A sound future: Raising expectations for children with deafness

Position Paper

2018
Introduction

At Auditory Verbal UK (AVUK), we want to see a world where all deaf babies and children have the same opportunities in life as hearing children.

In this position paper, we discuss the current challenges that young deaf people face, both educationally and socially, and how social policy, advancing technology and early interventions are starting to break down these barriers.

We give an overview of the international evidence base for the Auditory Verbal approach.

We also discuss what expectations parents and professionals alike should have of any early intervention programme, with regards to a strong evidence base and optimal outcomes for children with hearing loss.

We have included the stories of two children who attended AVUK when they were young demonstrating the impact of the approach. You can find more stories and see videos of both parents and children talking about their experience on our website. If you would like any further information on Auditory Verbal therapy or the international evidence please email abigail.hitchins@avuk.org.
Setting the scene

One to two of every 1,000 children born in the UK has hearing loss and around half of these children will be severely to profoundly deaf (NICE, 2009). At primary school age, this increases to over three per 1,000 children with permanent hearing loss (Davis et al., 1997).

Estimates of the number of children with severe to profound hearing loss in the UK under the age of five years are between 6,400 (CRIDE, 2017) and 7,200 (Clark, 2007).

Around 92% of deaf children are born to hearing parents (Mitchell & Karchmer, 2004; Cole & Flexer, 2015). Without early intervention, this could leave many deaf children without access to either a rich spoken language environment or access to a rich sign language environment as most hearing parents are not fluent in sign language.

Research suggests that over 90% of children born with hearing loss have the physical structures of the ear present that would allow them to receive maximum listening benefit from modern hearing technologies such as digital hearing aids, middle ear implants or cochlear implants (Adunka et al., 2006; Rance, 2005).

By the age of three and a half, the human brain has completed 85% of its physical growth, meaning the first three years of life are critical for developing spoken language through listening (Suskind & Suskind, 2015; Sharma & Glick, 2016). For deaf children, this represents a neurological emergency to access meaningful sound.
A new Progress 8 measure was introduced in the UK to compare what progress children have made between the end of primary and secondary school compared to other children of the same prior ability. Figures show that deaf children are not ‘catching up’ from their lower starting points as they move through secondary school (NDCS, 2018). Furthermore, an early language delay can continue to jeopardise future educational outcomes for deaf children.

Children who have hearing loss are at greater risk of experiencing social isolation, loneliness and difficulty with peer relationships (Young, Green & Rogers, 2008; Peterson, O’Reilly, & Wellman, 2016). This influences later adult relationships and social-emotional development. Early access to language is the decisive factor that drives development forward and provides good social-emotional functioning (Hintermair, 2015).

With over 40% of children with permanent hearing loss estimated to have mental health difficulties in childhood/early adulthood (NDCS, 2010), there is a vital place for early intervention programmes. At AVUK, we focus on listening and speaking and we support the drive to gain evidence about the efficacy of the Auditory Verbal approach (Lim & Hogan, 2017). We support parents to make an informed choice about their child’s communication approach.
Zack and Dylan’s story

Zack and Dylan were born with severe to profound hearing loss in July 2011 in New York. Their mother Deborah tells their story.

“The day we learnt about their hearing loss, we were shocked. We could not believe what and why this could have happened to us. Being an Italian family living abroad, we also questioned whether Zack and Dylan would be able to learn more than one language and we were concerned that exposing them to two languages would be too much for them.

The NYU Medical Centre Audiology team explained that cochlear implant surgery as early as six months, combined with Auditory Verbal therapy, would give Zack and Dylan the opportunity to live a very normal life without limitations as to what they could achieve. At one month of age we started Auditory Verbal therapy in New York and at six months the twins received their bilateral cochlear implants (CI). Two weeks after their CIs were activated, they started repeating some sounds during the Auditory Verbal therapy sessions and every day was a discovery of new sounds and words.

