



# SW **Every Deaf** **Child Matters**

## South West Every Deaf Child Matters Conference 2015

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Language, Communication and Mental Health: Why all three matter for deaf children and young people and what we can do

7 July 2015

## Conference Report

## Conference Report

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The fifth South West Every Deaf Child Matters conference – *Language, Communication and Mental Health: Why all three matter for deaf children and young people and what we can do* – brought together over 100 delegates from across the region to discuss some of the current and most important developments affecting deaf children and young people and their families, both in the South West region and nationally. The value of the conference was reflected in the evaluation feedback which indicated that **95% of delegates who fed back would attend the conference again and 98% would recommend it to a colleague.**

The event was sponsored by NHS England, Virgin Care, PC Werth Sound for Schools, Exeter Royal Academy for Deaf Education, the National Deaf Children's Society, Phonak and Advanced Bionics, Microlink PC, GN Resound, Starkey Hearing Technologies, Arlington Laboratories, Oticon, Lightspeed, Cued Speech and Action on Hearing Loss.

This year's conference focused on the essential needs of deaf children across the hearing loss spectrum and on the opportunities and responsibilities to ensure that these needs are met. The contributions of all sponsors ensures that the event continues to provide a high quality learning and networking opportunity for professionals across disciplines. This continued and growing support reflects a genuine commitment of each sponsor to deaf children and their families.

The first speaker of the day, **Diana Harbor from The Ear Foundation**, highlighted rapid changes in the landscape of hearing and communication technologies that are transforming opportunities and outcomes for deaf children and young people. These include the advancement and widening accessibility of a range of auditory implant technologies (cochlear implants, electro-acoustic implants, middle-ear implants, bone conduction implants, etc.). Most profoundly deaf children are now receiving implants very early and have the chance to acquire spoken language through hearing in a way that was unimaginable in the past, many acquiring language on a par with their hearing peers. Progress is undeniable, current evidence however, shows huge variability in educational and other outcomes, and research suggests persistent gaps between deaf and hearing children in their development of key cognitive, communication, language and social skills, including differences in higher order language skills, 'theory of mind' understanding and regulating and understanding emotion. These gaps are often most apparent among older children and young people. While new technologies have brought unprecedented opportunities for improving outcomes for deaf children and young people, these new developments also mean that the educational and other needs of deaf children are now probably more diverse and complex than they have ever been.

What the current evidence highlights clearly is the inadequacy of outdated assumptions about different categories of hearing impairment, particularly the notion that a 'mild' or 'moderate' hearing impairment will only have trivial implications for a child's learning, development and wellbeing. Diana pointed to the latest evidence from a UK-wide NatSIP benchmarking outcomes project which shows that, on average, profoundly deaf children are now achieving better educational outcomes than severely deaf children, those with cochlear implants outscoring other deaf children in Early Years Foundation Stage (EYFS) assessments, and that both profoundly and severely deaf children are achieving better educational outcomes than children with moderate or moderate hearing loss; overall, those with cochlear implants (CIs) are outscoring those without CIs in Early Years Foundation Stage assessments. A recent Ear Foundation study of the experiences of young people with mild and moderate hearing loss found that the terms "mild" and "moderate" to describe the hearing loss do not describe the level of impact, with the educational, social and emotional implications often much

greater than is generally recognised.<sup>1</sup> As suggested in the Q&A session, perhaps the time has come to change the language used to describe different levels of childhood deafness since it is clear that *any* level of hearing impairment can have profound implications for a child's development and attainment. Children with unilateral, 'mild' and 'moderate' hearing impairment, deserve significantly more support and awareness of their needs.

**Carolina Leal, audiologist at St Thomas' Paediatric Hearing Implant Centre**, presented on the role of audiologists in supporting the development of children's language and cognition. Like Diana, she pointed to the new challenges of a fast-changing world, emphasising how crucial it is for deaf children and young people to attain the high-level communication and literacy skills that modern life demands. For audiologists, this means taking their role beyond the soundproof booth to work directly with parents and other professionals and with deaf children and young people themselves to support the best possible use of the assistive technology available, and taking proper account of a child's listening and language environment. As the first point of contact for parents and carers, audiologists have a critical part to play in educating parents and carers about the importance of amplification and using it consistently.

