ABSTRACTS

THURSDAY, MAY 16th

MAIN-CONFERENCE

THEATRE HALL

Opening Keynote Connecting, Communicating and Collaborating to create the FCEI:DHH Principles

Presenters:
Trudy Smith, Sheila Moody, Elaine Gale, Amy Szarkowski, MaryPat Moeller, Snigdha Sarkar, Karolin Schafer, Frank Dauer, Richard Doku
(Australia, Canada, USA, India, Germany, Austria, Ghana)

Abstract:

The update of the FCEI:DHH Principles was a remarkable feat of connection, communication and collaboration. The writing team will share their experiences and provide a brief introduction to the newly published documents. This will be followed by a panel discussion featuring a professional, a Deaf leader, and a parent to discuss the implications of the FCEI:DHH Principles from their perspectives.

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Making space for intuitive early communication

Authors:
Dirks Evelien (The Dutch Foundation for the Deaf and Hard of Hearing Child, The Netherlands)
Lumby Hannah (National Deaf Children's Society, UK)

Abstract:

Every parent takes a little time to get to know their new baby. Time well spent gazing at their newborn, stroking their skin and intuitively smiling and chatting. These early **connections** between parents and their baby form a bond which is the foundation for children to develop.

When a parent finds out their baby is deaf or hard of hearing, they may feel unsure about how to **communicate** with their child and lose confidence in their own expertise.

Hannah will share her experience of the months after finding out that her newborn had hearing loss. Wanting to do the best for her daughter, she ensured they were using hearing aids consistently and applying the new communication techniques she was learning. As the months passed however, she noticed something more important was missing. Hannah will share her personal story of going back to basics and connecting more fully with her baby as a result. Evelien will present a project that aims to strengthen parents' trust in their intuitive interacting skills. Video-feedback techniques are used to discover with parents how they already connect instinctively with their deaf or hard-of-hearing baby.

The **collaboration** between Hannah as a parent and Evelien as a researcher will provide practical insights into how professionals can support families to recognise their instinctive interacting skills, highlight what parents are already doing well, and most importantly enjoy their baby.

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'Getting Them Set for Their Futures': The Importance of Hearing Parents Connecting Past, Present, and Future Time. Building Deaf-Child Futures

Author:
Jane Russell (Parent Researcher, University of Manchester, UK; GPODHH)

Abstract:

The future of deaf children is a significant concern for hearing parents, often triggering worry and distress. Research suggests that parents may experience grief due to the loss of their anticipated future for their child. However, as a parent-researcher and mother of deaf/hearing triplets born in 2000 I have found that exploring the concept of future time with experienced parents provides a deeper and more nuanced understanding.
In this presentation, I draw upon the findings of a qualitative interview study involving eight hearing mothers of deaf young people aged 11-23. Additionally, I incorporate my own autoethnographic commentary and draw on an analysis of wider literatures. The aim is to delve into the concept and power of what I now refer to as 'Deaf-Child-Futures.' To achieve this, I employ a hermeneutic phenomenological methodology and a modified version of Braun and Clarke's (2019) reflexive thematic analysis. Through this approach, I shed light on how parents' perceptions of future time influence their present actions.

The results of this study reveal that hearing parents' assumptions about the futures of deaf children can significantly shape their child's outcomes. Through engaging in Deaf-Child-Parenting-Practices, most mothers come to actively participate in envisioning and shaping multiple-possible-futures for their children. This sense of agency in "futures-making" expands upon the conventional understanding of parent involvement and its impact on deaf children's outcomes. Moreover, the concept of embracing multiple-possible-futures and learning to positively use and navigate uncertainty emerge as valuable perspectives. Such perspectives align with the ongoing focus on how childhood experiences contribute to the long-term outcomes for deaf adults. In conclusion, I advocate for early and continuous discussions on Deaf-Child-Futures among deaf/hearing practitioners and parents. By doing so, we can better support the well-being of deaf children and parents and positively shape the future life trajectories of deaf children.

