

AUDITORY VERBAL^{UK}

Creating a sound future for deaf children



Raising the bar for deaf children with additional needs

A study of spoken language outcomes for children attending Auditory Verbal UK from 2007-2017

June 2018

Foreword

Deaf children with additional needs are often excluded from national statistics and research into the outcomes for deaf children. With effective early intervention, we know that deaf children can achieve on a par with their hearing peers. We present research that demonstrates that deaf children with additional needs can do so too.

Since 2003, Auditory Verbal UK (AVUK) has worked with families of deaf babies and young children from across the UK. We are delighted to publish this report which demonstrates the effectiveness of a family centred, Auditory Verbal early intervention programme.

The study looked at 129 children who spent two years or more on the AVUK programme between 2007 and 2017. More than one-third of the children included in this study had additional needs over and above their hearing loss. The study shows that, on average, deaf children with additional needs doubled the rate of their language development whilst on the programme, and one in two reached age appropriate spoken language at the end of their programme. The analysis also shows that the earlier that effective intervention begins, the better the prognosis for language development. The report also found 97% of deaf children without additional needs reached at least age appropriate spoken language at the end of the programme.

In the UK, we have a world-class Newborn Hearing Screening Programme. We have access to state of the art modern hearing technology. But the gap between deaf children's achievements and those of their hearing peers, is widening. This should not be the case and far too many deaf children are missing out on vital support in the critical early years of their lives.

This research shows the significant benefits of an Auditory Verbal programme and crucially highlights the outcomes for children who are deaf and have additional, and often complex, needs. I hope that commissioners and service providers will raise the bar for these children and invest in the vital services that they, and their families, need – right from the start.

I am extremely grateful to Dr Sarah Hogan, Abigail Hitchins and Rebecca Crombleholme for the preparation of this report.

**Anita Grover
Chief Executive, Auditory Verbal UK**

Background

One to two of every 1,000 children born in the UK has hearing loss¹ and around half of these children will be severely to profoundly deaf². Estimates of the number of children with severe to profound hearing loss in the UK under the age of five years are between 6,400³ and 7,200¹. In addition, between 25-40% of these children have additional needs that are either evident at the time of diagnosis or become evident during their early childhood^{4 5 6 7}.

Around 92% of all of these deaf children are born to hearing parents⁸ and thus without early intervention, are left 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 at the time of their child's diagnosis. The early years are vital for the development of language⁹. For deaf children, this represents a window of opportunity to access meaningful language.

It remains of great concern that around two-thirds of deaf children arrive at primary school having not achieved a good level of development in the early years¹⁰ suggesting that at least some have not received the effective and necessary support they need.

Deafness is not a learning disability

In 2017, 61% of deaf children left primary school having failed to achieve the expected standard in reading, writing and mathematics, compared to 30% of children with no identified Special Educational Needs (SEN)¹⁰. The Department for Education have claimed that attainment for deaf children was at "a record high". However, the latest figures show that, in fact, the attainment gap between deaf children and children with no identified SENs is widening despite deafness not being a learning disability.

These national figures will exclude some of the 25-40% of deaf children who have an additional need. Cross-referencing with figures from CRIDE (Consortium for Research into Deaf Education), the National Deaf Children's Society estimate that around 42% of all deaf children are missing from the official statistics. These additional needs can cover a range including cognitive, physical, dual sensory, specific speech and language, and behavioural/emotional problems. This list is not exhaustive and many children have multiple needs across these categories. These needs can arise from the differing aetiologies of deafness such as meningitis, cytomegalovirus (CMV), hypoxia, genetic syndromes etc.

Due to the heterogeneity of this population, such children are frequently excluded from studies which aim to investigate language and educational outcomes for deaf children. As a unique situation evolves from the combined presence of two or more disabilities¹¹, these children require a flexible and thoughtful approach to providing effective amplification, habilitation and education¹². The complexity of the needs and challenges in these groups of children can pose difficulties for the child, the parents and for professionals supporting the child and their family. Nonetheless, such complexities should lead to appropriate and creative solutions being offered by the education system, social care system, and deaf intervention providers alike.