The opportunity that audiologists have to make sure that proper attention is paid to the quality, potential and limitations of children's aided hearing was highlighted, rather than simply focusing on unaided sound detection thresholds based on Pure Tone Audiograms (PTA), as a PTA on its own is not a good predictor of a child's speech perception and understanding or of language development following amplification. This echoed the message of the previous session that descriptions of the severity of hearing loss based on unaided hearing thresholds do not, on their own, provide a good basis for determining a child's support needs and prognosis. For hearing aid users, the Speech Intelligibility Index (SII) is proving more useful than PTA for predicting the benefits of amplification for a child's lexical development and other language outcomes: higher aided SII is associated with more accurate word recognition, non-word repetition and larger receptive vocabulary, whereas an aided SII of 65% or below is associated with a risk of delays in vocabulary development. In reports for parents and other professionals, audiologists should include information not only on the degree of hearing loss, but also about the child's speech recognition potential / SII, what added benefit the amplification can provide in different contexts (quiet / noisy), and the child's aided prognosis. Inappropriate use of PTA instead of functional hearing tests to determine candidacy for cochlear implants for children identified with Auditory Neuropathy Spectrum Disorder (ANSD) and the mismatch between PTA and perceptual abilities was also highlighted by Dr Kai Uus in her later presentation on the management of ANSD (discussed below).

Attention to other key variables is also essential, such as whether the child benefited from early diagnosis and intervention, the language environment at home, noise conditions at nursery or school, etc. Mainstream teachers for example need to be made more aware of the difficulties for any child using hearing aids in noisy situations such as classrooms, including a child with a mild hearing loss. Carolina stressed the importance of continuous collaboration of audiologists with families because of the direct impacts of the home environment and relationships on a child's language and cognitive development and because of the heightened risk of parents of deaf children experiencing stress, depression or attachment problems. The importance of intimate relationships between the child and parents at home was at the heart of a presentation from **Dr Tracy Rydin-Orwin, Chartered Principal Clinical Psychologist and Clinical Lead for Perinatal Mental Health for Devon (Integrated Children's Services, Virgin Care)**. Tracy highlighted the essential need that babies have for social communication from birth and the significance of a child's dyadic or interactive relationship and attachment with its primary caregiver over time. Evidence of how abuse and neglect can affect babies'

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<sup>1</sup> Full study available at: <http://www.earfoundation.org.uk/files/download/1052>

brain development points to how fundamental early relationships and attachment are for our later success as human beings. Issues around early attachment and communication between deaf babies and their parents / primary caregivers deserve far greater attention than they have been given to date.

The need for professionals to put individual children and their families at the centre of support and to recognise and respond to their unique and changing needs was also emphasised by **Louise Cole and Brian Kokoruwe from Heart of Deafness CIC** in their presentation of the findings of a recent NatSIP audit of BSL and sign systems in practice.<sup>2</sup> They advocated an ecological approach to supporting positive outcomes for deaf children and young people, based on a continuous and joined-up cycle of support from birth through to adulthood. This includes direct participation by children and young people, early identification of needs and early intervention to meet these needs, choice and control for parents and young people around support issues, strong collaboration between service providers, high quality provision, a focus on inclusion and removing barriers to learning, and successful preparation for adulthood, including independent living and employment. This cycle of support should be in place for all deaf children, including those who use BSL or other visual communication systems (e.g. Cued Speech), those who are oral, bilingual, multilingual, those experiencing mental health or communication difficulties, and those with a learning disability or additional complex needs. Skills development among hearing support professionals and parents / carers to provide mixed language and communication approaches and partnership working is essential. Additionally the case studies in the report spotlight the positive impact on deaf children's outcomes where parents are fully informed and supported. The report was recommended as an information tool for commissioners and professionals to raise awareness of the issues facing those children who require BSL and other sign systems to support language development which critically affects educational and mental health outcomes.

