



Audiology Seminar (Northern Ireland)

March 2019

Contents

Foreword	3
Introduction	4
Presenter profiles	6
Section 1: Update on services in Northern Ireland	
Paediatric Audiology Quality Standards	9
– Linus McLaughlin, Performance Manager, Health and Social Care Board	
The Newborn Hearing Screening Programme (NHSP)	10
– Dr Rachel Doherty, HSC Public Health Agency	
Section 2: New perspectives on sign language and development	
Reading Development in Deaf Children	11
– Dr Kate Rowley, University College London	
Can We Become More Like Colorado?	15
– Rachel O'Neill, University of Edinburgh	
Deaf Children and Families: Communication at Home	21
– Professor Ruth Swanwick, University of Leeds	
Section 3: Deaf-led services, and user perspectives	
Deaf Roots and Pride	24
– Sue Barry, Deaf Roots and Pride Manager, BDA	
Family Signing in the Home	28
– Majella McAteer, Community Development Manager, BDA	
The Family Perspective: Fitzgerald Family Case Study	31
Looking to the Future	34
Bibliography	37
The British Deaf Association	40

I Foreword



As a parent of a deaf child and chairperson of local support group 'listen hEAR' I warmly welcome this report. From the moment our son was identified as deaf we were set on a 'care pathway' with experienced professionals – audiologist, teacher of the deaf, speech and language therapist, ENT consultant. We had no experience of deafness and were presented with a lot of information.

During a time of great emotional difficulty, we felt a huge responsibility to make big decisions about our son's future – would he sign? Would he speak? Our days were quickly filled with so many appointments that we made a decision that I would take a few years off work. We spent a lot of time researching and reading everything available to help our child. Our son lived in a silent world for 2 years before he was implanted. Dr. Carol Flexer describes hearing loss as a neurological emergency with a short window of opportunity for developing the auditory brain. And yet waiting lists meant that we had to wait 14 months for our son to be implanted. That was 14 months from the first trip to the GP surgery when he was 7 months old. There is a contradiction here between the criticality of early intervention and practice.

To fill the communication gap we used family sign language – a mixture of Makaton, SSE and BSL. As our son didn't have access to spoken language until he was 2 years old it was critical that we were able to communicate with him to reduce his frustration. In fact, post implant, signing became a 'conceptual hook' for him to hang his developing spoken language onto which was an added bonus. We participated in the Family Signing in the Home project and found it to be so valuable to our family. While our chosen mode of communication is spoken language, our son is a member of the deaf community. He has lots of deaf friends. He inhabits both the deaf and the hearing world and we wanted to give him the tools to do so confidently. As he grows, he has the freedom to choose whichever language he prefers. The importance of meeting deaf role models will become increasingly important as he grows too.

I hope this report provides an insight into real family experiences of raising a deaf child. We are 7 years into our journey and feel very lucky. We are surrounded by a team of exceptional professionals committed to supporting our son to achieve whatever he sets out to achieve. We have always had high expectations for him and share these with all professionals we meet. Peer support has been vital on our journey and we have received so much help, guidance and support from other parents of deaf children in our local group, listen hEAR. Our early fears have been allayed. Our son speaks confidently and uses family signs when his 'ears' are off. My advice to new parents is to worry less. Enjoy your new baby and embrace all forms of communication. And remember you are an advocate for your child so read all you can, educate yourself and be prepared to speak up on your child's behalf.

Jo Doody,
Parent of a deaf child

This report summarises the presentations made at the British Deaf Association (Northern Ireland) Audiology Seminar, held in March 2019.

The event was made possible by funding secured from the Department for Communities through their Sign Language Partnership Group, under their key objective to:

[build] capacity to raise the profile of sign language as a “linguistic and cultural minority” language and a language of “need” for deaf people in order to raise awareness and understanding within the NI community.

Early intervention for families in particular is an important area highlighted in the Northern Ireland Sign Language Framework.

The event was initially conceived as a follow-up to the Early Years and Intervention event created by BDA NI in partnership with the National Deaf Children's Society (NDCS) in 2014. Feedback was received from professionals after the 2014 event indicating a periodic conference every few years would be beneficial for continuing professional development, and refreshing knowledge for professionals on BDA NI's working areas.

Attendees included a spectrum of health professionals involved in the care pathway of a deaf child, including audiologists, speech and language therapists, and those involved in newborn screening.

Presenters were selected academics, representatives from health services, representatives from BDA NI projects, a young deaf person and parents of a young deaf child. This enabled the conference to cover recent improvements to services for deaf children and their families in Northern Ireland, as well as research perspectives and lived experience from the young deaf person and mother of a young deaf child.

The agenda was shaped by challenges raised by BDA NI beneficiaries of the 'Family Signing in the Home' and 'Deaf Roots and Pride' projects. This included an active desire for greater knowledge and promotion of sign language by audiology professionals, particularly in the early stages following diagnosis.

Reports by deaf young people in the mentoring programme also highlighted the appetite for - and importance of - access to deaf role models. The seminar provided an opportunity for professionals to be made aware of and therefore signpost to these programmes, and inform families of the benefits of involvement with the Deaf community.

Seminar aims

The aims of the seminar, and this paper, were to:

- Provide evidence to change perceptions of health professionals about sign language as an option for deaf children;
- Offer professionals an opportunity to understand the latest evidence and academic research on sign language, language development, and early intervention for deaf children;
- Provide guidelines that can be turned into practice to make services more suitable and flexible in meeting the needs of varying deaf users;
- Demonstrate the benefits of inclusive and comprehensive information for families with newly diagnosed deaf babies and children;
- Create an opportunity for professionals to understand young deaf person and parent user experiences;
- Raise awareness of programmes such as Family Signing in the Home and Deaf Roots and Pride, to increase referrals;
- Raise awareness of benefits of involvement with the Deaf community and Deaf role models for young deaf people and their families;
- Assist professionals in raising confidence amongst parents that their deaf child can develop language and achieve the same life outcomes as their non-deaf peers.

**Linus McLaughlin****Performance Manager, Health and Social Care Board**

Linus worked as a certified accountant before joining the Western Health and Social Services Board in 1991. Since then he has held a number of senior management posts across a range of areas including audit, finance, business services, acute services, service improvement, and performance management.

**Dr Rachel Doherty****HSC Public Health Agency**

Rachel graduated from Queen's University Belfast (QUB) with honours in July 2006. She trained and qualified as a General Practitioner in August 2011 and then commenced training in Public Health Medicine. In 2013 she completed a Master's in Public Health with distinction from QUB.

Rachel was appointed as a consultant within the Public Health Agency in September 2018. She is the public health lead for the Newborn Hearing Screening Programme in Northern Ireland.

**Dr Kate Rowley****University College London**

Dr Rowley specialises in sign linguistics and sign language research. She has an MA in linguistics, and an MSc in Psychology Research Methods from University College London. In April 2018, she passed her PhD which explored visual word recognition and reading processes in deaf and hearing adults using eye-tracking technology.

She is now working part time as a Research Associate on the Language Attitudes project, exploring the opinions of the British Deaf community on BSL, SSE, and regional variation. She is also working part-time as a post-doctoral Research Fellow at City, University of London evaluating an integrated phonics and language programme to improve reading in deaf and hearing children.

She previously worked on Specific Language Impairment in BSL and looked at language and identity of young deaf people in different educational settings. She currently teaches sign linguistics and sign language acquisition at Deafness, Cognition and Language research centre.



Rachel O'Neill
University of Edinburgh

Rachel worked as a teacher in secondary, further and community education for 25 years before moving to the University of Edinburgh in 2006. She has been a teacher of deaf children and an English as an Additional Language (EAL) tutor and used both approaches in schools and colleges with deaf students.

At the University of Edinburgh, her main focus is researching deaf education, providing post qualifying education for teachers of deaf children. From 2014-18 she was programme director for the wider MSc Inclusive Education programme, merging two older programmes to create a new one.

She supports the work of the Scottish Sensory Centre, based in the School of Education. This involves liaison with a wide range of teachers, professionals, parents and deaf people on policy issues about deaf education.



Professor Ruth Swanwick
University of Leeds

Professor Swanwick is a Professor at Leeds University School of Education where she leads the deaf education research activities and contributes to the MA in Deaf Education/Teacher of the Deaf Programme.