Although a heavily under-researched area, a recurring theme from the authors investigating additional needs in deafness is the difficulty of defining the groups and lack of uniform descriptors of these children with disabilities¹³. Moreover, implementing standardised outcome measures has proven difficult and inaccurate. This population is referred to as having 'multiple', 'additional' or 'complex needs', or as 'handicapped'. The varying use of these terms has added further confusion to the interpretation of the literature. For this publication, we refer to 'deaf children with additional needs' to describe the population.

There are commonly 'low expectations' for the achievements of deaf children and the expectations for deaf children with additional needs are frequently the lowest. A study by McCracken & Pettitt¹⁴ stated that, although the variation of needs does preclude any simplistic approach, the lack of agreed outcomes for deaf children with additional needs makes it difficult to assess progress; that the lack of clearly defined benchmarks contributes to the poor recognition of potential and low expectation.



Our analysis

For the purpose of this report, the word 'deaf' is used to refer to all levels of hearing loss. In 2017 the Royal College of Paediatrics and Child Health (RCPCH) published an explanatory glossary of paediatric disability terms to contribute to the development of the Systemised Nomenclature of Medicine – Clinical Terms (SNOMED CT)¹⁵. For the purpose of this research, we have used the RCPCH glossary of terms to describe the categories of functional additional needs in deaf children (see table 1).

Table 1. Adapted from the RCPCH explanatory glossary of paediatric disability terms (British Academy of Childhood Disability, 2017)

Category	Example of functional needs
Intellectual abilities	Developmental delay, problems with executive functioning, specific learning disability
Physical, motor, musculoskeletal	Delayed gross/fine motor skills, balance difficulties, sensory motor difficulties
Cerebral palsies	Spastic cerebral palsy, Worster Drought syndrome, Ataxic cerebral palsy
Sensory impairment	Visual impairment, squint
Speech, language, communication	Language disorder, speech production difficulties, oromotor difficulties
Feeding and nutrition	Avoidant/restrictive food intake, liquid diet, soft diet
Behaviour	Sensory integration difficulties/sensitivities
Other conditions	Autism spectrum disorder, Down's syndrome, epilepsy

One communication route for deaf children is a listening and spoken language approach. This requires optimal access to sound using hearing technologies and effective early intervention to make sense of the sounds relayed by those devices. A 2016 Cost Benefit Analysis¹⁶ showed the long term costs and benefits of investment in an Auditory Verbal (AV) early intervention programme and reported a £4 return to every £1 invested. This report provides greater analysis of the outcomes of an AV therapy programme for deaf children who have been enrolled in an AV therapy programme in the very early years of their lives.

By reporting on the outcomes of children with additional needs whose families have followed an AV approach to communication, we celebrate the many successes of both the children and their families and call on commissioners and service providers to enable families to have the opportunity to access effective and evidence-based support in the critical early years of their lives.

Outcomes from an Auditory Verbal programme

Data from 129 children were analysed. Children had varying degrees of permanent hearing loss and at less than five years of age, were enrolled by their families onto an individualised AV programme at AVUK between 2007 and 2017. All the children had stayed on the programme for two or more years and completed two or more spoken language assessments (Preschool Language Scales (PLS))^{17 18}. See figure 1.

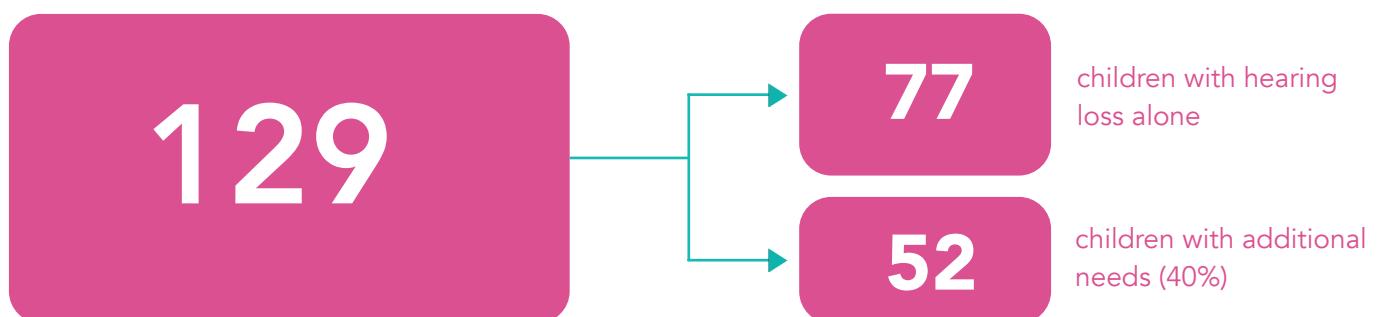


Figure 1. Flow chart to show numbers of i) children for whom spoken language data was analysed and ii) children with and without additional needs