The importance of centring provision around individuals' specific needs was also a central message from a break-out session facilitated by **Kaye Stevenson from the Exeter Deaf Academy (ERADE)** on meeting the needs of deaf learners with additional needs. The basic principles that underpin the approach to teaching and supporting children at ERADE include a commitment to all children's right to an education that enables them to make progress, achieve their best, become confident individuals and live fulfilling lives, and to make a successful transition into becoming an adult.

A highlight of the conference was a hip-hop street-dance performance by members of the **Plymouth & District Deaf Children's Society's (PDCS) Vibes Dance Crew, supported by Toby Gorniak from the Plymouth Street Factory community dance company.** The young people spoke in a break-out session about how the chance to meet together every week has made them feel happier and more confident, and about how rewarding it has been to learn something new as well as make new friends with other deaf young people. They expressed huge appreciation for everything that Toby and the PDCS have done to support them.

Families' participation and empowerment remained the focus of attention in a presentation on the experiences of parents of infants with Auditory Neuropathy Spectrum Disorder (ANSD) from **Dr Kai Uus, Lecturer in Audiology at the University of Manchester.** Kai reported on the findings of a recently published NDCS-funded study based on 21 narrative case studies and questionnaires that set out to enable parents to share their understanding with professionals and directly inform new professional guidelines for practice.<sup>3</sup> ANSD presents a number of challenges for parents and clinicians: Auditory brainstem response (ABR) tests cannot be used to estimate hearing thresholds, and even if hearing thresholds can be obtained, they will be a poor predictor of perceptual abilities;

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<sup>2</sup> Available at [http://swedcm.weebly.com/uploads/2/1/9/8/21988494/bsl\\_sign\\_systems\\_audit\\_report\\_natsip\\_published\\_march\\_2105.pdf](http://swedcm.weebly.com/uploads/2/1/9/8/21988494/bsl_sign_systems_audit_report_natsip_published_march_2105.pdf)

<sup>3</sup> Available at: [http://www.ndcs.org.uk/family\\_support/audiology/types\\_and\\_causes\\_of\\_deafness/auditory\\_neuropathy.html](http://www.ndcs.org.uk/family_support/audiology/types_and_causes_of_deafness/auditory_neuropathy.html)

ANSD-specific changes include the possibility of daily fluctuations, deterioration or improvement, and sometimes apparently complete recovery; the evidence base informing management of ANSD is very weak; and ANSD is itself a highly varied condition. Management options include visual communication, hearing aids, cochlear implants, or a combination of these, or, for transient ANSD, no intervention at all. The majority of families included in the study had attempted some form of visual communication, but many experienced uncertainty from clinicians about the advisability and appropriateness of different communication options and some parents were themselves diffident because their child's responses to sound seemed to challenge their acceptance that their child was deaf.

Parents of children with ANSD also experienced uncertainty and conflicting messages and advice about candidacy for hearing aids and cochlear implants. Current guidelines recommend trialling hearing aid fitting, as approximately half of the children diagnosed with ANSD are likely to benefit from hearing aids,<sup>4</sup> but some parents were still unsure whether hearing aids might be the right option for their children. Of the 21 families included in the Manchester / NDCS study, 16 had tried hearing aids: 5 found them very beneficial, 3 somewhat beneficial, and 8 not beneficial. Among the 5 who had received cochlear implants, all expressed that they felt it had been a good decision, but some had experienced anxiety around the decision to choose CIs, and while some parents experienced pressure from professionals to choose CIs, others had had to fight for the CI option, especially where candidacy was determined by outdated use of PTA instead of speech tests and other functional hearing tests.