She is also Director of Research and Innovation in the School of Education.

Her background is in education; initially in modern foreign language teaching and then in deaf education where she worked with sign bilingual deaf children and young people in inclusive settings, and developed approaches to teaching English as a second and/or foreign language for deaf learners.

She came to Leeds University to lead the MA in Deaf Education/Teacher of the Deaf programme, which was the first deaf education programme in the UK to recognise and support the use of sign language in deaf children's education.



Sue Barry

Deaf Roots and Pride Manager, BDA

Sue Barry has worked in the Deaf Roots and Pride project in the BDA since June 2013. She originally started as Project Co-ordinator for Northern Ireland and was then promoted to the UK Manager in October 2015. Her passion from the outset was seeing Deaf people successfully complete their Open College Network (OCN) training to become qualified Mentors, with pride in their work, and strong connections with the young people they worked with. When she sees Mentors talk passionately about their role, working with young people and families from all walks of life, and with various communication methods, she sees the empowerment that they have achieved. Importantly this has enabled these mentors to pass on this empowerment to young people.

Sue is a proud leader of a large team that is having a positive ripple effect throughout the community; encouraging young people to be proud of their Deaf identity, and providing them with the tools and strategies to live a successful and fulfilling life.

Throughout her time as Manager so far, 65 Deaf people have successfully become qualified Mentors. This has meant 139 young people have been able to benefit from the Mentoring services, and have had their lives change for the better, including improved confidence, and being enabled to live more independent and fulfilling lives.



Majella McAteer

Community Development Manager, BDA

Majella has worked in BDA NI for 20 years, overseeing a variety of domains including health, civic rights, early intervention, justice, and advocacy. Since 2011, she has been in the post of Community Development Manager for Northern Ireland, which encompasses a wide range of responsibilities including developing new initiatives and managing existing annual budgets and members of staff within the NI office.

Throughout her time in BDA NI, Majella has led, managed, and delivered a wide range of projects and programmes, involving a diverse range of funding sources and stakeholders. Her leadership role influences staff, the wider Deaf community, and service providers, encouraging all parties to work together to achieve the best possible outcomes for all concerned.

Majella has also worked with politicians, Assembly Members, and various other government departments, advocating and encouraging the Deaf community to speak out for what they feel is necessary to achieve equality. Majella has organised conferences, as well as workshops, which have resulted in changes that have had a positive and lasting effect on the Deaf community.

Section 1: Update on services in Northern Ireland

Paediatric Audiology Quality Standards

Linus McLaughlin, Performance Manager, Health and Social Care Board

The paediatric audiology quality standards for Northern Ireland are being brought forward in three stages:

- 1) Scoping, mapping and consultation
- 2) Drafting, and baseline assessment
- 3) Finalising and approving

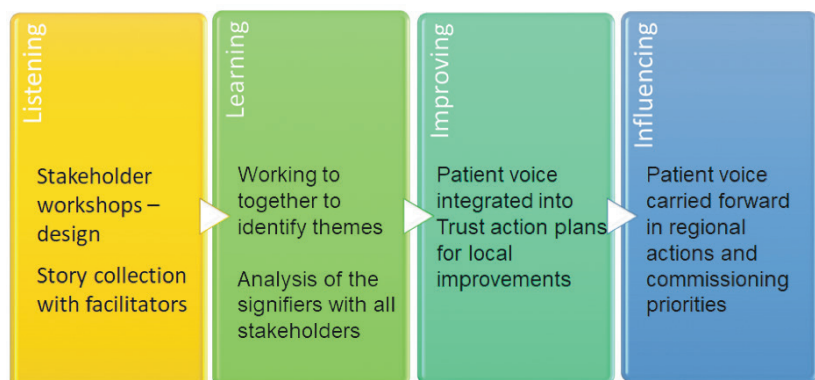
The standards focus on eight key areas:

- 1) Accessing the service
- 2) Information provision and communication with children, young people, and families
- 3) Assessment
- 4) Audiology Individual Management Plans (IMPs)
- 5) Hearing aid management, selection, verification, and evaluation
- 6) Skills and expertise
- 7) Service effectiveness and improvement
- 8) Collaborative working

Patient and client experience is recognised as a key element in the delivery of quality healthcare. The Health and Social Care Board (HSCB) and Health and Social Care Trusts are working with the Public Health Agency (PHA) to carry out work across all Health and Social Care Trusts (HSCTs), with the aim of introducing a more patient and client-focused approach to services in Northern Ireland. This project is called '10,000 More Voices'.

10,000 More Voices run a variety of surveys in an attempt to capture the diverse experiences within Health and Social Care services in a more thorough way. The aim is that lived experiences of children's audiology services from stakeholders should now shape both the quality standards and the ongoing delivery of the service.

The plan for integrating this input in Northern Ireland is as follows:



The Newborn Hearing Screening Programme (NHSP)

Dr Rachel Doherty, HSC Public Health Agency

Background

Newborn hearing screening as recommended by the UK National Screening committee was introduced in Northern Ireland in 2005. All babies born or living in Northern Ireland, are offered hearing screening, up to the age of six months old. The programme is commissioned and quality assured by the Public Health Agency (PHA), and is delivered by a wide range of dedicated professionals in each Health and Social Care Trust (HSCT).

Rationale for screening

1-2 babies in every 1,000 are born with a hearing loss. The Newborn Hearing Screening Programme (NHSP) aims to reduce the effects of permanent childhood hearing impairment, by allowing early diagnosis and timely intervention to improve outcomes for children and their families.

What does screening involve?

There are two types of hearing screening test that can be offered as part of the programme. These are the automated otoacoustic emission (AOAE) test and the automated auditory brainstem response (AABR) test. These tests are performed by trained screeners, they are painless and can be done whilst babies are asleep.

If a baby's response to a hearing screening test requires further follow up they are referred to an audiology team for further diagnostic assessment and treatment (if indicated). Also at the time of hearing screening, there is an assessment of risk factors for hearing loss and if a child has one (or more) of four nationally agreed risk factors they are referred for 'targeted' follow up by audiology, regardless of their screening test result.

Programme Performance 2016-17

The NHSP monitors performance of the programme and from 1st April 2016 to 31st March 2017 of 23,936 babies eligible for hearing screening in NI:

- 99.6% (23,830) were offered screening
- 98.9% (23,675) completed screening by the age of 3 months
- 2% (467) were referred to audiology services for diagnostic assessment by the age of 3 months.

Future developments

The programme is currently working to introduce a bespoke national IT system, which will help us to continue to improve in line with national standards.

Section 2: New Perspectives on Sign Language and Development

Reading Development in Deaf Children

Dr Kate Rowley, University College London

There has been very little change in reading attainment reported amongst deaf children in the past 40 years.

Reuben Conrad reported that deaf school leavers aged 16 years had a median reading age of 9 years¹, and reviews by Marschark and Harris in 1996² and Musselman in 2000³ found little improvement from this. Following this, in 2010, a study by Kyle and Harris reported 'significant delays' amongst the deaf group of learners⁴. A 2011 report by Qi and Mitchell⁵, and a recent pilot last year by Fiona Kyle replicating the Conrad study also suggest lower reading attainment amongst the deaf population.

We can also see that academic achievement of deaf children is not on a par with their hearing peers; in 2015 it was reported that only 36.3% of deaf children in England left secondary school having achieved national GCSE benchmarks, compared with 65.3% of hearing school leavers.⁶

However, many deaf people achieve reading levels that match hearing people^{7,8}, and some even achieve levels higher than their peers.^{9,10,11}

So what is the problem? Why aren't the majority of deaf people able to achieve good literacy skills? Let's go on to talk about 'reading'; what does it mean to read a word?

What is reading?

Reading is the process of extracting meaning from printed words. To achieve this, readers need access to prior language. For example, the ability to match concepts and the printed word.