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From LEGOs to Letting Go: How a Deaf Mentor Changed Our Family

Authors:
Leeanne Seaver (hearing mom), Dane Seaver (Deaf son), & Henri Medinilla Grau (Trilingual/ASL-English-Spanish Deaf Mentor)

Abstract:
Not long after our son Dane was late-identified as profoundly deaf, Henri came into our lives. His lived-experience as a Deaf man (native ASL & oral English fluent) had a seismic impact on us as hearing parents. We would learn things from Henri that no one else could teach us, and it changed us as a family, and as human beings. I have been writing about these themes (the difference between language and communication… IEP social goals vs being invited to birthday parties… the advocacy imperative… puberty… how to influence systems from a parent perspective… the high cost of misunderstanding… so much more) for years in my regular column in the H&V Communicator. It's high time Dane and Henri share their perspectives. This session is delivered as a shared (but structured) conversation between the three of us exploring the agony and the ecstasy of this pilgrimage through 30 years together.
Learning Objectives:

1. To understand the role of a Deaf mentor in a family—as experienced by the mentor and the family.
2. To increase awareness of the unique perspectives of Deaf adults, Deaf children in a hearing family, and Hearing parents.
3. To inspire and increase the practice of Deaf mentorship in family support systems.

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The EPID: Early Parent Interaction in Deafness - A New Assessment Tool Co-Produced with Parents

Authors:
Martina Curtin (National Health Service, Homerton Healthcare, UK),
Alison Miles (Parent Representative, Communication Support Worker for deaf toddlers, UK)

Abstract:

The quality and quantity of parent-child interaction (PCI) is a key predictor for the successful development of deaf children's language. Though professionals have assessments to monitor child language, a tool to observe parental interaction is yet to be developed. This four-stage, mixed-methods project, funded by the National Institute for Health Research (UK), addresses this gap.

The project's aim:

To develop an evidence-based, deaf-specific, observational assessment tool for early interventionists to use in collaboration with parents and deaf children aged 0-3 years. The tool will positively identify parent interaction behaviours that support language development.

Co-production and service-user involvement:

An involvement group of hearing parents of deaf children, and hearing and deaf practitioners, academics and charity employees were funded to collaborate with the researcher on each phase.

Methods:

1. A review of the research to identify which parent behaviours are assessed, how they assessed and which link to deaf children's language scores.
2. A national UK survey (and follow-up focus groups) to understand professional practice in the assessment of PCI.
3. An international consensus study using results from (1) and (2) to gain expert agreement on the core content of the tool.
4. A co-production phase to transform the outcomes of (3) into a family-centred tool.

Results

The results of each stage will be shared during the presentation, along with future directions and implications for families, practitioners, and deaf children.

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Understanding developmental trajectories of DHH children from birth to school-entry: First outcomes of the AChild study

Authors:
Daniel Holzinger, Magdalena Dall, Daiva Mülleger-Treciokaite, Johannes Hofer
(Institute for Neurology of Senses and Language, Research Institute for Developmental Medicine at the Johannes Kepler University, Austria)

Abstract:

The AChild study investigates child and family outcomes over the pre-school period (6 time points) in a epidemiological sample of about 260 DHH children in Austria, with a focus on the identification of early and malleable predictors. The multiprofessional team of speakers discusses the participative study design and study practice with a critical role of parents, and presents data on multidimensional characteristics of a total population sample of DHH

children. Data on children with a diversity of special needs are included. As a key emphasis of the AChild study, findings on the relationship between early child social communication skills and characteristics of parent-child communication, and its impact on later child and family outcomes are reported.

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THEATRE HALL

Early intervention following early identification

When families can't engage: an analysis of when and how families do not access early hearing detection and intervention

Authors:
Felicity Hood, Melinda Barker, Zeffie Poulakis
(Victorian Infant Hearing Screening Program, Centre of Community Child Health and Department of Psychology, Royal Children's Hospital Melbourne; University of Melbourne, Murdoch Children's Research Institute, Australia)

Abstract:
Background: The Victorian Infant Hearing Screening Program (VIHSP) Australia, consistently reaches and exceeds early hearing detection and intervention (EHDI) pathway benchmarks. However, at every point of the EHDI pathway, some infants either do not complete the next step, or complete it later than the benchmark age.
Aims: This paper asks: Are there factors that that lead to families not commencing or completing their babies' EHDI steps that could be addressed?
Methods: Records: VIHSP data from all babies born between January 2005 and December 2021 who did not complete their hearing screening pathway.
Analysis: The following elements were examined:

- rate of disengagement at each hearing screening pathway exit point
- type of disengagement
- timing of the disengagement
- demographic characteristics (residential location, communication methods used to interact with family, Aboriginal and Torres Strait Islander status, languages spoken in the home)
- medical history of infant; and
- pandemic public health restrictions.