Achieving age appropriate spoken language

Four out of five children who stayed on the programme for two or more years and completed two or more spoken language assessments achieved age appropriate language (AAL) on leaving the programme. The ways in which these children differ to those who did not achieve AAL are outlined in table two.

In line with population figures, 40% of our sample of deaf children have additional needs. **One out of two children with additional needs achieved AAL on leaving the programme.** The differences between children with additional needs who do and do not achieve AAL are outlined in table 3. The breakdown of aetiologies between these groups can be seen in figure 2.

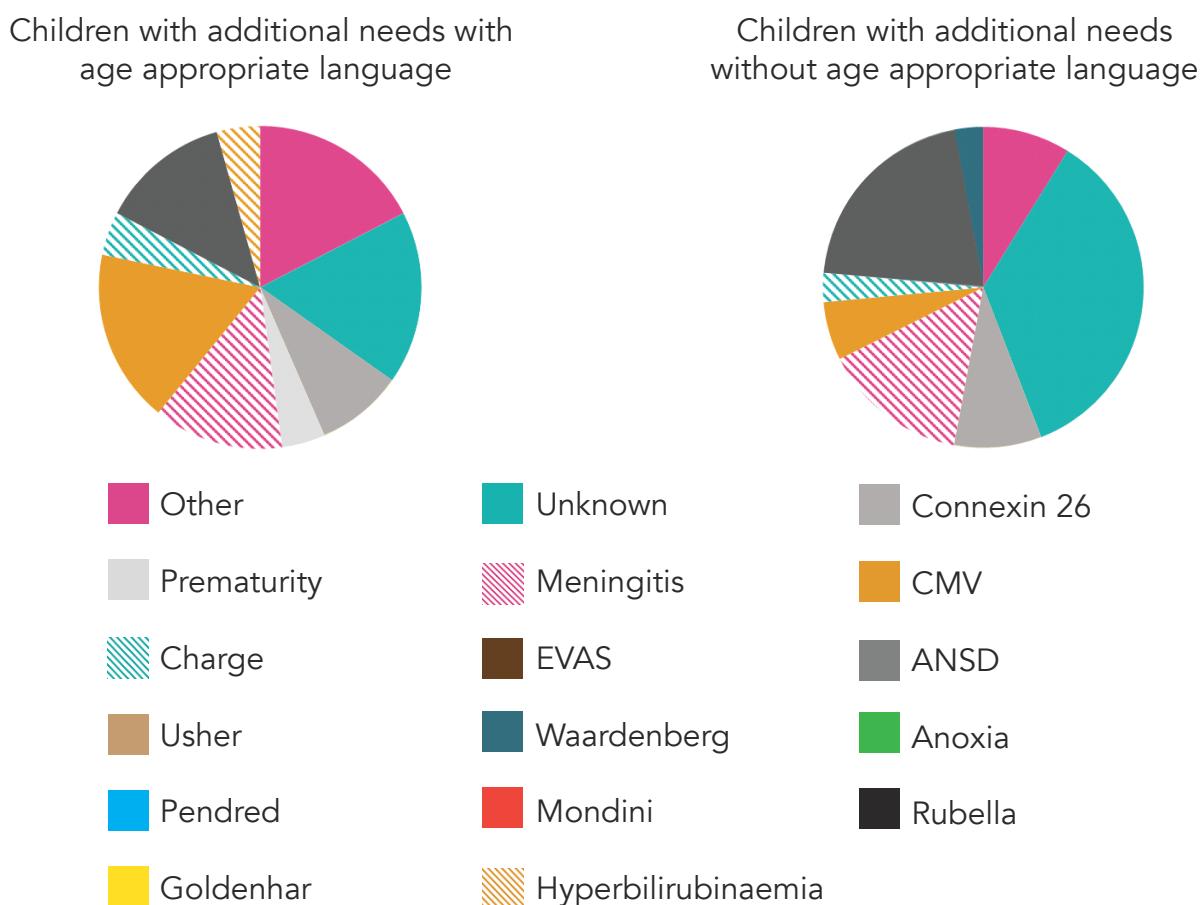


Figure 2. Aetiologies of children with additional needs.