For hearing children, when they acquire language, they are making links between concepts and

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1. Conrad, R. (1979). The deaf school child: Language and cognitive function. London: Harper Row.
 2. Marschark, M., & Harris, M. (1996). Success and failure in learning to read: The special (?) case of deaf children. In C. Cornoldi & J. Oakhill (Eds.), *Reading comprehension difficulties: Processes and intervention* (pp. 279–300). Hillsdale, NJ: Erlbaum.
 3. Musselman, C. (2000). How do children who can't hear learn to read an alphabetic script? A review of the literature on reading and deafness, *Journal on Deaf Studies and Deaf Education* 5 (1) (pp. 9–31). Oxford: Oxford University Press.
 4. Kyle FE. and Harris M. Predictors of reading development in deaf children: A 3-year longitudinal study, *Journal of Experimental Child Psychology*, 2010, vol. 107 (pp. 229–243). London: Elsevier.
 5. Qi, S., & Mitchell, R.E. (2011). Large-scale academic achievement testing of deaf and hard-of-hearing students: Past, present, and future. *Journal of Deaf Studies and Deaf Education*, 17(1) (pp. 1–18). Oxford: Oxford University Press.
 6. Swinbourne, C. (2015) The Limping Chicken [online] <https://limpingchicken.com/2015/01/30/deaf-news-figures-show-only-36-3-of-deaf-children-achieve-national-gcse-benchmarks/> [accessed 09/04/2019]
 7. Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Padden, C., Rathmann, C., & Smith, S. (2014). Bilingualism: A Pearl to Overcome Certain Perils of Cochlear Implants. *Journal of Medical Speech-Language Pathology*, 21(2) (pp. 107–125). Plymouth: Plural Publishing.
 8. Rowley, K. (2018). Visual Word Recognition in Deaf Readers. [Unpublished Doctoral Dissertation] Department of Experimental Psychology: University College London
 9. Chamberlain C. (2002). Reading skills of deaf adults who sign: Good and poor readers compared. Montreal: McGill University.
 10. Bélanger, N., Baum, S. & Mayberry, R. (2012). Reading Difficulties in Adult Deaf Readers of French: Phonological Codes, Not Guilty! *Scientific Studies of Reading*, 16:3 (pp. 263–285).
 11. Cooley, F. & Quinto-Pozos, D. (2018). Investigating Phonological Awareness of English, ASL, and Speechreading in Native Deaf Signers. [Poster Presentation at the Workshop on Reading, Language and Deafness] San Sebastian, Spain.

words they hear/speak. When hearing children learn to read they are mapping the words they have learnt onto print. These already learned words are linked to real life concepts, real world knowledge. So, for example, when a hearing child sees the letters 'd-o-g' in print, they match this to the word 'dog' and hence the concept of a four legged animal with a tail, that barks.

Similarly, native signers map their knowledge of signed words onto print. A native signer would see the letters 'd-o-g' in print, match this to the sign 'dog' and hence the concept.

Language, whether spoken or signed, enables children to develop world knowledge and concepts, which they can then map onto print.

The use of sign language in overcoming challenges

The challenges for deaf children are limited social interactions and inaccessible language environments. Inferencing skills, which are vital for reading, develop best in rich social and linguistic settings. In addition to this is the fact that Deaf adults report that they remember very little of what they were taught at school, and rarely enjoyed learning to read.¹²

These challenges can be overcome through use of sign language. This includes:

- Mapping signs onto print; utilising first language skills directly
- Creating a strong first language through sign language – an accessible language – enables access to semantic, cultural, and world knowledge, which are crucial for inferencing
- This strong first language can be used as a medium for explicit instruction
- This strong first language can be used to develop metalinguistic awareness.

Numerous studies show a correlation between sign language ability and reading ability.^{13 14 15}

A study centred on American Sign Language (ASL) also demonstrated a correlation between narrative fluency and reading ability¹⁶, and it has been demonstrated that size of sign vocabulary can predict size of print vocabulary.¹⁷

Phonology

There is a lot of research into the role of phonology for learning to read. Methods for teaching hearing children have been applied to deaf children, which are not always successful. Teaching phoneme to grapheme correspondences for beginner readers places emphasis on phonological skill being related to successful reading. There are indeed deficits in reading related to poor phonological awareness and skills, such as dyslexia.

12. Hoffmeister, R. J., & Caldwell-Harris, C. L. (2014). Acquiring English as a Second Language via Print: The Task for Deaf Children. *Cognition*, 132 (pp. 229-242).

13. Chamberlain C. (2002). Reading skills of deaf adults who sign: Good and poor readers compared. Montreal: McGill University.

14. Bélanger, N., Baum, S. & Mayberry, R. (2012). Reading Difficulties in Adult Deaf Readers of French: Phonological Codes, Not Guilty! *Scientific Studies of Reading*, 16:3 (pp. 263-285).

15. Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Padden, C., Rathmann, C., & Smith, S. (2014). Bilingualism : A Pearl to Overcome Certain Perils of Cochlear Implants. *Journal of Medical Speech-Language Pathology*, 21 (2) (pp. 107–125). Plymouth: Plural Publishing.

16. Strong, M. & Prinz, P. (2000) Is American Sign Language Skill Related to English Literacy? In Chamberlain, C., Morford, J.P. & Mayberry, R. (Ed.s) *Language Acquisition By Eye* (pp. 131-142). Mahwah, NJ: Lawrence Erlbaum Publishers.

17. Ormel, E., Hermans, D., Knoors, H., & Verhoeven, L. (2012). Cross-language effects in visual word recognition: The case of bilingual deaf children. *Bilingualism: Language and Cognition*, 15 (pp. 288–303)

However, deaf adult readers do not always activate phonology during reading, as demonstrated through both the Chamberlain and Bélanger et al. studies. Deaf adult readers do show evidence of phonological processing but do not always activate this to access meaning.¹⁸¹⁹

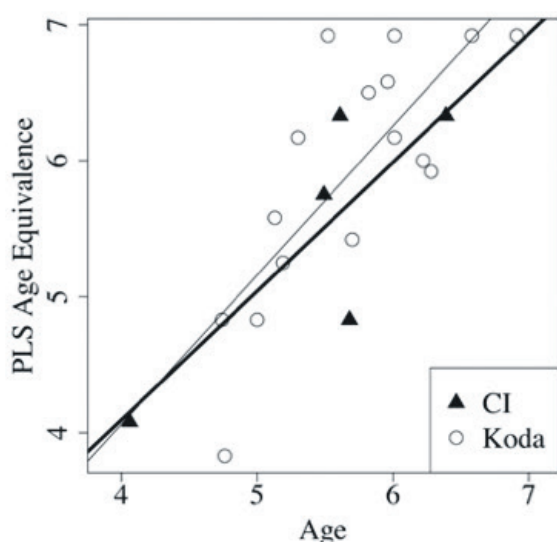
It is important to remember that phonology isn't only accessible via sound alone. Deaf readers do make use of lip patters/speechreading. There is a correlation between speechreading ability and reading ability, and some studies do show a correlation between phonological skill and reading success in deaf children.²⁰

However, speechreading ability develops over time, with deaf adults better speechreaders than deaf children, and some have suggested that deaf children develop phonological skills as they learn to read.²¹

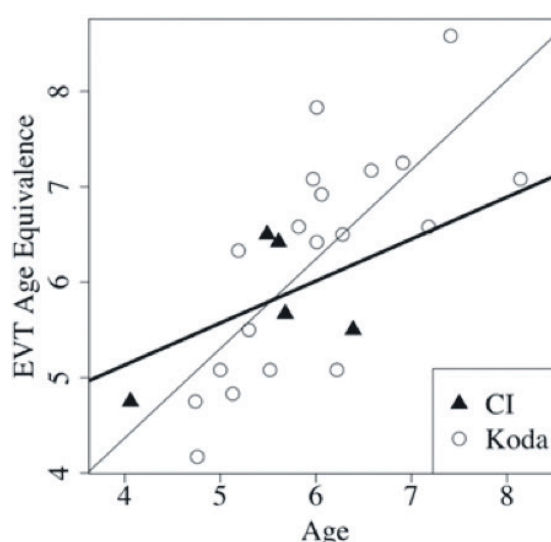
Deaf children and adults could access English phonological representations via residual hearing and/or lip-reading. This could in turn assist with reading attainment, however more research needs to be carried out to explore this.

Bimodal bilinguals

An increasing number of deaf children with deaf parents are receiving cochlear implants, and recent research shows evidence that this deaf children are developing spoken language at the same rate as hearing children.²²



Preschool Language Scales



Expressive Vocabulary Test

18. Emmorey, K., Weisberg, J., McCullough, S., Petrich, J. (2013). Mapping the reading circuitry for skilled deaf readers: An fMRI study of semantic and phonological processing. *Brain and Language* (pp. 169-180). London: Elsevier.