Results: Several challenges to engagement were identified. These include factors relating to

- hospital practices
- family social circumstances
- parent and carer communication preferences
- parent and carer beliefs.

Conclusions: Among reasons for disengagement were factors related to the relationships and communication methods between parents and professionals. Impersonal approaches (e.g. "no caller ID") and a lack of interactive ways of communicating (e.g. one way text messages) prevented engagement for some families. Based on these results changes have been designed and implemented to reduce the causes of disengagement that could be mitigated by more parent-friendly systems of engaging and communicating.
Future directions: This team is now examining geolocation and indices of advantage and disadvantage to see whether infants who are most likely to be at risk of not meeting EHDI benchmarks can be identified early.

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Towards evidence-based family centred early intervention: A look into a recent German guideline

Authors:
Karen Reichmuth, Katrin Neumann (Department of Phoniatrics and Pedaudiology, University Hospital Münster, Germany)

Abstract:
Background: Recently, a German interdisciplinary guideline on evidence-based recommendations for interventions for developmental language disorders was published. It also includes a chapter on interventions for children who are deaf/ hard of hearing (DHH) [1]. Findings on early intervention are presented here.
Methods: In a systematic literature review, the PubMed and Cochrane Library databases were reviewed for the period from 1/1/1995 to 15/8/2022 for child- and parent-based (early) interventions and speech and language therapy for DHH children. In accordance with the strict evidence-to-decision framework for German's highest "S3 guideline level", predominantly systematic reviews, meta-analyses, randomized controlled trials and controlled intervention studies were included. The guideline was consented by 23 German professional societies and the Deutsche Kinderhilfe as patient representative.
Results: The guideline strongly recommends family centred early intervention in the first six months after birth following early detection of hearing loss. Thereby it focuses on approaches with high parent involvement and coaching to improve parent-child interaction as well as quality and quantity of linguistic input. Among others, several new responsive parenting programmes, which primarily adapt and modify the content and methodology of the Canadian Hanen Early Language Program for DHH children, are recommended. They show short- and long-term effectiveness and are available for the age range from 3 months to 5 years. Further effective means are dialogic book reading, singing and music-based intervention.
In addition, studies often focus on Auditory Verbal Therapy and hardly on the Natural Aural-Oral Approach. For both approaches, no clear or strong exclusive evidence has been found.
Conclusions: For the first time in Germany, a guideline provides clear, empirical guidance regarding effective means for (early) interventions for DHH children and their families. Further goals are the availability of these programmes in German, more research on evidence-based interventions and specific training for professionals. The guideline recommendations are in line with demands of FCEI international and the WHO.

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Hearing Screening for congenital CytoMegaloVirus – exploring parents experiences of completing targeted congenital cytomegalovirus screening at the time of their infant's newborn hearing screening

Authors:
Emma Webb, Jan Hodgson, Alanna Gilespie, Cheryl Jones, Zeffie Poulakis, Janis Wong, Valerie Sung (The University of Melbourne, Murdoch Children's Research Institute, The University of Sydney, Sydney Children's Hospital Network, The Royal Chrildren's Hospital, Australia)

Abstract:
Background: Congenital cytomegalovirus (cCMV) is the leading infectious cause of sensorineural hearing loss. Recent evidence suggests treating cCMV with antiviral treatment within one month of an affected baby's birth may be beneficial to preventing progression or development of hearing loss. Diagnosing cCMV accurately requires early screening for the virus (<21 days). There has been little research into the acceptability and feasibility of targeted screening for cCMV in a timely manner in the postnatal period. Whilst screening programmes allow early identification and treatment, there

are potential burdens including psychological distress to families. To ensure the success of targeted cCMV screening, it is essential to ascertain parental perspectives and experiences before implementation.
Method: Semi-structured interviews with parents of infants who underwent cCMV salivary screening at the time their infant received a second positive 'refer' result on their Newborn Hearing Screening (NHS) result.
Results/Aims: Our aim was to investigate the parental perspectives and acceptability of additional salivary cCMV screening at the time of the second positive ('refer') on the NHS result. 18 parents participated in the semi-structured interviews. We identified several themes relating to parental experiences of targeted cCMV screening, including: parents lacked awareness around CMV prior to cCMV screening, parents had an overall positive experience completing the cCMV screening, parental understanding of CMV post cCMV screening varied and parents were glad they were able to screen their infant for cCMV. We also identified enablers such as the swab being simple and non-invasive, and barriers such as false positives possibly leading to an initial increase in anxiety.
Conclusions: This comprehensive understanding of parental experiences and factors facilitating successful delivery of cCMV targeted screening provides evidence of the benefits of implementing routine targeted cCMV screening.

