

EDITORIAL

Research priorities in deaf child mental health

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Deafness is a low incidence condition in children in many countries, but its implications for linguistic, cognitive and socio-emotional development are far reaching. In affluent countries such as the UK approximately 1 child in every 1000 is born with a permanent degree of deafness rising to 2 per 1000 by 9-16 years of age. However, up to a quarter of the world's population have hearing loss, with deafness being much more common in low income countries. In at least a third this is associated with many additional neurological, physical and mental health problems.

The introduction of the newborn hearing screening programmes in many developed countries has resulted in the age at which deafness is confirmed on average dropping from about 26 months to 10 weeks. When early intervention follows early identification it can enhance linguistic outcomes for deaf children. Cochlear implantation is becoming more common in affluent countries and the impact of newborn screening and cochlear implantation requires research. Recent studies show linguistic and cognitive gains, but language delays and rates of mental health problems remain high. The consequences for family functioning and quality of life is a research priority. The world should also not forget those countries not able to screen or use expensive interventions, and should not forget the evidence base we already have. We should begin to research how to better deliver relatively inexpensive educational, parenting and psychosocial interventions across the world. Alongside the crucial work in less affluent countries, more developed countries need to test internet and advanced communication technologies for provision of mental health information and services. Texting and other communication technologies are radically changing some deaf people's lives.

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The overall prevalence of child mental health disorders in hearing children is approximately 10%. In deaf children there is evidence across several countries that mental health problems are between 2-3 times higher. No research has yet attempted to quantify this in less affluent countries where it is likely to be considerably higher given high levels of co-morbidity, low levels of support and high levels of marginalisation. One UK study using a structured diagnostic interview with a sign language interpreter found that 50% of 11-16 year olds had psychiatric disorder. Deaf children face difficulties in language acquisition particularly those 95% born to hearing families and this presents challenges to parenting and family life. Parent rated quality of life is also poorer. Some deaf children have additional risk factors such as central nervous system damage, communicative isolation, delays in accessing services, problems with peer and family relationships which all contribute to more mental health problems. A large methodological criticism of many studies exploring mental health in deaf children is that the instruments used are inaccessible to deaf children (e.g. children with significant language delay or those whose main language is sign language find questionnaires impenetrable, and deaf parents cannot access questionnaires or interviews easily). Given that mental health problems in deaf children lead to long term psychological morbidity, poor educational attainment, unemployment, and delayed social skill development there is a great need for research that makes mental health screening instruments accessible to deaf children and deaf parents. There is also a need for assessment tools and processes that are designed for deaf children and not simply borrowed from hearing population studies. Three good examples of this are autism, schizophrenia and tic disorders. Autism screening instruments almost universally have items in them that have no face validity for deaf children and have serious confounding factors embedded within them (for example

one of the most widely used, the MCHAT, has a question that scores for autism if the parent ever thought their child was deaf). There has been only one attempt to validate any autism screening instrument in deaf children using a hearing instrument. Assessment for schizophrenia in deaf people is frequently carried out by clinicians who have little awareness of deaf culture (with its change in presentations) or of the various ways in which linguistic hallucinations can present in deaf people (often very different from hearing people). In the same way tics may present very differently in deaf people. In all of these and many other areas there is a great need for more research to improve screening and assessment and to validate new tools and develop new interventions.

Developmentally the finding that theory of mind (and socioemotional development) delays are more common in deaf children with early life communicative poverty is now well established. This means that autism spectrum disorders are more likely to be misdiagnosed, and also means that children face considerably more social challenges including low self-esteem, social problem solving difficulties, social rejection and anger management difficulties. The corollary of this is that we need to be better at understanding what the natural history of development is in deaf children, and be better able to tune learning experiences, parenting advice and developmental support to deaf children. In all of these areas, given the nuances and differences described, interventions need to be better differentiated for deaf children, with studies testing and validating new developmental interventions and treatment approaches. For example, the main focus internationally since newborn screening has been to improve language development and this appears to be contributing to some better mental health outcomes. They also have huge potential to improve mental health by reducing parental stress, promoting prosocial behaviour and positively affecting parental adjustment to

their deaf child. However programmes after identification of deafness frequently do not go far beyond language and communication interventions and further research would be useful to test whether interventions to improve emotional understanding or promote socio-emotional competencies for children, that are promising in small group research with deaf children, may be effective and cost effective if delivered universally. A range of innovative and culturally sensitive interventions need to be developed specifically for deaf people, and tested robustly in properly commissioned research.

Another important gap in the literature concerns the experience of children and families from ethnic minority populations. We know little about potential cultural differences and impact on the relationship to service delivery, and how this interfaces with deaf experiences and deaf culture. Health and social care agencies struggle to provide accessible and appropriate care for culturally and linguistically diverse populations. Our failure to engage with these challenges contributes to flawed understanding, inappropriate responses and wasted resources. We need to explore cultural differences more carefully as well as the different ways that deaf children from ethnic minorities experience the world. Research has a habit of focusing around clearly defined cultural sub-groups, but the experience of our services is that each child and family's experience is unique. Families frequently do not fit into cultural stereotypes. We need better ways to understand this, to avoid service polarisation and to be open minded in the provision of care to whoever needs it.

An international meeting in York in 2011 explored new research goals for autism spectrum disorders in deaf children and an international conference in June 2012 in Austria will look at interventions for family centred early intervention, so there is a growing international realisation that deaf

children require careful thought in resourcing, provision of health and social care and education, and future research. A recent conference in the United States, chaired by Professor Robert Pollard brought together researchers from around the US to develop the beginnings of a research agenda for improving the mental health of deaf people. It is hoped that these and future such initiatives will prompt those commissioning research in this field to back this important work.