19. Gutierrez Sigut, E., Vergara-Martínez, M., Perea, M. (2017). Early use of phonological codes in deaf readers: An ERP study. *Neuropsychologia*, 106 (pp. 261-279).

20. Kyle FE. and Harris M. (2010). Predictors of reading development in deaf children: A 3-year longitudinal study, *Journal of Experimental Child Psychology*, vol. 107 (pp. 229-243). London: Elsevier.

21. Kyle FE. And Harris M. (2010). Predictors of reading development in deaf children: A 3-year longitudinal study, *Journal of Experimental Child Psychology*, vol. 107 (pp. 229-243). London: Elsevier.

22. Davidson, K., Lillo-Martin, D., & Pichler, D.C. (2014). Spoken English language development among native signing children with cochlear implants. *Journal of Deaf Studies and Deaf Education*, 19(2) (pp. 238-250)

Parents and educators are presented with a binary choice of speech-only method or sign-only methods; why not both, when there seems to be clear benefits to doing so?²³

To ensure deaf children become successful bilinguals, early exposure to language is very important. Hearing children are exposed to language while in the womb and from the moment they're born, so for them pre-linguistic communication and language acquisition develop very early.

We need to teach parents how to communicate with their deaf child; communication strategies include turn taking, establishing eye contact, ensuring you have the child's attention, and tapping, among others. Early introduction to reading can be established through basic steps such as the use of sign-print pairs. Plenty of reading experience is also particularly important.²⁴

It is also important that we closely monitor language development; deaf children need language to read. It is vital to track language development using assessment tools so that action can be taken the moment a child starts falling behind.

The consequences of language deprivation, limited language development, are severe and long-lasting. Language development affects not just literacy, but cognitive, social, mental and academic development. Starting with sign language prevents language deprivation, as every deaf child can learn to sign. Not all deaf children can learn to speak.

Conclusions

Deaf children who sign can develop good literacy skills, however they need to be in environments in which they are receiving the highest amount of language access and good communication practice in order to be able to do so. Early communication and access to good language models is important, as is providing deaf children with plenty of reading experience.

23. Lillo-Martin, D. (2018). Differences and similarities between late first-language and second-language learning. *Bilingualism: Language and Cognition*. 21:5 (pp. 924-925)

24. Nation, K. (2017). Nurturing a lexical legacy: reading experience is critical for the development of word reading skill. *Npj Science of Learning*, 2(1), 3.

Can We Become More Like Colorado?

Rachel O'Neill, University of Edinburgh

It is important that we as professionals explore the views of parents living on a low income. Nineteen per cent of children in Northern Ireland are classified as living 'in poverty'²⁵, and 30% are from low-income families and are entitled to free school meals.²⁶ These families face particular challenges and barriers within the current system.

We must consider what challenges and barriers families from a low income background face in how they support their deaf child's development in language and communication. The research questions for this study were:

- What factors increase fluency?
- Which interventions work best?
- What do parents think about their access to information and support?
- What do families say about their challenges and the support to overcome them?

Telling It Like It Is

During 2018, the Scottish Sensory Centre explored the views of families raising a deaf child or children while living on a low income, in a project funded by the National Deaf Children's Society. The project title Telling It Like It Is shows that straight-talking was expected from families as they discussed their experiences.²⁷

We were interested to find out what families know about language choices, technology, and services for deaf children. We wanted to know what parents think about the support they had to make decisions and get the information they needed for their deaf child or children. What did these families think were the challenges and supports for their deaf child's language and communication development?

Twenty-one families from across the UK were interviewed in their own homes, or in a nearby community centre. All families had a deaf child aged twelve or under, and remain anonymous in the research.

25. Department for Communities et al. (2019) Poverty Bulletin: Northern Ireland 2017/18. Belfast: Department for Communities

26. Department of Education et al, (2018) School Meals in Northern Ireland, 2017/18. Belfast: Department of Education

27. Scottish Sensory Centre (-) Telling it like it is: families living on a low income with deaf children [online] <http://www.ssc.education.ed.ac.uk/research/tellingit/> [accessed 25.04.19]

Literature Review

Some of the themes brought up during the initial literature review highlighted:

- A higher incidence of deafness in the low income group
- Language outcomes are often weaker
- Higher incidence of stress and adverse life events
- Diagnosis and intervention pathways should be based on 1-month, 3-month, and 6-month benchmarks: screening by 1 month, diagnosis by 3 months, and starting regular support with the family by 6 months
- Parental knowledge of health and education systems affects language acquisition
- Home culture and language are important sources of strength.

Study families

The profiles of the families involved in the study were as follows:

- 12 were single parents
- 7 families had four or more children
- 5 families were from an ethnic minority
- 6 families used spoken languages other than English at home
- Over half of all the families used some sort of sign
- 4 families had deaf parents.

Findings from families

These findings are supported by extracts from family interviews, taken from transcripts.

Parental confidence

It was found that parental confidence was related to having information and support, involvement with an excellent professional, or sometimes additional monetary resources to give choices to the family.

Parent's view:

Well I had Jenny. She was appointed to Joe and she was amazing. Like she was very helpful so she was. So she'd come in and like speak through anything, any a' my concerns. Like speak, have a wee bit a' speech and stuff wi' Joe and she was brilliant. So...she's visited him like since he's been born through here and all in school and stuff.

Knowledge of language development

Parents involved in the study often had experience of bringing up other children. However, they usually did not have the confidence to challenge the system.

Parent's view:

But it's like I want more you know? I'm not greedy, I just want there to be...I, I just want...There's nothing wrong wi' that [laughs], you know. You know I just, I just want more. Like we could have

conversations and we could think but as she gets older, you know, we need more.

Informed choices

Thirteen of the 21 families had children diagnosed shortly after birth. Six were satisfied with the information and choices that they had, but seven were unhappy. Of these seven, two were deaf families, one had little English, and four had prescriptive professionals.

Parent's views:

I think you're given the information but you're not given the tools. So you're told a lot about sign language but then you're not really put in a position where you can learn...so you're told a lot about British Sign Language, how it benefits children, how, you know, an even approach is the best, how it won't delay her...But...so we were given all the right information but then how do you go about learning it?

[The SLT's] expectations for Martha were very low, as was the teacher of the deaf...Again she'd said that it would be good for Martha to be signing and that NDCS were supportive of that as well, of learning, teaching Martha to sign. I felt that they were really...pro signing, everyone that was with us. And again I understand that but what I felt was that was the kinda really only option that was put forward...everything that we did we did on our own without any local services support.

The education system

There was evidence from the families that their views were not being listened to within the education system, and they were not able to influence the support their child was being provided.

Parent's views:

They kept saying, 'oh she's not presenting like that in school, she's always smiling'. Cause my daughter's always, like all my kids are always smiling. She was coming home and saying, 'it's a bit too much, I'm struggling. I need a...' But they weren't, they weren't registering. They were saying, 'we're not seeing that in school'. So...I had to get on and get on and then the teacher of deaf phoned me and said, 'would you like me to come and speak to them?' And I said, 'yeah that'd be great'. So she arranged a meeting. As soon as we done that...they sorted it yeah.

If you talk to the teachers they go, 'well, you know she's got this'. And you go, 'well, that's great', and the teacher for the deaf will come in and go, 'well, you know, she has a Soundfield system, she's fine'...Oh, and you're being over-dramatic, or you know, well, your children aren't that bad...We've had all of it, you know, well they're not that deaf. Okay, thanks for that.

Judgement from professionals

Some families also reported that they were being judged harshly or unfairly by professionals.

Parent's view:

But at the time you tell a young person that they just believe you. These are the professionals, you believed them didn't you [laughs]...I, I was angry. I was angry for a while. See when I was still getting, I couldnae get rid a' them, like oot in, they were constantly in, then at some points the way he was feeling they were asking me, 'are you doing what, are you doing the work in the house with him?' So then I was getting upset, sometimes questioning my, questioning myself, you know as you do as a parent. You sometimes, you're like, 'oh am I doing this?' I'd be questioning myself. So I was angry for a long time.

Resources for language development

Evidence from the families showed that they sought out resources for language development, but their low-income status had a direct impact on the resources available.

