

Parents and their deaf child's futures

Jane Russell shares her details of her current PhD study that is grounded in hearing parents' 'knowledges' about good outcomes for their child and describes why she wanted possible futures for her child, writing about futures plural rather than future singular

As a hearing mother to deaf and hearing triplets, who are now 20, I started a part-time PhD in 2013 because I was curious why my experiences of parenting my deaf son felt so different to parenting his siblings. My PhD is designed to be grounded in hearing parents' 'knowledges' about good outcomes for their child. 'Knowledges' are plural because knowledge is more than formal academic knowledge; it includes experience, intuition and instinct, plus informal information and other ways of knowing, ie, how parents come to know what they know. I used to think in terms of 'what I know now that I did not know', but I frame it now as 'what I know now that I could not have known in the past', which addresses (part of) the guilt I feel about some of my past parenting decisions.

My research suggests that hearing parents with deaf children spend much of their time, even when their child is a baby, worrying about their child in the future. I certainly did. I still consider my deaf child's futures feelingly – I did not only think about his future, I felt it. I am not alone in

having a strong response to futures. Parents within my study also had emotional reactions that seemed to start from a place of fear and uncertainty: fear of not being able to advocate for their child if they died, and questions, such as would their child be lonely in the future? Many people have expressed difficulty in living with the constant uncertainty of the Covid-19 pandemic and I see similarities with deaf-child parenting. It was, and remains for me, an experience of living with constant uncertainty about the future.

Parental concerns stemmed from their awareness that they lacked skills, knowledge and experience of deafness. We, for example, wanted our son to grow into a happy, confident young deaf adult but did not know how to make it happen. When a child is deaf, the topic of futures comes onto parents' radar really early on, when the future is yet unknown and the present may also feel unrecognisable. For some parents the future may not even yet exist as a concept. One mother in my study could not





There were wide variations in how mothers thought about futures. Futures for me included independence, confidence, my child being the best he could be, being happy, having positive relationships and having a sense of belonging. Other parents saw futures as having an education, a job, being able to communicate and having friends. What parents considered as futures was complex. Some mothers said they only realised during the interview that they had not actually thought about

even think about her child in the future – it was too distressing for her, while another felt her child had no hope and therefore no future. However, parents whose children are deaf are still required to make early decisions about identity, language and technology and make these decisions not for themselves but on behalf of their child. Parents knew these choices would influence their children's futures but not how.

Deaf children's futures differ from those of children who are not deaf. Deaf-child parenting may involve alternative processes, for example, when applying for a school place. Parents may also have to complete forms, such as Disability Living Allowance, and assessment requests for educational support or for an education health and care plan. These activities are not one-offs, they are repeated throughout childhood. Practitioners may not even talk about futures with parents because the focus is usually on outcomes, a word more associated with business organisations than raising children. There is the potential for miscommunication if practitioners talk of outcomes and parents think about futures. A focus on outcomes also tends towards only what is measurable, missing, perhaps, what parents actually value. The mothers in my study told me they had never been given the opportunity to talk about their children's futures, yet seven of the eight had children with educational health & care plans.

futures at all in relation to decisions in the early years, and they only started actively thinking about them just before the move to secondary school.

What really mattered to the mothers in the study was that their child, as a young person, had the confidence to choose their futures for themselves. A simple statement



perhaps, but as a mother of a deaf child I appreciate so much lies behind it. There seems a deliberateness about futures, which does not occur for children who are not deaf, and my research suggests that futures have to be actively made for deaf children. The wider research also supports parents as the biggest influence on deaf-child outcomes; however, specific studies define specific outcomes.

I also explored ten books written by parents raising deaf children, which showed how parental thinking about futures can be based on assumptions that parents later found to be incorrect. Many parent authors used images from films with deaf characters and stories from others about the sad lives of deaf people when thinking about their own deaf child's futures. These early-imagined futures were based on the stereotypical and anecdotal. This should not be surprising since hearing parents cannot know what it can mean to be deaf. It is simply outside our understanding. Paddy Ladd, a Deaf academic, acknowledges the confusion for hearing parents surrounding the idea of their child being deaf. Ladd includes an excerpt from a deaf woman, Lorna Allsop, about how deaf children from hearing families can grow up with low expectations for themselves whereas "Deaf children from deaf families are raised expecting things to be normal and equal" (Ladd, 2003). To borrow from Meghan Markle, hearing parents need to know that the issue should not be whether our deaf children survive, when the real goal is deaf children being able to thrive.

There are other reasons that limit parents thinking about futures. One mother in my research said she did not know she had to think about her child's future as she thought professionals would do this, and she regretted that she did not do more when her child was younger. This lack of parental experience about being deaf has an impact on how parents contemplate deaf children's futures. If deaf children's future/s are determined by parental decisions made in the present, but parental thinking is based on incorrect assumptions from the past, this can be difficult. Having an awareness about some of the issues around decision-making and futures may be helpful. For example, thinking can decisions be regularly revisited or made only once, such as whether to have a cochlear implant?

Certain futures for deaf children are emphasised and supported over other futures, which may be hidden from parents or not be as easily available. For example, clinical commissioning groups (CCGs) provide funding for cochlear implants, which are in the National Institute for Health and Care Excellence (NICE) guidelines, but they do not routinely fund families to learn BSL (British Sign

Language) and/or have specialist speech and language therapy for their deaf child, which are not covered by a NICE guideline. Information and how it is framed can limit parents' thinking about futures in the early years without parents being aware this is happening.

Knowing about predictable, probable and possible futures may be helpful for parents. Predictable futures are when someone says that evidence X means Y will happen. As a parent researcher I have learned that prediction about outcomes for specific deaf children is problematic when based on evidence of likely outcomes within a larger sample, especially given that variation within a group of deaf children is typically greater than within a group of hearing children. Also, each child is unique and raised in their own family and geographical area. The use of levels of hearing loss as the sole basis for decisions by parents may not be the most reliable for optimum deaf child outcomes, let alone desired futures. For example, we could never have predicted, based on his audiological status, that our son would attend mainstream school with full-time sign support, then want to move to a residential, specialist, oral deaf school then change to a sixth form at a grammar school with no signed input. Probable futures are those people say are likely to happen for deaf children, such as probable GCSE results based on the present trends for deaf children. Possible futures are what could happen where nothing is counted out or closed down. I wanted possible futures for my child, which is why I write about futures plural rather than future singular.

As parents we may have limited or no opportunities for meaningful conversations about the assumptions we make about futures for our deaf child. If our family, friends and community have little or no experience of being deaf, the possibilities for parents' thinking will be limited to considering what we already know (Bodner-Johnson, 2001). Parents need time, support and encouragement to reflect and think on an ongoing basis. Developing relationships with other parents with deaf children of different ages, as well as meeting a range of deaf practitioners/deaf people are vital ways for parents to see possible deaf-child futures for themselves.

References

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