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SEMINAR ROOM 1

Collaborative Practice

Synergy of specialists and parents in the formation of communicative competences in children with hearing impairment. (Project "Summer School" according to the RV program)

Authors:
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Doroshenko Olena (Central Ukrainian State Pedagogical University named after Volodymyr Vinnichenk)
Chekanova Oksana (Communal institution "Inclusive Resource Center No. 1" of the Kropyvnytskyi City Council)
Kateryna Taran (Public Organization Union of Special Families Ozhyna)
Ukraine

Abstract:
The Summer School project has been implemented by a team of specialists for 9 years in a row. This type of corrective and developmental influence is in high demand in the parent community. The number of summer school participants who want to get practical advice and experience on organizing a quality educational environment for people with special educational needs is increasing every year. The summer school did not stop its work despite the difficult socio-economic situation in Ukraine.
The uniqueness of the Summer School project

1. Family-centricity
2. Team approach
3. Active inclusion of parents
4. Observation and holding of daily consiliums
5. Exchange of experience
6. Individual development program for each child

Learning outcomes

Participants will learn about the peculiarities of the organization of work under the program of early intervention in the Summer School and will get acquainted with the author's method of team influence, regarding the development of hearing perception and the formation of pronunciation in people with hearing impairments, including those with comorbidity.

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Collaborative teamwork among professionals

Establishing a collaborative Australian Family Research Advisory Group to support children and young people who are deaf or hard of hearing: A Case Study

Authors:
Emily Shepard (UsherKids Australia),
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Jermy Pang (National Acoustics Laboratory, Macquarie University),
Hollie Feller (UsherKids Australia, Genetic Support Network of Victoria),
Valerie Sung (The Royal Children’s Hospital, Murdoch Children's Research Institute),
Karen Liddle (The University of Queensland, Queensland Children’s Hospital),
Kayla Elliott, Libby Smith (Murdoch Children's Research Institute)
Australia

Abstract:
Background: Community engagement is a crucial element in health research as it helps to ensure that research is designed with the needs and perspectives of those with lived experience at the forefront. With this in mind, we have established the *Australian Child Deafness Research Community Advisory Group* (Aus Child Deafness CAG), a research advisory group for children and young people who are deaf or hard of hearing, the first of its kind in Australia. The aim of this group is to strengthen partnerships with researchers working in childhood deafness and ensure the voices of those with lived experience are being valued and heard.

Aims: The Aus Child Deafness CAG has recently been established to fill a gap in the current childhood deafness research landscape in Australia. Although community consultation is highly regarded in Australia, it can be tokenistic and lacking genuine involvement, and often excludes marginalised communities such as those from culturally and linguistically diverse backgrounds.

Our case study will highlight the values and principles we were guided by in establishing this important group, including:

- ensuring systemic respect for community participation through formal means such as remuneration, terms of reference, familiarisation and induction, and attribution in outcomes.
- acknowledging and appreciating community expertise, knowledge, perspective and needs.

Conclusions: This case study provides rich information and learning opportunities for other parties interested in establishing a research advisory group.

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Chances, contingencies and challenges of 3 C‘s in Early Intervention from Newborn Hearing Screening to School Age

Authors:
Doris Binder, Daiva Müllegger-Treciokaite (Institute for Neurology of Senses and Language, Austria)

Abstract:

The Family Centered Early Linz Intervention Program (FLIP) has established a proactive approach towards possible partners in the field of early intervention for all kinds of cooperation. This requires a clear understanding of the purpose of networking, but also high effort and arespectful style of interaction.

