruik in 7-11% van de verwezen auditief beperkte kinderen suggereert een aanzienlijk risico van misbruik bij kinderen met auditieve problemen. Bovengenoemde bevindingen illustreren de complexiteit van de problematiek van ernstig auditief beperkte auditief beperkte kinderen en adolescenten met psychische problemen.

Hoofdstuk 7 behandelt de belangrijkste conclusies, beperkingen van de besproken studies, en bevat aanbevelingen voor toekomstig onderzoek en voor de klinische praktijk. Met betrekking tot de hoge prevalentie van psychiatrische stoornissen in de onderzoeksgroep in de onderzoeksgroep schoolgaande adolescenten van gemiddelde intelligentie wordt gespecificeerd dat het in de helft van de gevallen om stoornissen zonder noemenswaardige sociale impact gaat en in de andere helft om stoornissen met een aanzienlijke sociale impact. De bevindingen suggereren dat vooral de prevalentie van emotionele stoornissen is verhoogd.

Niet uitsluitend ongunstige omgevingsfactoren van communicatieve aard, of doofheid op zichzelf, maar de interactie tussen intra-persoonlijke kenmerken, doofheidskenmerken en met de sociale context gerelateerde factoren lijken van invloed op het ontstaan respectievelijk het beloop van psychopathologie. Post-hoc analyse van de prevalentie van onder andere emotionele stoornissen in de subgroepen adolescenten met een verschillend sociaal competentie cluster profiel laat zien dat emotionele stoornissen het meest frequent voorkomen in de groep adolescenten met het gemengde sociaal competentieprofiel (46,2%), dat wil zeggen een laag gevoel van zelfwaardering in het domein van de sociale acceptatie en een hoog gevoel van zelfwaardering in het domein van de fysieke verschijning. Adolescenten uit deze groep hebben in de meeste gevallen een normaal globaal gevoel van eigenwaarde, gemiddeld het hoogste ego ontwikkelingsniveau, volgen regulier onderwijs, en groeien op in een horende sociale context. Iets minder vaak worden emotionele stoornissen gevonden in de groep adolescenten met een laag sociaal competentieprofiel (36,0%) en veel minder vaak bij adolescenten in de groep met een hoog sociaal competentieprofiel (10,0%). Deze bevindingen suggereren gedifferentieerde verbanden tussen de aanwezigheid van psychische stoornissen en subgroepen adolescenten met omschreven zelf-concept profielen.

Het cross-sectionele karakter van deze onderzoeken laat geen conclusies toe over de causaliteit van de gevonden verbanden. Andere beperkingen in de drie onderzoeken bij de groep dove adolescenten betreffen de beperkte omvang van de onderzoeksgroep, een non-respons percentage van 26%, en een betrekkelijk hoog aantal adolescenten dat een voorkeur heeft voor gesproken Nederlands. De non-respondenten onderscheidden zich in een lager IQ en een voorgeschiedenis van meer psychosociale stressoren. Daarnaast was het percentage caseness en het percentage gedragsstoornissen bij oraal communicerende adolescenten lager dan dat bij gebarende adolescenten. Het lijkt daarom niet waarschijnlijk dat de gevonden prevalentie van psychische problemen in de onderzoeksgroep, de problemen in de zelfwaardering of de lage niveaus van ego-ontwikkeling overschat zijn.

Een tweede beperking in deze onderzoeken is het ontbreken van specifiek voor het gebruik bij doven ontwikkelde instrumenten die het zelf-concept of de

ego-ontwikkeling meten. Een mogelijk beperkt begrip van de schriftelijke vragen bij de dove deelnemers werd ondervangen door met alle dove adolescenten in hun preferente communicatie modus te communiceren en hen aan te moedigen vragen te stellen en hulp te zoeken in hun preferente taal.

Een van de beperkingen van de klinische studie is dat de data gevonden in een klinische populatie niet gegeneraliseerd kunnen worden naar de niet klinische populatie dove en slechthorende kinderen en jongeren. De gespecialiseerde voorziening - de enige in Nederland - was goed ingebed in het reguliere geestelijke gezondheidszorgnetwerk en in het specialistische netwerk van hulpverleningsvoorzieningen voor doven en slechthorenden in het land. Het is dan ook waarschijnlijk dat de bevindingen een reële weerspiegeling geven van de psychische problemen en kenmerken bij dove en ernstig slechthorende kinderen en jongeren.

Een bijkomende beperking van de klinische studie is echter dat er geen gegevens voorhanden zijn van kinderen en jongeren waarvan de psychische problemen niet herkend zijn, evenmin als van kinderen en jongeren die wel werden verwezen maar niet in onderzoek zijn gekomen.