Parent's views:

I did toy, my husband and I did toy with trying [a radio aid] from the NDCS, cause you can trial stuff, but to be perfectly honest, they [education services]'re not gonna give us one, and I didn't want to try it, give it to him, for him to go oh, that's amazing mum, and then have to take it off him...But, cause there's no way we can afford one. As I say, I'm currently working all the hours I can, my husband's unemployed, and I've got mouths to feed and roof to keep over their heads, so there's no way that we could afford one ever in a million years, so...

Two years ago he went into the early years nursery. Cause obviously I was working and you need like a good reason for them to go into nursery at two. And mine's was so that we brought on his speech and stuff, get him interacting wi' other children and stuff. And it's worked wonders I think That's because he has been in there.

Advice for other parents

Parents provided a variety of advice for other parents in similar positions:

Well mainly I'd just be involved, you know, and make sure you know everything that's going on and make sure everything goes through you, especially wi' school.

I was just constantly, I was just asking loads and loads a' questions. And like I was dead curious. I think if other mums have got any doubts and stuff about it they should definitely, for instance the deaf teacher, just ask for as much stuff as you can. Find out groups, find out, just things about like maybe when they're going tae school and they're gonnae be older.

The Colorado Case Study

Professor Christine Yoshinaga-Itano at the University of Colorado Boulder, has led 30 years of continuing research on services for deaf children in Colorado, USA.

Colorado is a unique state in that it is a pioneer of newborn hearing screening and early intervention, as well as strong involvement by audiologists in language development. Newborn screening began in the state in 1992.

The state supports the Early Hearing Detection and Intervention (EHDI) 1-3-6 guidelines, which are:

- 1 month old – screening complete
- 3 months old – diagnosis and aiding
- 6 months old – language intervention.

Research carried out by Yoshinaga-Itano²⁸ shows that low-income families in Colorado particularly benefit from adherence to these guidelines.

Yoshinaga-Itano's research shows that aiding and starting work with families before 6 months can lead to near-average language levels.²⁹ Colorado has a high incidence of families who speak Spanish at home, and again research highlighted the importance of culturally specific interventions for this group.³⁰

The early intervention programme in Colorado entails 1.5 hour weekly sessions with spoken English/Spanish early years specialists, or deaf early years American Sign Language specialists.

Hands and Voices

Provision is also strongly supported by charities, and user-led groups. Hands and Voices is a leading charity in Colorado, 'dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology'.

The charity offers various services, including a parent-led 'guide by your side' service, facilitating parent-to-parent networking and support. It is also a strong proponent of the EHDI model; an example 'Roadmap' from their parent resources can be found overleaf.

Conclusions

A large number of families in Northern Ireland live on low income or below the poverty line. These families are faced with particular barriers which are often not specifically addressed by teachers and professionals; however, the picture is mixed and many families do report they are receiving good services from health and education.

28. Yoshinaga-Itano, C., Sedey, A., Wiggan, M. and Chung, W. (2017). Early Hearing Detection and Vocabulary of Children with Hearing Loss. *Paediatrics* 140 (2)

29. *ibid*

30. De Diago-Lázaro, B., Restrepo, M.A., Sedey, A.L., Yoshinaga-Itano, C. (2019) Predictors of Vocabulary Outcomes in Children Who Are Deaf or Hard of Hearing From Spanish-Speaking Families. *Language Speech and Hearing Services in Schools* 50 (1)

31. Hands & Voices (-) Welcome! [online] <http://www.cohandsandvoices.org/newsite/welcome/> [accessed 24.04.19]

These families have skills and particular cultural strengths, but have less actual and social capital influence to make changes for their deaf child/children. Systems and services are often too prescriptive, and don't listen enough to these families.

There are examples of good practice models that we can look to when trying to make improvements for these families. For example, the 1-3-6 month benchmarks, which are shown to particularly benefit families from these demographics. A good, and well-researched, model can be found in Colorado, and we should be seeking and out and replicating these good-practice models.

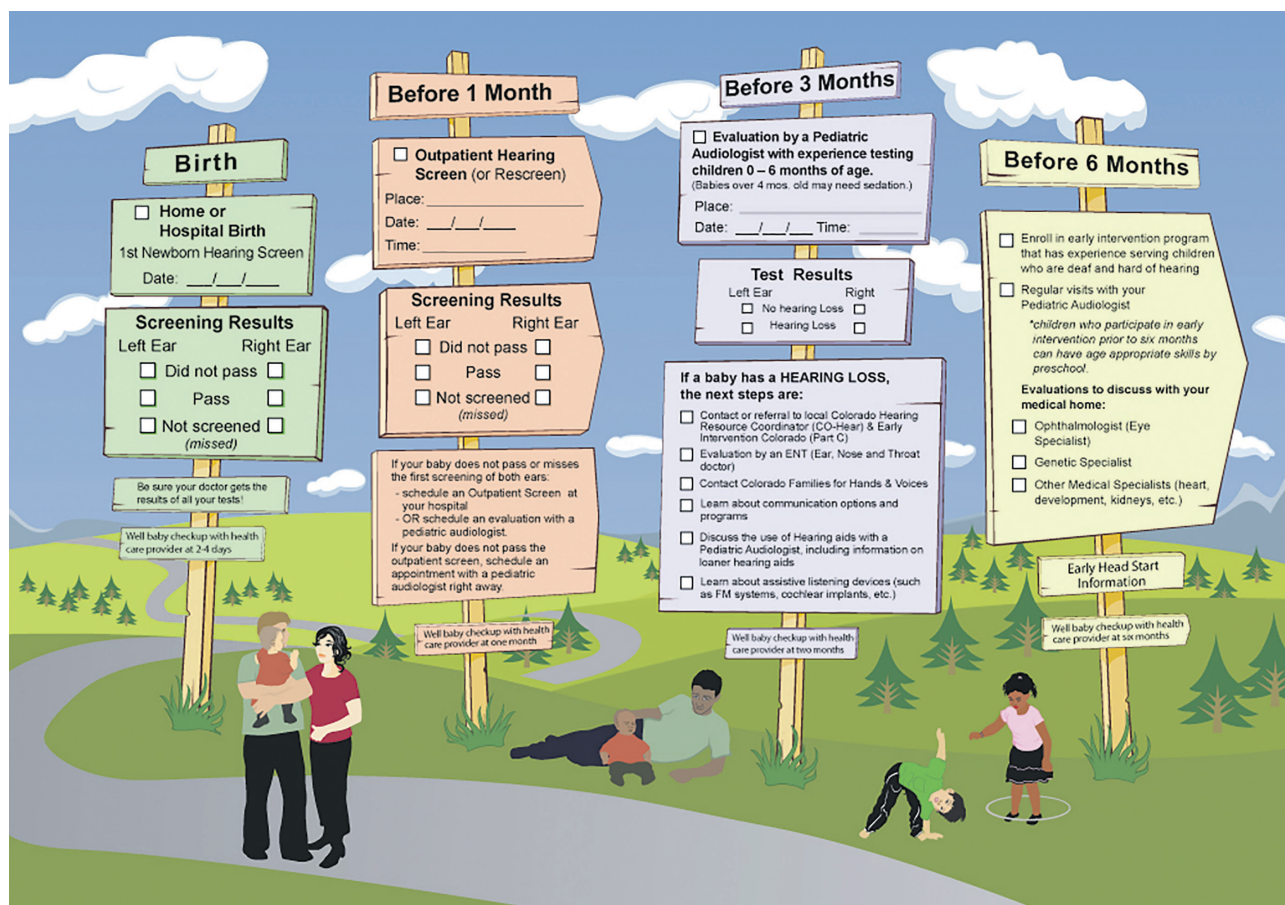


Figure 1: Diagram of EHDI benchmarks³²

32. Hand & Voices (2010) Roadmap [online] <http://cohandsandvoices.org/rmap/roadmap/> [accessed 25.04.2019]

Deaf Children and Families: Communication at Home

Professor Ruth Swanwick, University of Leeds

Unaddressed childhood deafness presents a risk to linguistic, intellectual and social development, and with these risks is a risk of jeopardy of the rights of the child. The United Nations Convention on the Rights of the Child states that children have the right to:

- Be fully prepared to live an individual life in society
- Learning and the achievement of educational potential
- Communication and social engagement (play and recreation) at home, school, and in the wider community
- Self-reliance and active participation in society
- The ability to express or voice their own views through appropriate forms of communication or media.³³

Families are recognised within the convention as the 'natural environment for the growth and well-being'³⁴ of an individual.