After two years of Auditory Verbal therapy we asked my husband’s employer to be transferred to the UK because I knew that AVUK was one of the best centres in the world for this therapy and we wanted the best for Zack and Dylan. We quickly started seeing them make incredible progress; they began to understand that they have their own ideas and opinions and they started to talk, ask and interact more and more with their peers.

We are hugely grateful to AVUK. Our therapist helped me to understand there are no limits for kids with cochlear implants, and no limits for bilingual cochlear implanted children either. We are convinced every cochlear implanted child can be bilingual or even learn more languages comfortably. Zack and Dylan are currently fluent in English and, during summer holidays in Italy, they speak good Italian with their friends and cousins. They have started Reception and despite being amongst the youngest children in their class, are doing very well. I want to tell any new parents that Auditory Verbal therapy was the most important training for our childrens’ brains and to remember that the sky is the limit!”
Changing times

Early diagnosis and the provision of early intervention have opened up new avenues for deaf children. In the UK there has been substantial investment in the Newborn Hearing Screening Programme, with millions of babies having been tested for hearing impairment at birth since 2006.

There have been, and continue to be, significant advances in assistive hearing technologies, such as digital hearing aids, cochlear implants, frequency modulation (FM) devices, other radio aid systems and other implantable devices.

Amplification alone does not allow for optimal spoken language development (Wilkins & Ertmer, 2002), nor does amplification alone support growth in other developmental areas such as social competence (Hoffman, Cejas, Quittner & CDaCI Investigation Team, 2016). The Newborn Hearing Screening Programme in the UK was introduced on the premise that outcomes for deaf children could be improved by early identification of hearing loss and effective, early intervention (Yoshinago-Itano, Sedley, Coulters & Mehl, 1998).

Effective therapy is crucial if we are to benefit from this investment and technology. We now know that excellent outcomes for spoken language can be achieved if children with hearing loss are fitted expertly with the most appropriate technology and if their families are supported with effective early intervention (Moeller & Tomblin, 2015).

Auditory Verbal therapy is an effective early intervention that has demonstrable outcomes regarding spoken language and educational outcomes (Hogan et al., 2008; First Voice, 2015; Kaipa & Danser, 2016; Percy-Smith et al., 2017). We have seen the rate of language development increase once Auditory Verbal therapy has commenced, and for profoundly deaf children who have received cochlear implants, there has been a second increase in their rate of language development following their implantations (Hogan et al., 2008).

Approximately 80% of children who spend at least two years on our programme at AVUK achieve age-appropriate language (Hogan, 2016) and most attend mainstream school (Hogan et al., 2008).

One challenge of deafness is that it does not always occur in isolation – 30% of children on AVUK’s Auditory Verbal therapy programme have additional needs, with challenges ranging from oro-motor disorders to complex physical needs to cognitive difficulties. Of these children, 64% have achieved age-appropriate language (Hogan, 2016).
For deaf children to best develop their listening capabilities, a combination of optimally fitted hearing technology (i.e. hearing aids or implantable hearing technology) and early intervention is needed.

Optimal development of speech and language skills is preceded by developing optimal listening skills. Listening is dependent upon the stimulation and development of the auditory cortex in the brain. We now know there is a sensitive period during which the central auditory system remains maximally plastic. Effective early intervention needs to occur as early as possible and certainly within the first three and a half years in order to maximise spoken language development (Sharma, Dorman & Spahr, 2002). Long-term deafness extending beyond the early school-age years without adequate auditory stimulation may result in significant re-organisation of the brain, with areas of the auditory cortex becoming involved in visual processing (Sharma, Campbell & Cardon, 2015).

If parents desire listening and spoken language outcomes for their child with hearing loss, a communication approach that emphasises the development of auditory brain pathways through listening and spoken language is necessary (Cole & Flexer, 2015). Research conducted in the United States by Geers et al (2017) provides support for the benefits of prioritising spoken language input alone for promoting verbal development in children who receive cochlear implants by three years of age.