The need for active engagement by all services and stakeholders and the importance of equitable access to assessments and support for all deaf children and young people was a key message from a break-out session on supporting deaf children with additional and complex needs in special schools, facilitated by **Jacqui Gardiner, joint Team Leader and Senior Educational Audiologist for the Somerset Hearing Support Team, and Caroline Payne, Principal Audiologist for Chime Social Enterprise**. Jacqui and Caroline shared learning from experience in Somerset and Devon respectively. Studies have suggested that up to nearly 40% of children and young people attending specialist schools and provisions will have an identified hearing loss. In Somerset, however, the number of children on role in specialist provisions known to have a hearing loss hasn't been in line with expectations for this cohort of children and young people, and many children and young people with complex profiles have lacked clear data about their hearing thresholds in school or clinical records. Jacqui reported how, in 2013, Somerset's Hearing Support Team initiated a project to assess the hearing of all pupils on role at specialist provisions across Somerset. Among the 273 pupils assessed, 11% were newly identified with a hearing loss (including one profound, one severe, and one unilateral profound hearing loss). Some of the key factors to the success of the screening process included support from parents, joint working with school staff and health colleagues, and using appropriate assessment materials and locations within schools. A programme of training, partnership working and structured approaches within the schools was essential following the screening project to raise awareness of the importance of audition for all pupils with an identified hearing loss among both parents, school staff and health professionals.

Caroline explained how, similarly, in Exeter, Mid and East Devon there has been a gap in support for children with hearing loss who attend local special schools. While audiology-run school entry screening clinics have been run in local special schools for many years, teacher of the deaf support has tailed off in the past and it – as illustrated by case studies described by Caroline – it has become increasingly obvious that there is a gap in provision for children with hearing loss in these schools and

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<sup>4</sup> Cf. Gary Rance (2005) 'Auditory Neuropathy/Dys-synchrony and Its Perceptual Consequences', *Trends in Amplification* Vol.9(1), Winter 2005; available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4111505/>

poor awareness of the importance of hearing and listening in the classroom. The issue was raised in the local Children's Hearing Services Working Group (CHSWG) and working jointly with a local paediatrician, changes to practice were identified which could be readily implemented. As a consequence of this work, the audiology service is routinely inviting parents to attend their child's appointment at school and (especially when parents can't attend) actively seeking information from parents about any concerns about their child's hearing; the service is also using Individual Management Plans to inform parents and school about outcomes, identifying a lead teacher within the school to ensure that staff are informed of and engaged with the process, and working to try and involve the advisory teacher of the deaf service in attending clinics jointly with audiology. The plan in Devon is to replicate these changes across all special schools in the area, to clarify the support to be provided by the advisory teachers of the deaf through dialogue with managers, commissioners and taking the issue to the Devon Strategic CHSWG, and investigate the need for training of staff at special schools around listening and hearing impairment, potentially drawing on learning from the Somerset study.

Further questions around the criteria determining deaf children's eligibility for support or interventions emerged repeatedly as a key issue in a number of presentations and break-out sessions. Following the earlier discussions of problems with using Pure Tone Audiograms (PTA) to predict education and other support needs, and, for children with ANSD, using PTA to decide their eligibility for hearing aids or CIs, attention was also given to the criteria for accessing the specialist mental health service for deaf children and young people (National Deaf CAMHS / NDCAMHS) and local mental health services and for accessing social care. In a break-out session discussing support for the emotional and social wellbeing of deaf children and young people facilitated by **Dr Hilary Sutherland and Jenny Kent from NDCAMHS South West**, deaf young people talked about how important the expertise and support of the highly specialised NDCAMHS service has been at critical crisis points in their lives. However, some delegates expressed concern that NDCAMHS' relatively narrow referral criteria (in practice, defined largely by a child's level of hearing loss (profound or severe), combined with high thresholds and lack of expertise on hearing loss in local CAMHS services, leaves a gap in mental health provision for the majority of deaf children and young people. The personal experiences shared by deaf young people from the PDCS Vibes Dance Crew highlighted the importance of community-level initiatives such as their dance group as a form of preventative social and mental health support, partially compensating for the lack of access to statutory mental health and social care services. A presentation by **Charlie Martin from Gusto** highlighted the important social benefits and personal empowerment that social media can also provide for deaf children and young people.