This presentation draws on two research studies undertaken at Leeds to discuss the analysis, understanding and support of communication among deaf children and their families. The rights of the child provide a context for this research, which centres on language, communication and modality. The research seeks to develop methods for seeing and analysing communication at home (and at school), and to focus educational and health support.

Both studies observe multilingual communicative contexts where participants have asymmetrical experiences of being deaf and being hearing, and where 'codified' resources in either speech or sign language are little shared among participants. Both studies are concerned with:

- Language and communication
- Diverse multilingual language contexts
- Sensory asymmetries
- Overlapping precarities
- Focus on repertoires and resources
- Issues for multi-professional support.

The following examples taken from these studies demonstrate communication strategies of deaf children and their families, and highlight the meaning-making resources evident in diverse and sometimes challenging communicative contexts.

33. The United Nations. (1989). Convention on the Rights of the Child. Treaty Series, 1577, 3.

34. *ibid.*

Making meaning, making signs: semiosis through the lens of deaf-hearing interaction

At time of presentation, this study³⁵ was unpublished, and so findings discussed are provisional.

The study analyses ways in which multimodal resources are used in contexts where there are sensory and communication ‘asymmetries’ in terms of language access, experience, and skills, and the use of hearing technologies.

Using a social semiotic approach to multimodality – analysis of video-recorded data of interactions among deaf children and hearing adults – the study observed how actors use semiotic resources and communicative strategies to fulfil their communicative needs.

The study discusses ways in which these findings deepen understandings of:

- 1) deaf/hearing communicative practices
- 2) Principles of semiosis enabling human communication in general.

The study outlines the practical implications for education in particular and for facilitating communication practices in shared deaf/hearing spaces and multilingual/multicultural contexts. The project took place in an educational context, where sign language is one of the languages of education. This supported investigation of an educational question about developing ways to support families and teachers.

Deaf Children from Roma Families in the UK

This project³⁶ was funded by a University of Leeds Institute for Social Sciences ESRC Impact Acceleration Account. It was led by Professor Ruth Swanwick with Jess Elmore and Jackie Salter at the School of Education, University of Leeds in partnership with five deaf education local authority services (Sheffield, Rotherham, Peterborough, Leeds, and Bradford), BATOD (British Association of Teachers of the Deaf), The Ear Foundation, and NDCS (the National Deaf Children’s Society). The project ran from January to December 2018.

The project involved a demographic survey of all deaf education services in England, a questionnaire and interviews with five deaf education services, and four case studies of deaf Roma children and their families. The data was analysed using an intersectional approach in order to identify the overlapping issues for deaf Roma children and their families, and for educational and health professionals.

Findings from this project suggest that the number of deaf Roma children is under-reported due to families’ reluctance to self-ascribe and yet the high prevalence of deafness in Roma communities has significant implications for education, health, and social participation. Through

35. Adami, E. and Swanwick, R. (accepted/in press) Signs of understanding and turns as actions: A multimodal analysis of deaf-hearing interaction. *Visual Communication*.

36. Swanwick, R., Elmore, J. and Salter, J. (under review) Educational inclusion of deaf Roma children and implications for multi-professional working. *Deafness and Education International*.

our examination of the relationship between being deaf and being Roma, we also identify overlapping areas of precarity that have serious implications at an individual level for childhood development, education, and achievement, as well as for longer term health and wellbeing.

We recommend that deaf education professionals find appropriate ways to ask families if they are Roma rather than relying on external data. There is also a need for further outreach within Roma communities to identify these individuals and offer appropriate support. The value of employing Roma staff within organisations not only as interpreters, but at all levels, is evident within our research and the wider literature.

Professionals can usefully develop a greater understanding of these families who are already managing complex lives where a diagnosis of hearing loss can compound a general mistrust of education and health authorities. An understanding of families' previous experiences and current expectations, and recognition of their existing resources is key to successful partnerships.

Finally, we identify a need for further research that investigates the cultural, linguistic, and social experiences of Roma families with deaf members, and develop understandings of the exceptional circumstances and precarities in terms of individual development and societal inclusion.

Summary

Both studies lead us to some key conclusions that should inform practice, and the information, advice, and support being provided to deaf children and their families.

Multimodal analysis can throw light on communication resources and meaning-making strategies, as well as aspects of synchronicity and contingency that might not be seen through a language focus. However, it is important that we do not lose sight of the social dimensions of language learning. There is the innate power of the family as a community of practice to facilitate language learning, and language learning opportunities present in everyday family life.

In order to support communication at home, we therefore need to ensure our approaches are:

- Child and family centred
- Child and family derived (observation, assessment, discussion)
- Asset-focused (the environment, the resources of the child and the family)
- Making use of multiple modalities (sign, speech, etc.)
- Dynamic (sensitive to change over time).

Section 3: Deaf-led services, and user perspectives

Deaf Roots and Pride

Sue Barry, Deaf Roots and Pride Manager, BDA

Deaf Roots and Pride (DRP) is one of the BDA's flagship projects, and focuses on support for young deaf people and their families. The project was created in response to common issues faced by young deaf people, which include:

- Isolation
- Barriers in communication causing a lack of incidental learning and language development
- Low emotional well-being
- Lack of opportunity to meet positive Deaf roles models
- Lack of opportunity to meet deaf people of similar age
- Higher propensity to disengage from education than hearing peers
- Lack of self-awareness or strong Deaf identity.

The incidence of mental ill-health is much higher amongst deaf populations than the general population, and this is usually linked by professionals to some or all of these factors.³⁷

The project

DRP was first established in Northern Ireland, funded by the Big Lottery Fund from 2013. Due to the success of the project, the same model was rolled out across the UK, in Scotland, Wales, the Midlands, the North East, Devon and Somerset.

DRP's main beneficiaries are deaf children and young people aged 8-20, and their families. The project offers three main elements:

- 1) Mentoring
- 2) Transitions
- 3) Signposting

The project aims to build resilience, providing deaf children and young people regular opportunities to develop a 'can-do' attitude in developing and reaffirming positive self-identity.

37. SignHealth (2014) Executive briefing on mental health services for deaf and hard of hearing people [online] <https://signhealth.org.uk/wp-content/uploads/2014/02/ExecutiveBriefing.pdf> [accessed 15/04/2019]

Mentoring

The mentoring programme aims to provide deaf children and young people with the opportunity to:

- Receive one to one mentoring sessions from a trained Deaf role model
- Improve confidence and well-being
- Increase independence and empowerment
- Discover the Deaf community
- Increase ambitions and aspirations for the future
- Get involved with enjoyable group activities with other deaf children and young people.

Over half of all referrals to the mentoring services come from external statutory organisations. In the past reporting year, 35% of referrals came from Social Services, 15% from Educational Services and 10% from Child and Adolescent Mental Health Services (CAMHS).

There are many success stories, including young people referred from CAMHS being enabled to live more independent lives, and young people being referred from educational services having improvements reported from school. One parent reported “[he] has come out of his shell, is getting trains by himself, and overall becoming a more confident and social person”.

Transitions

The transition programme focuses on transitions in stages of education, and between education and employment or further education/training. This element of the project aims to provide the opportunity to:

- Feel empowered to remain engaged in education
- Develop new skills and coping strategies
- Receive information about support and advice available to them in educational environments
- Overcome barriers in educational environments
- Attend DRP-led events, workshops, apprenticeships days, and college/university tours.

Successes to date in Northern Ireland include ‘Taste Your Future’ – an innovative careers fair held at Queen’s University (Belfast) in which deaf young people had an opportunity to meet a wide range of Deaf professionals. 50 young deaf people attended, the majority of whom came from mainstream education backgrounds.

In feedback collected at the end of the sessions, some of the young deaf people involved expressed a wish that their schools would invite some of the deaf professionals to their own careers conventions to raise aspirations for deaf students. Feedback from parents was similarly enlightening about the impact of these events; one parent wrote that at an event they were “seeing that deafness does not have to hold my daughter back, there is every opportunity out there is she wants to pursue it”.