Throughout the first year of life infants learn language in the context of infant-caregiver interactions (Levine, Strother-Garcia, Golinkoff & Hirsh-Pasek, 2016). It has also been shown that optimal language acquisition depends upon engaged parents (Topping, Dekhinet & Zeedyk, 2013). Auditory Verbal therapy is a parent-coaching programme that develops children’s spoken language through listening. It focuses on using sound as the primary channel for learning and equips parents with the skills to maximize their child’s speech and build a communication foundation for language development. By stimulating auditory brain development, Auditory Verbal therapy enables deaf children with hearing aids and/or cochlear implants to make sense of the sound relayed by their devices. As a result, children are better able to develop speech and language skills, laying strong foundations for literacy and numeracy (Robertson, 2013).

Auditory Verbal therapy is government funded in Australasia and a mainstream approach in North America for teaching deaf children to listen, speak, and to achieve long term social and educational outcomes (Estabrooks, Maclver-Lux & Rhoades, 2016).

Coaching parents  
Stimulating the listening part of the brain  
Play-based approach
An Auditory Verbal programme at AVUK typically lasts two to three years and consists of 20 fortnightly sessions per year. Auditory Verbal therapy is delivered by listening and spoken language specialists (LSLS CertAVT®) who have undergone three years of post-graduate training and have been certified by the A.G. Bell Academy – an internationally recognised qualification.

There are 20 Auditory Verbal therapists in the UK as of February 2018. Ten of these therapists work for AVUK. With full caseloads, these UK-based therapists can only provide therapy for less than 5% of the deaf children under 5 years old in the UK. AVUK provides training for speech and language therapists, audiologists and Teachers of the Deaf who wish to become Auditory Verbal practitioners to address this severe need.
Research shows that children with hearing loss in an Auditory Verbal therapy programme can:

- Graduate with no gap between their chronological and equivalent language ages and develop spoken language in line with typically hearing peers (Constantinescu et al., submitted; Dornan, Hickson, Murdoch, & Houston, 2007, 2009; Dornan, Hickson, Murdoch, Houston, & Constantinescu, 2010; Fulcher, Purcell, Baker, & Munro, 2012; Hogan et al., 2008; Hogan, Stokes and Weller 2010; Rhoades & Chisolm, 2000; First Voice, 2015; Hogan, 2016).

- Progress at the same rate for listening, spoken language, self-esteem, reading and mathematics as a matched group of children with normal hearing (Dornan et al., 2010).

- Make, on average, 12 months progress in 12 months for their spoken language development, which is in line with expectations for children with normal hearing (Dornan et al., 2007, 2009; Dornan et al., 2010; Rhoades & Chisolm, 2000). In addition, children graduating from AVUK demonstrated accelerated language competence in advance of their hearing peers (Hogan et al., 2008).

- Show marked language benefits from earlier amplification (Dettmen et al., 2016; Dettman, Wall, Constantinescu & Dowell, 2013).

- Demonstrate advanced spoken language skills relative to other children who had received standard early intervention. (Percy-Smith et al., 2017).

“When our son started at AVUK he had over a two year language delay, was struggling to make friends and was a very frustrated child. AVUK transformed his life and he is now flying at school, has age-appropriate speech and lots of friends. We will be forever grateful.

Parent of a young deaf child who has graduated from AVUK
Kurran’s story

Kurran was born two months premature, in 2003, and quickly fell victim to a severe necrotizing enterocolitis (NEC) infection. He spent the first two years of his life in hospital, underwent three life-saving operations and has only 40% of his bowel intact. Having survived the first two years and, just when Kurran’s family thought their life was stabilising, they learnt that their son is profoundly deaf. Kurran received a cochlear implant at four years old. He also has mild cerebral palsy and developmental delay. His father, Avy, tells their story.

“It felt like there was a constant barrage of bad news every day – ‘he’s not going to walk’, ‘his limbs aren’t working’, ‘his femoral artery has been damaged’ and so on. Two years of coping with this and living in a hospital came close to destroying us. Then came the deafness diagnosis. To be honest, I felt helpless for the first time in my life and I was probably at my lowest ebb. Hearing aids made no difference and by the age of four, Kurran still hadn’t uttered a single comprehensible word. Despite Kurran being older than most children who are implanted, Great Ormond Street Hospital agreed to a single right-sided cochlear implant in September 2007. I’ll never forget the first time he was ‘switched on’! His eyes were like a rabbit in the headlights but though he could hear, crucially, he couldn’t interpret what the sounds meant.