Parents and families appreciate these cooperations and can profit through:

- relief after many often challenging steps seeking the „right“ professionals
- information exchange between professionals
- a professional overview of the child's development
- an equal and current state of knowledge of all network partners
- a medical and therapeutic home for families

Our cooperations start with newborn hearing screening (screeners, ENT specialists, pediatricians, acousticians, …) and continue through all ages as far as school life (special education teachers, psychologists, …).

The presentation focuses on:

- What helps to establish, develop and stabilize the cooperation?
- How can we make cooperation successful for all of those involved?

Possible challenges on the way are:

o Clinical teams find it hard do find time in their daily work

o Therapeutic work is mostly seen as working directly with the child and family only; sponsors and government will hardly allow for sufficient conversation and exchange time done in addition to direct intervention

o How to motivate the early intervention team in case of little interest of others

We want to show a practicable model and encourage other teams to establish similar networks.

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SEMINAR ROOM 3

Language & communication

Project TREE: Transforming Reading in Early Education for Deaf Children

Authors:

Christopher Kurz, Patrick Graham (Rochester Institute of Technology, USA),
Krishneer Sen (Deaf Consultancy Pacific, Fiji),
Michael Vea (College of St. Benilde, Philippines)

Abstract:

Background: Project TREE addresses the gap by providing DHH children greater access to sign languages, early-grade reading materials, sign rhymes, and learning assessments. Project TREE produced Sign Language Rhythm and Rhyme and Shared Reading Strategies with Technology training materials and provided training in three different countries: Fiji, Papua New Guinea, and the Philippines. It promoted community engagement and inclusion by including parents/families with DHH children and deaf community members. Each team implemented the home visit program and collected language skill assessments.

Methods: The aim of this study was to evaluate whether deaf children can learn new vocabulary from their interactions with interactive storybooks and deaf mentors. The Repeated Acquisition Design is a single-case research design with strengths which made it suitable for use in educational contexts, including its ability to assess how interventions are effective in authentic settings (Kirby et

al., 2021). This design also allows researchers to track skill development in various areas, such as vocabulary knowledge.
Results: The findings from the country samples (n=24) suggest that while the intervention was highly effective for some participants (See Figure 1), it produced mixed results for others. Further investigation provides a more comprehensive understanding of the factors that might have impacted the results of this intervention.
Conclusions: The intervention's impact was more prominent among the deaf children in Fiji than in the Philippines. The cross-country contrast in outcomes suggests that contextual factors could influence the intervention's effectiveness, such as differences in the approaches that deaf mentors use, language abilities of the children, levels of familial involvement, frequency in using the tablets, and the quality of interaction between the deaf mentors, the children, and their families. Understanding these variables will provide greater insights into why the intervention was more successful among some children and not as effective with the other children.

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Recent Findings on Family Language Planning and Policy: Families with Deaf and Hard of Hearing Children

Authors:
Christi Batamula, Bobbie Jo Kite, Candace Jones, Julie Mitchiner, Victorica Monroe
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Abstract:
Background: This presentation shares findings from a current study investigating multiple language use among families with deaf and hard-of-hearing (hoh) children in the northeast US, utilizing the Family Language Policy Framework (FLP). FLP delves into family language ideology, practice, and management (King & Fogle, 2014). Recent FLP research focused on bilingual and multilingual families, including those with deaf/hoh children (Crowe, 2014; Mitchiner, 2014; Kite, 2017). However, there is a shortage of research on how these families navigate multilingualism, underscoring the need for this study.
Methods: Framed by Weisner's ecocultural theory (2002), the study adopts a mixed methods approach (Greene, 2007), blending qualitative and quantitative data collection. Quantitative data, obtained through surveys, gauges families' attitudes, beliefs, and self-perceived language skills. Qualitative data, collected via one-hour semi-structured interviews, explores values, language use patterns, and language development goals for their deaf/hoh children.
Results/Aims: The presenters will share findings from the study, with the expectation that families will express positive attitudes and beliefs regarding multilingualism in ASL, English, or their home language for their children. The study also anticipates that families' perception of their language skills will influence their attitudes toward multilingualism.
Conclusions: This study's insights into the experiences and perspectives of these families can offer valuable guidance to other families considering bilingualism for their deaf/hoh children. Furthermore, professionals can gain insights to better support these families and understand the significance of multilingualism. Given the limited existing research on beliefs and language use in bilingual families with young deaf children, this study contributes to developing theories for effectively navigating multilingualism, thus mitigating the risks of language deprivation and delays in this population.