It is a cause for celebration that, as a result of early diagnosis of hearing loss through the UK's Newborn Hearing Screening Programme, through early intervention with hearing technology and through an effective, family-centred AV programme, **97% (n=75) of children with hearing loss and without additional needs achieved age appropriate language.**

The most common age for the diagnosis of hearing loss in children without additional needs was one month (a mean age of four months) and the most common age for initial hearing aid fitting was three months (a mean age of eight months). This approaches the international 'Best Practice' standard of "diagnosis of hearing loss by one month of age and hearing evaluation by three months of age"¹⁹.

The international 'Best Practice' standard also aims for effective early intervention to begin by six months of age. While statutory services will have been involved with all families from the point of diagnosis, the mean age for starting the AV intervention was 18 months.

Factor	Children achieving age-appropriate language (n=102)	Children not achieving age-appropriate language (n=27)	Level of significance
Age of diagnosis (in months, excl. acquired losses)	Mean=4 sd, Mode=1 Minimum=1 Maximum=26	Mean=13 sd, Mode=1 Minimum=1, Maximum=39	Highly significant
Proportion with additional needs	26%	93%	Highly significant
Age when starting AV programme (months)	Mean=18.6 Mode=7	Mean=34.8 Mode=38	Highly significant
Initial rate of language development (RLD)	Mean=0.7 Minimum=0.1 Maximum=1.5	Mean=0.4 sd Minimum=0.2 Maximum=0.7	Highly significant
RLD when finishing AV Programme	Mean=1.4 Minimum=0.3 Maximum=2.5	Mean=1.0 Minimum=0.5 Maximum=2.1	Highly significant
Proportion of children with age-appropriate language	79%	21%	

Table 2. Profiles for children on the programme for two or more years with two or more PLS results

Accelerating listening and spoken language competencies

For children who achieve AAL the mean rate of language development (RLD) at the start of their AV programme was 0.7 (compared to a RLD of 1.0 for a child with typical hearing). This suggests that at the time of enrolment there was already a gap in their spoken language communication competencies compared with their typically hearing peers. The mean RLD was doubled to 1.4 while on the programme. These children have closed ‘the spoken language gap’ that existed prior to enrolling on the programme by accelerating their RLD beyond that of children with typical hearing. Adopting the AV approach from the point of diagnosis could give an even better start for deaf children.

The rate of language development for children with additional needs

The most common age for the diagnosis of hearing loss in children with additional needs was also one month (excluding those with acquired post-natal hearing loss, n=10). However, on average, this group were diagnosed at a significantly higher age than children with hearing loss alone (mean age of nine months).

The most common age for their initial hearing aid fitting was two months (mean age of 14 months). The overall mean age for starting AV was 27 months with a mean interval between their hearing technology being fitted and starting their AV programme of 15 months. This is a significantly larger time interval than for children without additional difficulties (mean interval age of 10 months).

Approximately **half of the children with additional needs achieve AAL** by the time they leave the programme. These children are significantly younger at the diagnosis of their hearing loss, have fewer additional needs and start their AV programme at a significantly younger age (see table 3). Those families of children with additional needs who achieved AAL on leaving the programme started their AV programme before their child was two years of age.

On average, children with additional needs started the programme with an initial RLD that was half the rate of a typically developing child. **The average programme RLD more than doubled and was in excess of the RLD for a typically developing child.**

Table 3. Profiles for children with additional needs on the programme for two or more years with two or more PLS results.