Discovering AVUK was like finding a huge inflatable balloon full of hope, help and real progress. Every time we went to AVUK, we were inspired and had complete confidence that we were in the safest, expert pair of hands. Through intensive Auditory Verbal therapy, Kurran managed to hear his first sound, a door bell, six months after implantation and our therapist helped us put the very first words in Kurran’s mouth. For my wife, who had not heard her son say a single word, the best part of four and a half years came when he uttered his first word, “Mummy”. It started to feel like we were on a roll and very soon Kurran had 50 or 60 words and was able to articulate most of his needs and demands.

Mobility was still a huge issue for Kurran but in 2008, Kurran took his first independent steps. This small miracle was now unfolding and he could walk, listen, talk and read! Thanks to Auditory Verbal therapy, he had a rapidly developing vocabulary. He was also starting to eat everything orally and the doctors decided to close his gastro peg permanently.

He is now 12 years old, standing upright and walking and talking, a lot. He doesn’t stop talking to be honest and he asks so many questions! Kurran is a vegetarian by choice and he hopes one day to work with pets. He is such a curious boy, very sociable and has all of the normal teenage demands; the mobile phone, the iPad and a bedroom littered with car or pet magazines. He is currently rehearsing a central part for his school play and he’s learning German too, scoring 9 out of 10 in his German test today! We are so proud of him.”
AVUK’s mission is to raise expectations and outcomes for deaf children. Parents should be best informed about what their child can achieve from any given communication approach. This enables them to make an informed choice about their child’s future. Advances in hearing technologies, changing candidacy criteria for cochlear implantation and effective early intervention have driven a change in the expectations for spoken language outcomes, as documented by the evidence base. Parents and professionals alike should expect these optimal outcomes from their Early Intervention Provider. As a community, we should expect Early Intervention Providers to have strong, evidence-based answers to the following questions:

**Questions**

- How will you support my child’s communication development before the onset of spoken language? How will you do it if my child is already two years old?
- How do you know what stage my child is at currently and how will you assess their progress throughout your programme?
- How do you measure outcomes?
- What outcomes can be expected in your programme and how do these outcomes compare for children with typical hearing?
- Where do you think my child will be in 5 years’ time and in 10 years’ time?
- What should I be doing as a parent to enable my child to have the best possible outcome?
- How do you support children to interact with and contribute independently to the broader community?
- How do you continue to support children with hearing loss once they have achieved spoken language on par with their peers?

“AVUK has allowed us to dream again, they have provided us with the foundation for Eisa, to enable him to do whatever he chooses to do and achieve his aspirations”

Mother of Eisa, who lost his hearing through meningitis
Programme content

- What communication choices do you offer parents for children who have a newly identified hearing loss? What communication and educational philosophy does your programme follow?

- How does your programme make the best possible use of the latest hearing technology?

- What skills and qualifications do members of your team have? What is the nature of your programme and how often will you meet with my child and our family?

- What is expected in terms of the commitment of families to your programme?

- What research evidence shows that your early intervention programme is effective? How does it compare to other programmes?

- There is a lot of variation in treatment and availability of services nationally. How can I be assured that my child is receiving the right support for them?

- How do you develop and improve your services so that the information your team provides is based on the latest evidence?

Family support

- What specialist support do you provide for parents/carers?

- What happens if your programme doesn’t work for a particular child and family?

- What are the risks in choosing this Early Intervention approach?

- What support do you provide in choosing the best school for a particular child?

- How do you engage with feedback from parents/carers?
References


Updated February 2018

Auditory Verbal UK is the operating name of the Auditory Verbal Centre.

Registered Charity No: 1095133
Company Limited by Guarantee.
Registered in England No 4569764

© Auditory Verbal UK 2018

www.avuk.org