Een laatste beperking van alle studies is dat beide onderzoeksgroepen weinig adolescenten met een cochleair implantaat (CI) bevatten. Desalniettemin zullen studies van onderzoeksgroepen die niet geïmplanteerd zijn, van belang blijven omdat naar verwachting cochleair implantaten voor de meerderheid van de wereldbevolking niet beschikbaar zullen zijn. In de weinige studies in de Angelsaksische literatuur naar verschillen in psychopathologie tussen doven met en zonder CI werden tot nu toe geen verschillen in prevalentie van psychische stoornissen gevonden.

Samenvattend onderstrepen de bevindingen in de studies het belang van goede specialistische geestelijke gezondheidszorgvoorzieningen voor doven en slechthorende mensen welke in voldoende mate tegemoet kunnen komen aan hun geestelijke gezondheidszorg behoeften, de complexiteit en de heterogeniteit daarvan.

Toekomstig onderzoek dient bij voorkeur betrekking te hebben op (1) de ontwikkeling van betrouwbaar en valide diagnostisch instrumentarium dat in

voldoende mate is aangepast dan wel speciaal ontwikkeld is voor het gebruik bij ernstig auditief beperkte mensen, (2) voorspellers van psychopathologie waarbij rekening wordt gehouden met de interactie van intra-persoonlijke, doofheid- en omgevingsgerelateerde factoren, en (3) het effect van interventies die zijn aangepast aan het niveau van ego-ontwikkeling van dove en slechthorende kinderen en jongeren.

Curriculum Vitae

Tiejo van Gent was born in Breda, The Netherlands, on December 28th, 1951. He graduated in 1971 from secondary school at the Stedelijk Gymnasium in Breda. He then studied Medicine at the University of Amsterdam. From 1976 to 1979 he was appointed Bachelor Assistant at the department of Medical Psychology at the University of Amsterdam and in 1982 he graduated as Doctor of Medicine. From 1982 to 1983 he worked as a nurse at the alcohol detoxification unit of the Jellinek Center in Amsterdam. In 1983 he started his education in Psychiatry at the Psychiatric Center Sint-Bavo (under Dr. J. L. van der Lande) in Noordwijkerhout, which he then continued at the Psychiatric Hospital Vogelenzang (under Dr. F. van Ree; Drs. R. van den Berg; Dr. P. Bierenbroodspot) in Bennebroek from 1983 to 1987.

From 1987 to 1988 Van Gent followed an internship in Child and Adolescent Psychiatry at the Academic Child and Adolescent Psychiatric Centre Curium (under Prof. dr. Ph. D. A. Treffers) in Oegstgeest. After his graduation as a Psychiatrist-Psychotherapist in 1988 he specialised in Child and Adolescent Psychiatry in 1989 at Curium. From 1989 to 2008 he worked as a child and adolescent psychiatrist at Curium, affiliated with Leiden Medical University Centre (LUMC). Until 1993 he worked both in regular out-patient service and in-patient service. In 1991 he was appointed as Assistant Professor at LUMC, and as Deputy Chief of the in-patient service at Curium. From 1993 to 2007 van Gent worked as Consultant Child and Adolescent Psychiatrist in charge of the national in-patient and out-patient service for deaf and hard of hearing children De Vlier, a department at Curium/LUMC, and from 1999 as Cluster Manager.

In 2007 van Gent accepted an assignment by The Royal Effatha Guyot Group in Zwolle, which delivers education and care facilities for children, young people and adults with hearing, speech or language problems. His brief was to advise on the development of preventive diagnostic and therapeutic strategies for their clients with mental health problems. Since 2008 he works full-time at Royal Dutch Kentalis, a national organisation formed from the merger of Viataal in Sint-Michielsgestel, The Royal Effatha Guyot Group in Zwolle and Sint-Marie in

Eindhoven providing diagnostic, care and educational services for people with hearing or communication problems. His main task is to advise the Directory Board, managers and behavioural professionals on organising and delivering mental health services. In addition he is seconded as a Consultant Child and Adolescent Psychiatrist to ambulatory mental health services for deaf and hard of hearing children and adolescents in The Netherlands: from 2009 to 2010 at Psydon (department of PuntP in Amsterdam) and since 2009 at De Riethorst (department of ProPersona in Ede). In 1994 van Gent co-founded the Specialist Interest Group for Deaf Children and their families of the European Society for Mental Health and Deafness (ESMHD), organising regularly recurring international meetings for deaf, hard of hearing and hearing professionals working with deaf and hard of hearing children and adolescents. In 2011 he was appointed a member of the Executive Board of ESMHD and, later that year, a member of the advisory editorial board of the International Journal on Mental Health and Deafness.