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Shared Book Reading Practices of Parents with Deaf and Hard of Hearing Children: Predictors, Challenges and Requirements

Authors:
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Abstract:
Background: Research has shown the beneficial impact of parents engaging in shared book reading during early childhood development and especially in language acquisition in deaf and hard of hearing (DHH) children (Desjardin et al., 2023). Much less is known about the predictors that influence the frequency and quality of shared book reading of parents with their DHH children, their specific challenges and requirements.
Methods: Data on shared book reading practices, challenges and requirements were gathered using a mixed-methods approach with a quantitative online survey (N=127) and qualitative interviews (N=8) with hearing and DHH parents of DHH children aged 0-13 years. Factor and regression analyses and qualitative content analyses were applied to the data.
Results: Using multiple linear regression analysis, the quality of the home learning environment, the parental self-efficacy experience and the level of challenges faced were detected to significantly predict the frequency of shared book reading. The most frequently reported challenges were controlling the DHH child's attention and using sign language.
Conclusions: The findings indicate that parents of DHH children need tailored support through early intervention to be engaged in shared book reading. The results contribute to the development of digital picturebooks with spoken and sign languages aligned with a digital training program for parents and pedagogical professionals as part of the research project "Reading Digital - Inclusive language education with multilingual picturebooks".

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Family ASL: Monitoring Shared Attention Through Deaf Eyes for Families and Professionals

Authors:
Elaine Gale, Amber Martin, Eileen Lograno (Hunter College, USA)

Abstract:
Best Practice Principle 9, Progress Monitoring, is guided by regular monitoring/assessment of child and family outcomes. This presentation focuses on progress monitoring visual shared attention when interacting with young DHH children. When interacting with young DHH children, visual strategies are essential for language to be accessible. While visual strategies are an important scaffold for language development for DHH, hearing parents with DHH children do not often use them effectively. For example, studies show hearing parents with DHH children are less likely to meet their children's visual communication needs and that hearing parents with DHH children need visual communication training and support. Because deaf children who have access to a visual language from their deaf caregivers have positive language outcomes, an approach hearing parents can use to increase visual communication is to apply the strategies that deaf caregivers use to manage visual communication with their young DHH children that enable visual language access. This study investigated duration of time in visual shared attention through deaf eyes between DHH children and their hearing parents, and ist relationship to language development. A joint attention coding scheme proposed by Gabouer & Bortfeld (2021) was used to code visual shared attention from a 10-minute joint free play language samples of deaf toddlers and their parents. We coded the duration of shared attention between dyads and assessed the relationship between visual shared attention and language scores. We will present preliminary results of this analysis and discuss ways the FCEI community (DHH and hearing

professionals and families) can monitor visual shared attention when interacting with young DHH children. Monitoring visual shared attention can allow professionals and families to work in partnership to better support young DHH children’s language development.

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Beyond Language: Fun Hearing-Rehab with Music and Sound

Authors:
Stefanie Muck (MED-EL, Austria)
Teresa Schneider (LZH Dornbirn, Austria)
Dagmar Herrmannová (Smiling Crocodile, Czech Republic)

Abstract:

Music is part of social life and ensuring well-being for many people, for children it is part of many games. And it gives language-independent possibility to train the capabilities necessary to understand speech (including nonverbal information - prosody) in everyday situations. The joy children have with music will increase the training effect wide above training effect of straight speech training.

Method: While speech understanding is the main goal for most CI-users, experiencing sounds and music are quite important hearing impressions as well. Sufficient scientific data proofs the role of music for hearing rehabilitation.

Further, Presenters will explain features of signal processing for enhancing best music understanding. And they will demonstrate four digital resources, which provide fun for children and at the same time train sound recognition and understanding, music understanding and/or speech understanding.

- Meludia
- ReDi
- Musical Ears
- Listen with Smile

Results: Teresa Schneider presents her promising experience as therapist when using online-application Meludia and the motivating feedback of her patients.

Stefanie Muck shows the exciting possibilities to use mobile-App ReDi for children. Further on she presents the potential of online-tutoral Musical Ears.

Dagmar Hermannova reports about the wide scope of the mobile-App “Listen with Smile”, based on hearing and recognition of non-verbal sound. The app is part of the project Smiling crocodile, an education programme for parents to children of the group DEAFplus.