Factor	Children achieving age-appropriate language† (n=24)	Children not achieving age-appropriate language†† (n=20)	Level of significance
Age of diagnosis (in months, excl. acquired losses)	Mean=5, Mode=1 Minimum=1 Maximum=19	Mean=13, Mode=1 Minimum=1, Maximum=39	Significant
Age when starting AV programme (months)	Mean=22 Mode=25	Mean=33 Mode=40	Significant
Initial rate of language development (RLD)	Mean=0.7 Minimum=0.1 Maximum=1.2	Mean=0.4 Minimum=0.2 Maximum=0.7	Highly significant
RLD when finishing AV Programme	Mean=1.4 Minimum=0.8 Maximum=2.1	Mean=1.0 Minimum=0.5 Maximum=2.1	Highly significant

† excluding 3 children with post-natal, acquired hearing loss

†† excluding 5 children with post-natal, acquired hearing loss

Mia's story

Mia is a bright, social and determined little girl who has defied all the odds. Mia was born with CHARGE syndrome, a rare genetic condition that can affect different parts of the body; the most common problems are with hearing, vision, the heart, airways and growth.

At only a few hours old and having trouble breathing, our local maternity hospital had concerns about Mia's heart. She was rushed to GOSH for further investigation. The cardiac intensive care unit doctors discovered Mia had a life threatening heart defect and she would need major open-heart surgery to fix it. At two days old we met with a lovely geneticist by Mia's bedside who explained to us she had many clinical features of CHARGE syndrome. More investigation was needed, but it became clear that Mia would have many challenges ahead of her. At four days old Mia underwent open-heart surgery to correct her heart defect. Her recovery was textbook and after 11 days she was discharged. Overjoyed and traumatised all at the same time we took our beautiful daughter home, knowing this was just the start of our journey.

In the coming weeks we learned that Mia was severely visually impaired, severe to profoundly deaf, had missing semi-circular canals meaning she would struggle to learn to walk and had problems with her swallowing and breathing. Each one of her senses impacted on the other and this complex condition needed careful management. After weeks of being bombarded with long lists of serious medical diagnosis we began to think about what the future held for Mia.

I was particularly upset about her vision, as I couldn't imagine what it would be like to not see properly. Despite the severity of Mia's hearing impairment, this diagnosis didn't seem to worry me as much. Maybe it was the softly spoken audiologist who reassured us there were lots of things they could do for Mia's hearing. Or maybe I saw a beautiful baby who kicked ass when it came to major open-heart surgery; a superhero who could defy all the odds placed before her.

Mia has had a lot of ups and downs. We were lucky to have a strong team of health professionals supporting us at GOSH and working with us locally. With lots of hard work and determination, Mia slowly started to learn to live with and overcome many of her health problems.

It is a hard journey having a child with complex needs. I spent a great deal of time researching each one, finding resources and organising assessments. Dealing with such a large team of health professionals, at times, has been difficult. There were often conflicting views about what was best for Mia. Sometimes I struggled to hold on to my gut instinct about what was right for my child. People varied and despite getting on with everyone and appreciating their help, I had to learn diplomacy and how to get my wishes across without disparaging anyone's advice.

It took a while to get Mia's audiology right due to her complex mixed hearing loss, practicalities of a baby wearing hearing aids and difficulties testing such a young child. We have explored every avenue available to us like 'bone anchored hearing aid' and cochlear implants. However Mia has always tested best with hearing aids, despite struggling with high frequencies. She is an excellent hearing aid user and this has really helped her develop her speech and language. At times some people have underestimated Mia's ability to develop speech because she struggles with her clarity or needs more time to process information. Perhaps this is partly due to a lack of training about children with a multi-sensory impairment, the impact this has on development and the strategies needed to help support the child.

I became Mia's advocate. I had to be strong and pushy, making sure she has every opportunity available to her. I make sure people understand her, that she is bright and able and with the right support will reach her full potential. To be treated like any other child and not held back because of her difficulties. To be independent and given every opportunity to develop and learn.

Auditory Verbal UK have been amazing. They have never underestimated Mia's abilities. They have worked with Mia's multi-sensory impairment and adapted her therapy to take into account her vision, hearing and balance difficulties. Mia's AV therapist has supported us with getting the right audiology, schooling and local speech and language therapy. Combining AV therapy with our local speech and language support has really pushed Mia's speech along, closing the gap in her speech delay and getting her ready for mainstream school.

We have very high expectations of Mia and have never underestimated her abilities. Mia has made amazing progress. Her speech and language is within the normal limits for her age and she is very happy, social and confident. Despite having to work four times harder to walk, talk, listen and learn, Mia is keeping up with her peers and going from strength to strength.