Widespread difficulties for deaf children and young people to access appropriate social care services was confirmed by **Chris Kang-Mullen, Social Care Policy Adviser at NDCS**, reporting on the outcomes of a recent NDCS survey of social care provision. The survey indicates rising thresholds to access services and common use of eligibility criteria that are poorly attuned to the needs and vulnerabilities of deaf children and young people. Expertise in specialist social care for deaf children and their families has diminished nationally, and in many areas it is assumed that education professionals provide de facto social care support for deaf children. The result is that deaf children and young people are struggling to access children's social care. NDCS is advocating for children's social care providers to make specific arrangements for deaf children and young people on the basis of 'reasonable adjustment' principles, to ensure that their specific social care needs are recognised, particularly in respect of early intervention and safeguarding.

The challenge of ensuring access for all deaf children and young people to the quality assessments, support and services that they need at a time of austerity was also at the heart of discussions led by **Brian Lamb OBE** in a break-out session focused on how the SEND reforms are working out in practice. This session linked back to discussion at last year's conference of the Children and Families

Act and associated statutory guidance on special educational needs and disability. Brian reviewed many of the distinct challenges as regards implementation of the reforms for children and young people with sensory impairments, including the low incidence combined with the need for specialist expertise and specialised services and a continuum of provision for varied needs making planning and provision particularly complex. Key areas for attention include the so far low level of engagement of deaf children and young people and parents / carers in the development and review of Local Authorities' Local Offers, lack of progress in joint commissioning of services across education, health and social care, weaknesses in Education, Health and Care Plans (EHCPs), particularly as regards the focus on outcomes, fully engaging health and social care providers in assessments for EHCPs, and the need to clarify obligations attached to EHCPs for young people post-19. Discussion highlighted the difficulties of implementing the reforms when services are ever-more stretched and under pressure to deliver more with less. Professionals are struggling to find the time and resources needed to ensure quality EHC assessments and plans involving all the relevant experts and services across education, health and social care.

## **Delegate Feedback**

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Delegates were asked to identify the most valuable aspect of the conference for them. The most common reasons given were:

- Networking with other professionals
- Sharing ideas and experiences
- Getting up to date information and latest research from the speakers
- Signposting to further information and support
- The presentation on ASND
- *"I work with 0-8 in mainstream school where I often feel they miss the importance of my work - I feel empowered again!!"*

The vast majority of delegates who expressed an opinion – 43 out of 48 (90%) – felt that the exhibition stands added value to the conference for them.

Delegates were also asked to identify one thing that they would do proactively as a result of the conference. Responses included:

- Feedback and share experience and learning with other colleagues
- Source more resources for supporting emotional and social needs/mental health
- Use new awareness of existing services, such as making referrals to ND CAMHS
- Consider role/input of services outside direct line of work (e.g. audiologists to find out more about education, teachers to develop links with social services etc)
- Follow up contacts made at the conference, develop networks and liaise more with other professionals

## **Conference Organisation**

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SWEDCM Steering Group includes Dr Sarah Collinson, SW Regional Director NDCS, Louise Cole Director Heart of Deafness, Rosie Denham Director BSL Sign-Up and Angela Deckett NDCS.

We are supported by a Virtual Reference Group by Brian Lamb (OBE) SEN Consultant, Adam Beckman Head of Audiology Services Plymouth Hospitals NHS Trust, Jim Edwards CEO Signature, Brian Kokoruwe Director Deafinitequality and Lindsey Rousseau NatSIPFacilitator, to help us ensure the best possible sector knowledge is fed into the conference design.

For 2016 we will again be approaching a range of sector specialist to ensure this learning event is the best value for money.

## **Sponsorship & Exhibition Space – Expanding Reach**

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This year's conference exhibition space was significantly larger and populated with a wider range of organisations and sponsors. Evaluation responses and direct feedback on the day indicated that the exhibition space was greatly valued by delegates and sponsors alike, providing a great opportunity to network and share innovations. We are keen to widen the representation of organisations and companies involved in supporting deaf children and young people in any area.