Conclusion: Beside audioverbal communication, hearing is important for sound recognition and music experience. Leading hearing technology should allow for these needs. There are different digital ressources available, that use sound and music for joyful training the abilities necessary to understand speech, also in challenging hearing situations. In the means of successful users, MED-EL collaborates with different institutions for successfully implementing such applications.

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SEMINAR ROOM 4

Family support and/or decision making

Exploring the support needs of Australian parents of young children with Usher syndrome: A qualitative thematic analysis

Authors:
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Lemuel Pelenstov (Clinical and Health Sciences, University of South Australia),
Lisa Keams (Royal Victorian Eye and Ear Hospital, Australia),
Karyn Galvin (Departent of Audiology, University of Melbourne, Australia)

Abstract:
Background: Usher syndrome is the most common cause of deaf-blindness, affecting up to 1 in 6000 people. Advancements in genetic testing have now led to Usher syndrome being diagnosed at a much earlier age than in the past, enabling the provision of early intervention and support to children and families. Despite these developments, anecdotal reports suggest there are substantial gaps in the services and supports provided to parents of children with Usher syndrome. UsherKids Australia, a parent-led support organisation, in collaboration with the Melbourne Disability Institute, the University of Melbourne, the University of South Australia, Royal Victorian Eye and Ear Hospital and the Centre for Eye Research Australia, investigated the support needs of parents of children with Usher syndrome Type 1 when their child was aged 0 to 5 years.
Method: Purposive sampling was used, and six semi-structured interviews were conducted with Australian parents of children with Usher syndrome, Type 1. Data was analysed using reflexive thematic analysis.
Results: Four key themes were identified as being central to the support needs of parents of children with Usher syndrome aged 0 to 5 years. *(1) Social Needs* referred to parents need for various sources of social support, *(2) Informational Needs* described the lack of information parents received regarding Usher syndrome from treating professionals, *(3) Practical Needs* included supports needed to assist parents in managing the day-to-day tasks of caring for a child with a disability, and *(4) Emotional Needs* represented the emotion support (formal and informal) that parents needed so to be a positive support to their child.
Conclusions: Findings provide rich information for relevant support organisations, policymakers, individual healthcare professionals, and professional governing bodies regarding the education of stakeholders and the development and implementation of best-practice treatment guidelines.

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Literacy is all around us

Authors:
Faith Robyn, Nadine Fitzpatrick, Kin Hagen, Emma Fraser, Molly Dibblebrowne

Abstract:
Background: *Sharing REAL with Parents* is a sister programme to Making it REAL, an evidence-based literacy approach for disadvantaged families developed by the National Children's Bureau (NCB). The course was adapted for online delivery by the National Deaf Children's Society (NDCS) including tailoring all materials in conjunction with families of deaf children aged 0-5 years to produce a literacy programme that met deaf-specific needs. Of the cohort from Greater Manchester who took part, 92% of children had permanent deafness ranging from moderate to profound, all were oral language users and 75% spoke other languages with their deaf child. 44% of families were living in the most deprived areas.
Methods: This online pilot course was co-delivered by NDCS and NCB across four weekly, 2-hour sessions. Each week, families would engage in activities/discussions about supporting their child's literacy development across 4 specific areas: environmental print (e.g., signs, logos), books, writing & mark-making and oral language. Via peer-to-peer learning, ideas around opportunities, recognition, interaction and modelling of literacy were elicited and celebrated.

After the course families shared their experience through a questionnaire and 1:1 interview.
Results: Families shared how environmental print offered a blank slate for new opportunities to communicate more with their deaf child as it was so readily available: “literacy is all around me”. Alongside increased parental confidence of which 89% of the cohort felt they had gained, family members became more able to recognise and adapt what was important in improving literacy outcomes for their deaf child and subsequently, were also educating other family members and the wider community both directly and indirectly.
Conclusion: Attending the *Sharing REAL* course encouraged families to recognise and seek specific opportunities to support their child’s literacy development through interactions and modelling how to have fun with literacy at home.