The transition service now works with one Education Authority which reported a 67% dropout rate of young deaf people from colleges. As part of this programme of work, the DRP project ran two 'Outside of the Box' events, which were created for young deaf people thinking of going to college to provide an insight into what support could be provided.

Signposting

The signposting element of the project is simple in conception; deaf children and young people, and their families, are given opportunities to receive relevant information, empowering them to make informed choices and explore opportunities available to them.

This element of the project draws from the knowledge base created by project staff of local services, resources, and choices available for young deaf people. Throughout the last reporting year, 115 deaf children and young people were signposted to different organisations and projects. Parents have also found the service particularly useful; as one parent reported, "trying to find specialist information is very difficult, so to have the signposting has been crucial".

Challenges

The key challenge in running the service is covering the cost of delivery, as many of those making referrals or being referred expect this to be free of charge.

With over 50% of all referrals coming from external statutory organisations, it is clear that DRP is plugging a gap in current provision. Providing adequate funding for 'preventative' programmes such as DRP is a solid strategic investment against more expensive long term mental health provision later in a deaf person's life. However, the current climate of austerity has provided funding challenges.

Investment in earlier intervention such as DRP supports life-changing positive outcomes for young deaf people. The programme focuses on enabling young deaf people to lead active lives and become active contributors in society, diminishing dependence on statutory provisions that in some cases would be for life.

Case Study

A young deaf person involved in the DRP project, 16 year old Esha, attended the seminar to describe her involvement in the project in her own words. The following is a transcript taken from the video of Esha:

My name is Esha. I'm 16. I go to school and when I'm older I want to be a midwife. [Before DRP] life was very hard because I thought I was on my own, and growing up, I'd never seen a Deaf person before. I felt like I was the only one. It was hard because I felt like I was abnormal and I was different and I grew up thinking I had something wrong with me.

I used to get bullied a lot because of my deafness and because people didn't understand, and I used to blame that on myself. I didn't wear my hearing aids to just be like everyone else.

But now I know it's ok to be different.

[At first] it felt hard to cope with because I was the only deaf person in my primary school. They didn't really know anything about deafness so they didn't know how to help me. I just felt different, because I was the only one in a hearing world. I didn't know how to cope myself. If someone could have gone back to tell me I wasn't the only one, I would have coped better. If I had met people who were deaf as well, I would have coped better...it was really really hard growing up...I used to be picked on and just used to take it out on myself.

[What was it like meeting a deaf person for the first time?] It was weird! Because...I was just like 'there's someone like me; there's someone who knows what I'm going through!' I was kind of shocked about her ability to do things because I never thought that I could do those things. Like, for example, she got there by driving. I never thought that, as a deaf person, you could drive because you wouldn't be able to hear anything...and I was like 'woah, I can do the same thing that she did'.

I wouldn't be the person I am today if I wasn't involved in this [DRP]. Before I ever met a deaf person, I thought my life was going to be very difficult, and I think my family thought my life was going to be very difficult, because I don't think they were really knowledgeable enough about my disability. They thought I wasn't going to be able to do things.

Now that I've realised that I can...it's taught me that I can do anything anyone else can do, apart from that one thing, and that one thing I just need extra help and support with.

[Should every young deaf person be involved?] Definitely! It does, basically, change your life. Because I went from this, you know, unconfident...feeling like I had a disease or something to, you know, being able to accept my disability and being confident and to say 'I accept that I am deaf', and not feel so isolated.

Family Signing in the Home

Majella McAteer, Community Development Manager, BDA

Family Signing in the Home (FSH) is a Deaf-led project run by BDA NI, tackling language acquisition challenges. The project first developed from the Deaf Roots and Pride (DRP) project, which identified a lack of effective communication within the families of many of the deaf children involved. Mentors had recorded numerous instances of communication frustrations between the young people they worked with and their parents and siblings.

The demand was established for a project that focused on promoting effective communication in the home through the use of sign language. A pilot project was established in Northern Ireland, and completed in 2015. Based on the outcome success for the families involved in the pilot, funding was subsequently secured from the Department of Culture, Arts and Leisure, which later became Department for Communities, who funded the project for the following years.

How has FSH evolved?

The project was initially conceived as a ten week course, delivered by a Deaf teacher of sign language in a home setting.

Parents, siblings, and wider family and friends as well as the deaf child were invited to attend. The benefit of an individualised home-based setting was that the course could then be tailored to the individual communication needs of the family. Tutors incorporated any specific subject areas that would be particularly useful to specific families, such as an upcoming holiday, or a common discussion point in the home.

Following feedback during the initial stages, the ten-week course time was felt by most families to be too short. The course was doubled in length to twenty-weeks, with most families now feeding back that this is an appropriate length of time.

The pool of tutors included Deaf tutors, and Deaf people who had achieved a Post-Graduate Certificate in Education. The pool was selected so that all regions of Northern Ireland could be covered. All teachers involved in the project must:

- Undergo safeguarding training
- Have a valid Access NI check
- Be trained in accordance with the BDA's lone-working policy
- Participate in FSH Teacher Support Meetings, and online support mechanisms.

Teaching methods include:

- Games and learning through play
- Using books and magazines as source material
- Arts and crafts
- Signing and signed song
- Visual aids
- Trips out, for example to theatre shows that incorporate signing
- Use of objects within the home environment as reference points.

Family profiles

In the last reporting year (2017-2018) data was gathered from twelve families who had completed the course within the period.

The profile of this group was as follows:

Age of deaf child	Numbers*
0-5	6
6-8	7
9-14	1

*Some families had more than one deaf child.

Participant group size	Frequency
1-3	3
4-7	7
8-10	2

Deaf children had a range of hearing loss levels, and all used technological aids to develop listening and/or speech, with a majority using cochlear implants. Interestingly, however, preliminary data for the 2018-2019 project year reports a greater proportion of young people using hearing aids and fewer using cochlear implants.

Referrals to the project (in order of frequency) were made by:

- Social workers
- Speech and Language Therapists
- Self-referral
- Sign language tutors
- Deaf organisations

Outcomes

79 families have completed the FSH course to date. Advantages of the FSH project model reported by families include:

- All family members can be involved; other courses often have a lower age limit of 16 years
- The home delivery of the programme is more relaxed, and it is easier to involve young children in the comfort of their own home
- The course is tailored to suit individual family needs, and they can set their own curriculum
- Training feels more personalised than a large class setting.

In the last reporting year, 95% of parents indicated an increase in their confidence communicating with their deaf child, with the remaining 5% indicating no change. Of the deaf children, 96% themselves indicated, or parents indicate, that they had had an increase in confidence (4% indicating no change).

These families recorded the following outcomes:

- Improvement in behaviour and less frustration
- Child demonstrating increased confidence
- Better communication between child and family
- Child has better understanding of the world around them
- Child is more expressive and can be understood
- Child is finding it easier to integrate with the family
- Family feels more relaxed.

The Family Perspective: Fitzgerald Family Case Study

Background

The Fitzgerald's daughter, Isla, was diagnosed as deaf in July 2015 at the age of two years and nine months, while undergoing routine vent surgery. She had passed her newborn screening, and there was no history of deafness on neither the maternal nor the paternal side.

Isla first used hearing aids, and now uses bilateral cochlear implants, following sequential surgeries in December 2016 and December 2017.

Before diagnosis

Before diagnosis, Isla had very little speech and was late to crawl and walk. She was shy with new people, prone to frustration and did not develop sibling or parent attachments that were typical of her age.

The family was a busy young family, with one older child, and when the parents brought their concerns about Isla's development to doctors, family, and nursery staff, they were advised that comparisons with her sibling were not useful.

After diagnosis

Following diagnosis, and the use of hearing aids, Isla's speech did start to develop, and she was very receptive to the use of aids. The family felt that her confidence and personality started to develop.

The family used a Total Communication strategy, and to start with would give choices using visuals (e.g. pancakes or crackers). The family greatly enjoyed learning sign language, finding it very helpful, and expressed surprise at how quickly it was picked up by their children.

However, the year after diagnosis also presented some large challenges. Isla's mother took a year off work, in which time she and Isla attended over seventy appointments, which included:

- Audiology for regular hearing tests and mould fittings
- Assessments at the Auditory Implant Centre
- MRI scans
- Speech and language therapy
- Teacher of the Deaf sessions
- Genetic testing and counselling
- Paediatric appointments with child development services

There was huge impact on family life caused by the additional work, appointments, and self-teaching. The family's first summer holiday after diagnosis was at the Elizabeth Foundation two-week deaf summer school in England, and this was highly valued.