Written by Mia's mother, Claire



Thinking differently

Our analysis shows that deaf children with additional needs are diagnosed with hearing loss significantly later than other deaf children. This is not altogether a surprise as the incidence of deafness increases 10 times in children who require intensive treatment as newborn infants^{20 21}. In some cases, a correction factor of as much as three months would need to be made to the age of diagnosis of hearing loss to account for the premature birth of these babies. In this study from 2007 - 2017, a significantly greater proportion of children with additional needs were born prematurely than those with deafness but no additional needs. One in four of the children (n=31; 24%) were cared for on Special Care Baby Units (or Neonatal Intensive Care Units), 70% (22/31) of whom went on to have at least one additional need.

The families of children with additional needs enrolled on the AV programme significantly later (mean age of two years four months) than families of children without additional needs (mean age of one year six months) and with a significantly greater time interval between diagnosis of their hearing loss and starting their AV programme. In addition, the children had a mean RLD at the start of programme equivalent to half of the RLD of a child with typical hearing. However, with the benefit of new skills acquired by their parents through the AV approach and with the liaison of AV therapists with their local teams, the children mirror the acceleration shown by children with hearing loss alone, on average showing an increase in the RLD from 0.5 to 1.2, again exceeding that of typically hearing children. **One in every two of the children with additional needs reached AAL at the end of their programme.** On average, the children with additional needs made highly significant gains in their RLD while on the programme compared to their initial RLD.

Auditory Verbal practice is diagnostic: It enables practitioners to work with families and other professionals to ensure that deaf children with additional needs access appropriate support to make progress with their communication. For some families this means signposting to alternative communication approaches at the earliest opportunity.

Call to action

An international consensus statement for 'Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing' was developed and published by a panel of experts in 2013¹⁹. There was agreement that the primary goal of early intervention for hearing loss in infants would be to ensure all newborns are screened by one month of age, have their hearing evaluated by three months, and are enrolled in early intervention by six months in line with evidence that reducing the age of diagnosis, together with early support for communication development, results in improved outcomes for the child and family. The early support needs to be effective for the best outcomes in communication, literacy and cognition to be achieved.