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Preventive Education for Parents (PEPP): a starting engine for young children’s language and listening development and empowerment tool for parents

Authors:
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Abstract:
Background: Universal newborn hearing screening was implemented in 2008 in Sweden. However, there is still a lack of national guidelines related to Family-centered early intervention (FCEI). PEPP is a 12-week program created by experienced clinicians and senior researchers. The purpose of PEPP-coaching is to increase parental engagement, and support the use of communication strategies in interactions with their child, from day one. The aim of the present pilot-study was to evaluate if PEPP coaching and the data-driven feedback tools contribute to the dyadic communication patterns (between infant-parents), and to explore how parents experienced to participate in PEPP.
Methods: Ten families of infants who were diagnosed with hearing loss participated in the pilot study (12 weeks of one-to-one PEPP). Motivational interview techniques and data-driven measures: Language Environment Analysis (LENA), video-analysis, and a new mind map technique. Five parents agreed to participate in the focus-group interview, which was analyzed with content analysis.
Results: Results show that the infants were involved in more turn-takings after PEPP. Parents changed some of their communicative behavior, and expressed that they were more aware of their own use of parentese. Parents also felt more empowered after PEPP.
Conclusions: The preliminary results are promising for further development of the PEPP model. Data-driven tools are appreciated by parents, and should be used to motivate parents to change their communicative behavior, from the start. The next step is to conduct a national efficacy study.
During the presentation we will describe the theoretical background for the PEPP model, how we use data-driven tools, and present preliminary study results.

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Exploring families’ early experiences of receiving information and support for informed decision making about language and communication

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Abstract:
Background: Creating a support environment in which families receive full, unbiased information, and the experiences in which to explore what different choices may mean for them, is a key aspect of FCEI. In a context in which there is some concern about whether all families receive the breadth of support they need to make truly informed decisions, and whether there are sufficient resources to enable it, this project undertakes to understand the practical implementation of support for family decision making, the barriers / enablers in professional practice, and to make recommendations for service development.

Methods: An online questionnaire in both English and BSL, (co-produced by DHH and hearing professionals and with input from parents of DHH children) gathered information from families of DHH children under 5 about their experiences: the professionals and other supports they encountered (including access to DHH adults/Deaf community and parent peers), the information they received about language and communication, and the experiences they were supported to access.

Individual interviews and informal focus groups were held with families recruited via the National Deaf Children's Society, as well as with professionals in education, audiology and auditory implant centres and voluntary sector, to explore in depth family experiences and the attitudes / approaches of service providers in sharing information about language and communication options, the barriers / enablers for families in accessing supports, and resources needed for informed choice making.

Focus groups and interviews were recorded, transcribed and analysed to identify key themes.

Results /Conclusions: The attitudes and values of those providing support and information about language and communication opportunities, as well as the resources offered and the constraints which exist, are influential in shaping the context for informed choice and decision making.

A shared understanding of the issues in supporting and resourcing informed decision making amongst different service providers is essential, both to reduce conflict and to support more positive, less stressful experiences for families.

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Forms of verbal and written communication provided to parents at the time of the child's diagnosis of hearing loss

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Abstract:
Background: Parents of deaf and hard of hearing (DHH) children have an important role in their child's communication journey; however, previous research suggests the quality of verbal and written information provided to support parents' decision-making is lacking.

Methods: Over 1106 parents of DHH children have participated in the Victorian Childhood Hearing Longitudinal Databank (VicCHILD), a statewide databank of children with permanent hearing loss in

Victoria, Australia since 2012. Parents completed a survey that explored information provided by health professionals. Survey topics included communication approaches, types of information provided (journal articles, websites, discussion), access to services, and statistics regarding long-term outcomes.

Aims: The primary aim was to identify what information parents received at the time of their child's hearing loss diagnosis. The secondary aim was to explore whether this content was delivered to them primarily verbally or via written forms of communication.

Results: A subset of 154 (13.9%) parents reported on the information they were provided at the time of diagnosis. Of these, 83 (53.9%) reported they received information that included statistics about long-term communication outcomes for DHH children and 139 (90.3%) received information about access to services. Regarding communication approaches, 153 (13.8%) reported these were discussed, with a subset of 127 (83.0%) recalling they discussed more than one approach. Parents reported receiving information in a range of verbal and written forms; these data will be presented.

Conclusion: Results suggested a wide range of information topics and both, verbal and written forms were provided at their child's hearing loss diagnosis. Furthermore, only half of parents recalled receiving information on long-term communication outcomes. Further qualitative research will help understand how parents are using verbal/written information to make decisions for their DHH child.

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