

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 Gent, T. van

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# Mental health problems in deaf children and adolescents

Tiejo van Gent

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# 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:  $\geq$  96 dB respectively [see Stephens 2001] versus mild: 15-30 dB, moderate; 31-60 dB, severe: 61-90 dB, and profound  $\geq$  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 >40dB; 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 8<sup>th</sup> 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., Rönnberg 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 parentchild 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 selfesteem 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 selfperceived 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., Marshark 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 longterm 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 visualspatial 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 problemsolving and learning is complex and warrants further study (Rönnberg 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 stratagies 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 deafblindness 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 deafblind normalities having balance problems, and becoming progressively visually restricted due to the Usher syndrome, the most common cause of deafblindness (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., Fellinger 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).

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

<sup>1</sup>Hearing 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). <sup>2</sup>Assessment 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. <sup>3</sup>Data 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 sideeffects 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 nonverbal 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 (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 oneparent 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., Remmel &

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; Fellinger 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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