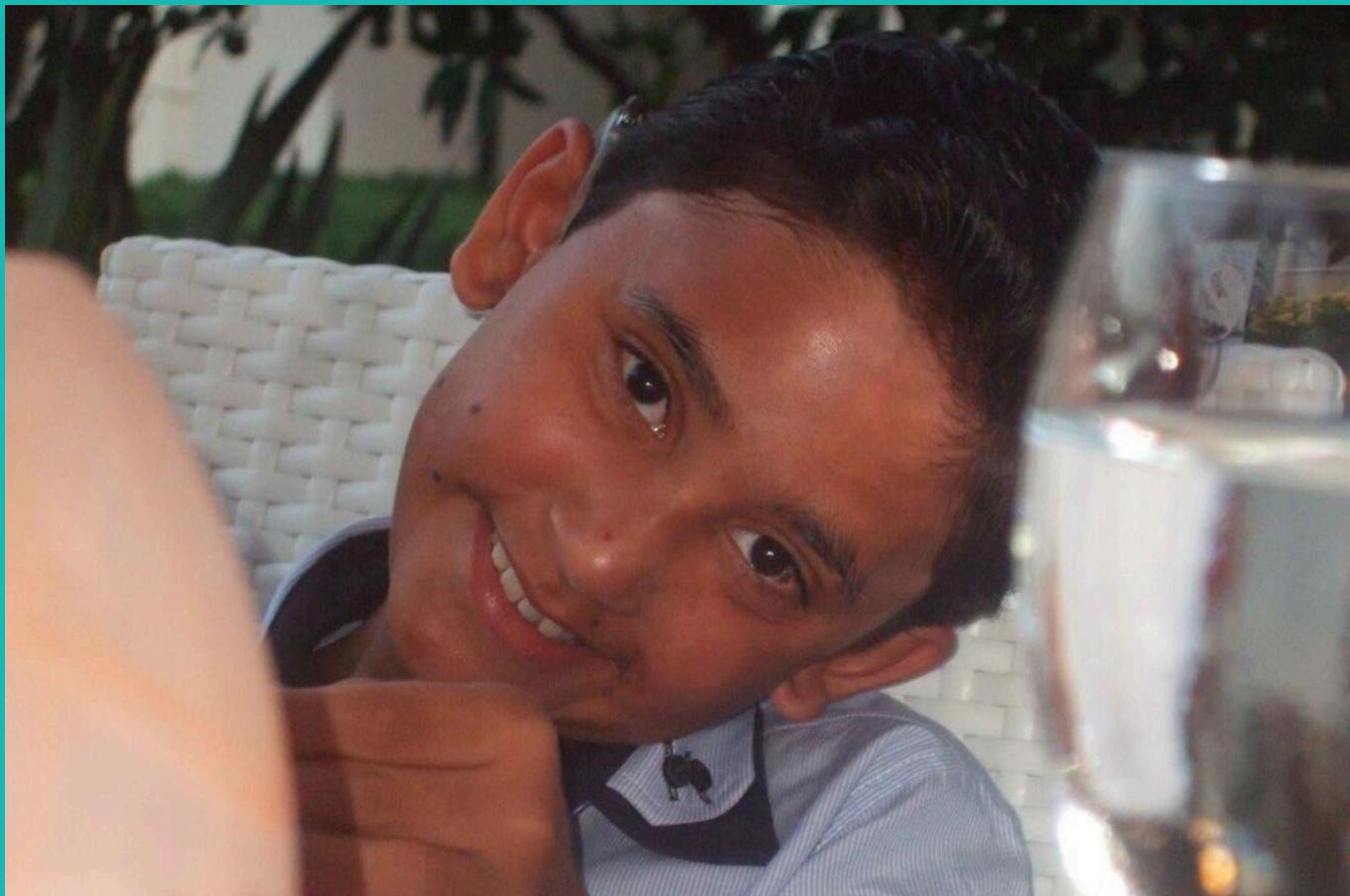
If the families enrolling in our AV programme are representative of the population of deaf children in the UK, then the data suggests we are well on the way to diagnosing hearing loss in the majority of well babies by one month of age. Are we doing as well with our effective early support? The families who have enrolled their children in an individualised AV programme have, on average, supported a significant improvement in their children's rate of language development. Could this change have happened earlier? Do we need to re-visit how effective we are at supporting all our deaf children in our early intervention? The evidence from this study suggests it's time to make a change.

What could change for deaf children with additional needs?

- Have higher expectations for what they can achieve.
- Start the AV approach as the first intervention – it is diagnostic – if progress is not being made, something needs to change.
- Make it local. Families with additional difficulties can be overwhelmed by the number of professionals supporting their child's development and neither want nor need to be travelling to additional, numerous appointments. Technologies to support remote intervention such as Skype and Facetime make it possible for some families to engage with the programme without travelling from home.
- Train more certified Listening and Spoken Language Specialists and embed Auditory Verbal practice in the NHS and local authority services.
- Prioritise more collaborative working between professionals: make it creative, thoughtful, and flexible, focussing on the needs of the 'whole child' and their family.

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 lifesaving operations and has only 40% of his bowel intact. Having survived the first two years and, just when we thought our life was stabilising, we learnt our son was profoundly deaf. Kurran received a cochlear implant relatively late, at four years three months. He also has mild cerebral palsy and developmental delay.



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 comprehensive word. Despite Kurran being older than most children who are implanted, Great Ormond Street Hospital agreed to a single right side 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, most expert pair of hands.

Through our intensive AV programme, Kurran managed to hear his first sound – a door bell – approximately 6 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. He spent a lot of time in splints and crutches, as well as the walking frame. He had regular physiotherapy and everything in the house was adapted, but we kept his life as normal as possible, never restricting his capabilities or hope. Progress was painfully slow but I could see results. Around 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 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 - he loves animals and believes they are sent from God for us to enjoy and not to eat! He is such a curious boy and very socialable. He's growing at a really fast rate and has all of the normal teenage demands expected; the mobile phone, the iPad and a bedroom littered with car or pet magazines. He loves animals and hopes one day to work with pets. He is currently rehearsing for his school play – he tells me he has a central part and is practising his lines every day. And he's learning German too, scoring 9 out of 10 in his German test today! We are so proud of him.

written by Kurran's father, Avy



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Published June 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

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