This year we have expanded the reach of the conference via our social media platforms, with delegates and sponsors using our hashtag #SWEDCM15.

## **Participation and Planning – Partnership in Action!**

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- It is important that we are able to evidence the impact of the conference and its role in helping to implement culture and practice improvements and on the achievement of outcomes for deaf children, young people and their families. **Please let us know about the difference this and previous years' conferences (if attended) had on you and your organisation.** What actions did you take away? What did you share with your teams and networks? We will actively be seeking feedback on these questions from delegates who have attended previous conferences through a survey in autumn 2015.
- Please feel free to **share the report** with the session presentation link, and ensure that as many commissioners, professionals and parents as possible are able to access the information and learning from the conference.
- The **SWEDCM Facebook Group** is a dynamic social media forum to share and seek information and exchange views or to keep an eye on sector developments and regional events. Please send us a request to join via: [www.facebook.com/groups/swedecm](http://www.facebook.com/groups/swedecm)
- **SWEDCM 2016: themes emerging from the 2015 conference:**

As the conference itself highlighted there is no room for complacency and there is much to do to improve. We want to ensure that the conference itself is continuously improving and tackling issues of real importance in a way that will make a positive difference to deaf children and young people. In the final session, delegates were invited to note down the main issues from the day and highlight areas that they feel warrant further attention or action. Suggestions included further consideration of deaf children's mental health needs, and greater input and involvement of deaf young people. Other potential themes for future attention that have emerged from the 2015 conference include:

- Gaps in social care for deaf children and young people
- Language development
- Support to parents
- Responding to bullying of deaf children
- Support for professionals implementing the Children and Families Act



- Social and emotional needs: supporting good mental health, confidence and theory of mind development
- Supporting deaf young people into independence and employment.

To provide an opportunity to explore these issues more fully, and to strengthen the voice of deaf children, young people and their parents / carers and maximise the positive impacts of the conference for them, we will be seeking to link the conference next year with an additional event that will directly involve deaf young people and their families in discussions and activities around these themes. We will keep you informed as we progress this initiative. Please get in touch if you would be interested to get involved.

**Your input counts** so please get in touch with us to input your views and ideas into the shaping of next year's conference.

Contact Details for the SWEDCM Steering Group are:

Sarah Collinson: [sarah.collinson@ndcs.org.uk](mailto:sarah.collinson@ndcs.org.uk)  
Conference Administration: [swedcm@gmail.com](mailto:swedcm@gmail.com)

## Thanks and Acknowledgements

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The Steering Group (Sarah Collinson, Louise Cole, Angela Deckett and Rosie Denham) are grateful to all those who attended the conference as delegates, to our speakers and panellists, young people and parents from the Plymouth Deaf Children's Society and Toby Gorniak from Plymouth Street Factory, to the Rougement Hotel, to the Conference Chair Brian Lamb, to the Advisory Panel, to Deafinite Interpreters and AI Communications and all our sponsors and exhibitors and to Chime Social Enterprise - Audiology Services (Exeter). Special thanks to Brian Kokoruwe who supported the financial management of the conference and to our 'on the day' volunteers Emily Cutler and Catherine Hall. Our thanks to all of you who contributed to making this year's conference a great success.

**And finally...**

**Save the Date!**

**SW Every Deaf Child Matters 2016**

**Tuesday July 5<sup>th</sup> 2016**

- Please hold **5<sup>th</sup> July 2016** in your diary for next year's conference in Exeter. Remember to identify the cost in your training budget. There will again be an early bird delegate rate and we will commit to keeping delegate fees highly competitive to ensure cost effectiveness and affordability.
- Sponsorship is essential to ensure the conference remains affordable for delegates. Please contact us if you would like to sponsor SWEDCM 2016 or have ideas about additional **sponsors and exhibitors**.