Involvement with organisations

The family contacted and became involved with a number of organisations, including the British Deaf Association. Key benefits included:

- Meeting and getting to know a deaf adult
- Having a deaf role model for Isla and the family
- Link to deaf culture and sign language, creating options for Isla in the future with regard to preferred language, and access to communities
- Sign language taught weekly in the home, in a neutral and relaxed environment, which also enabled family input into the curriculum
- Finding the link between sign language and oral words, and that learning a word in one language supports Isla when she is struggling with e.g. a spoken word.

With the National Deaf Children's Society (NDCS), the family were able to access:

- A 'newly diagnosed' support weekend
- Advice and support with preparing for entry into education
- Opportunities to try out different technologies.

A local family group, 'Listen hEAR' has also provided the family with a number of useful tools, including:

- A group of other families who have been through similar journeys, and who can provide a support network
- A network of deaf children and siblings of deaf children, which both Isla and her sibling have benefited from
- A forum for sharing practical everyday advice.

The family also attended Action DeafYouth (ADY) Saturday morning play pack sessions, designed for deaf children and their families.

'Wish list' for the future

The family expressed a 'wish list', based on the barriers and difficulties that they and Isla have faced since diagnosis, and which they hoped organisations and professionals could work towards.

Their points included:

- Delivery of diagnosis could be better handled
A diagnosis of deafness should not be solely framed in a negative light, and it should be followed up with appropriate resources. For example, a leaflet would have been useful detailing some of the available support services and agencies (the family listed the BDA,

NDCS, ADY, audiology, teachers of the deaf, and various therapies on offer).

- Being put in touch with another parent or family on diagnosis.
- Services to be more 'joined up'; the family cited having to attend audiology services in two different clinics, duplicating many tests.
- More engagement with and listening to parents, as they know their child best.
- Less pressure on the 'oral' route
The family stated that they felt families were being persuaded to only go down an oral communication route by Teachers of the Deaf and speech and language therapists. The family felt that they were lucky in that they were able to take up a Total Communication approach, but hoped that this choice would be more readily available.
- More positive and aspirational attitudes towards the capabilities of deaf children
The family was advised that they should not have the same expectations for Isla that they do her sibling, and they felt that this was not accurate nor fair.
- More of a child and whole-family focus
There was a big impact on family life that the family were not prepared for nor supported in.

Positive outcomes

The family expressed that although having a deaf child in Isla has created some challenges, their hard work was definitely worth it.

Isla is flourishing in her many different pursuits, and is not being held back by being deaf.

Looking to the future

Establishing better practice

The presentations delivered in the conference each sought to explain current practices and make recommendations, based on research or field experience, to improve services delivered in Northern Ireland.

Each presentation identified ways in which service delivery is being – and could be – improved to the benefit of young deaf people and children, and their families.

Utilising the recommendations provided at the conference, BDA NI have drawn together key guidelines that can be turned into practice to make services more suitable and flexible in meeting the needs of varying deaf users. These include:

1.0 Diagnosis

1.1 Professionals should have appropriate confidence that deaf children can develop language and achieve the same life outcomes as non-deaf peers with appropriate support. This should be explicitly communicated to families.

1.2 A diagnosis of deafness should not be presented to families in a solely negative light; there are many misconceptions about what deaf people can and cannot do, and some of these can be addressed from the start.

2.0 Language

2.1 Professionals should be aware of the misconceptions around the use of sign language, and counter it where appropriate with reasoned evidence.

2.2 Professionals should promote the use of sign language, particularly in cases where poor access to language causing a language delay is suspected. Early intervention with sign language should be a high priority in these cases.

2.3 Using sign language, or a blended approach of speech and signing within a strong language model, can have many benefits in the home and in language development. Families should be advised that this is the case, signposted accordingly, and enabled to learn sign language through appropriate, affordable, and tailored sign language training and resources.

2.4 Families should be encouraged to provide diverse reading experience to their deaf child to promote literacy from a young age.

3.0 Child Development

3.1 Recommendations and interventions for deaf young people and children, and their families, should be dynamic (sensitive to change over time). Review and action should be taken the moment a child appears to be falling behind their peers.

3.2 Recommendations about the development of a deaf child should be asset-focused, and take into account the home/school environment, and the resources of the child and the family.

3.3 Deaf role models are key for development of resilience and a strong, stable deaf identity. All young deaf people should be signposted to appropriate mentoring schemes or deaf groups.

4.0 Family Support

4.1 The burden placed on families from diagnosis in coordinating services and liaising with various professionals should be recognised and diminished. Services should liaise directly with each other where possible, and avoid duplication of tests or consultations.

4.2 Families should be supported from diagnosis in navigating the complex systems with their deaf child. This should include explanations of the roles of various health professionals that may be involved, and any related advocacy services or support groups.

4.3 Specific outreach and targeted support should be developed for families who may be at a 'dual disadvantage' (i.e. English is not a home language, they are from a minority ethnic group, they are a low-income family, etc.).

5.0 Signposting

5.1 Inclusive and comprehensive information packs should be provided for families with newly diagnosed babies, particularly given the current emphasis on early diagnosis. These should include details of local resources and charities, their roles, and the options available to them.

5.2 Professionals should be confident and familiar with making referrals for deaf young people and children, and their families, to programmes such as Family Signing in the Home, Deaf Roots and Pride, and other external projects.

5.3 Professionals should be conversant in the benefits of involvement with the Deaf community and Deaf role models for young deaf people and children, and their families.

6.0 Service Direction

6.1 Services delivered in Northern Ireland should be:

- Child and family centred
- Child and family derived through observation, assessment and discussion. Young deaf people and their families can provide useful lived experiences for shaping services, and ongoing consultation should be targeted and well-structured.

6.2 All agencies should work towards Early Hearing Detection and Intervention (EHDI) 1-3-6 guidelines, in which diagnosis happens before 1 month, any aiding before 3 months, and appropriate language intervention before 6 months of age.

6.3 Changes and practices should be evidence-based, and more research is needed, particularly into factors influencing individual development and societal inclusion.

6.4 The majority of referrals received by BDA projects are from statutory agencies, and have demonstrated a high success rate. Consideration should be given to adapting the care pathway to ensure all families can access a fully funded support package, utilising external specialist groups and charities such as the BDA.

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The BDA stands for **D**eaf **E**quality, **A**ccess and **F**reedom of choice

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in wider society.

Mission

Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL and ISL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL and ISL.

1. **Protecting our Deaf culture and Identity** – we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging.
2. **Asserting our linguistic rights** – we value the use of BSL and ISL as a human right. As such, BSL and ISL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
3. **Fostering our community** – we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.
4. **Achieving equality in legal, civil and human rights** – we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
5. **Developing our alliance** – we value those who support us and are our allies because they share our vision and mission, and support our BSL and ISL community.

About BDA

Founded in 1890, the British Deaf Association (BDA) is a national Deaf-led organisation that works directly with Deaf people who use British Sign Language (BSL) and Irish Sign Language (ISL). Our work concentrates on campaigning for equal rights on a national level and working at a local level empowering Deaf people to achieve access to their local public services. This is carried out through projects delivering individual and community advocacy. We also work to ensure BSL/ISL is included by public bodies by delivering a public commitment through signing the BSL and ISL Charter.

Our Board of Trustees are all Deaf (we use the capitalised 'D' to denote the fact that we have a separate language and culture), and, 80% of our staff are Deaf.

Many Deaf people who use BSL/ISL lack access to education, health services, employment and other public services. Our work is designed to empower Deaf people and to improve access to general information and public services. We seek to achieve this by working with Deaf people at the local level through setting up forums to lobby public bodies and supporting Deaf people individually.

This is in line with the overall BDA objectives, which are: **D**eaf **E**quality, **A**ccess and **F**reedom of choice

For a list of signatories to our BSL and ISL Charter, FAQs, and other information, including what the BDA can do for your organisation, please look at our website: www.bda.org.uk







020 7697 4140 | www.bda.org.uk | bda@bda.org.uk

The BDA stands for **D**eaf **E**quality, **A**ccess and **F**reedom of Choice

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