



# The Lived Experience and Legacy of Pragmatics for Deaf and Hard of Hearing Children

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# The Lived Experience and Legacy of Pragmatics for Deaf and Hard of Hearing Children

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## abstract

In this article, we discuss deaf and hard of hearing (DHH) children's pragmatic difficulties and strengths from within the lived experiences of 5 hearing parents of DHH children and 5 DHH adults (one of whom is also a parent of a deaf child). We define lived experience as both a specific form of knowledge (first-hand stories from everyday life) and a unique way of knowing (reflecting and telling from insider perspectives). The parents and DHH adults involved coauthored the article alongside 2 experienced researcher-practitioners. Key themes include what pragmatic challenges feel like for a DHH person, why they arise, how they might result in longer-term consequences (such as implications for well-being) that can continue into adulthood, what might be pragmatic strengths in this population, and what might be done to ameliorate pragmatic difficulties. We end the article with reflections on the significance of individual parents and DHH adults in the coproduction and execution of research on this topic and make suggestions for future directions of inquiry.

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Dr Young conceptualized and designed the coauthorship approach to this publication, drafted the initial manuscript, and reviewed and revised the manuscript; Dr Szarkowski codesigned the approach to this work and contributed to the draft of the initial manuscript and subsequent revisions; Dr Ferguson-Coleman, Ms Freeman, Ms Lindow-Davies, Dr Davies, Ms Hopkins, Mr Noon, Dr Rogers, Ms Russell, Ms Seaver, and Ms Vesey contributed content to the article and reviewed the draft manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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As the parent and deaf and/or hard of hearing (DHH) coauthors of this article reflected, pragmatics is not a topic that is commonly discussed in their networks. The parent authors rarely, if ever, encountered the topic in discussions with professionals when raising their children. In sign language communities, the DHH authors reflected that the lack of familiarity with the term means there is yet to be an agreed-on sign for it. Yet the parent and DHH coauthors of this article have lived the additional struggles faced by DHH children in gaining age-appropriate pragmatic development, even if they could not have articulated it in those terms at the time. That lived experience has a vital contribution to make as we work toward better understanding how best to support age-appropriate pragmatic skills development for DHH children. Parents and DHH adults bring to this goal a particular form of knowledge (first-hand stories from everyday life) and a unique way of knowing (reflecting and telling from insider perspectives).<sup>1,2</sup> Deep understanding of the importance of the role of pragmatics as it relates to DHH children would be incomplete without their perspectives. We present that contribution here, in line with the increasing focus on what is termed patient engagement or patient-orientated research in North America<sup>3-5</sup> and patient and public involvement and engagement in the United Kingdom.<sup>6-9</sup>

## THE COAUTHORING PROCESS

Parent and DHH contributors were drawn from the United States and United Kingdom and approached directly through the professional and personal networks of the 2 researcher-practitioner authors (A.Y. and A.S.). Five hearing parents of DHH children and 5 DHH adults (one of whom was also a parent of a deaf child) contributed. The DHH contributors varied in their preferred language(s) and communication modalities,

including signed, spoken, and written languages, as did the children of the hearing parent contributors. There is, however, no claim that the group of authors is representative of the diversity of hearing parents and DHH adults; some authors are involved in leadership roles in parent and deaf organizations, whereas others have pursued advanced educational training. Given the significant physical distances between authors and the multilingual nature of the group (authors used spoken or written English, American Sign Language, and British Sign Language), the group agreed to offer their reflections individually to a set of common trigger questions. Responses could be written, spoken, or signed. Each author's reflections were then read, listened to, or viewed and captured in written language. Authors' reflections were shared among the entire group, allowing for feedback and clarification on the content as needed as well as for further development of ideas (eg, after reading another author's response, many authors shared additional revelations of their own or endorsed having had similar experiences: "That happened to me, too!"). From the initial reflections and responses to others' statements, the key points were determined. The structure of the presentation was initially drafted by A.Y. and A.S. Additional rounds of response followed in relation to both the structure and the content of the article. All participants reviewed and agreed on the final manuscript. Through these collectively unique insider perspectives, we set out to articulate why pragmatics in DHH children should be of relevance to medical providers and allied health professionals working to support DHH children and families.

## WHAT DO PRAGMATIC DIFFICULTIES FEEL LIKE?

Much of the literature on pragmatics is focused on the identification of linguistic and interactive features that

could suggest pragmatic difficulties and deficits. However, from our point of view and experience, a more immediate question is, "What do pragmatic difficulties feel like?" T.S. Eliot<sup>10</sup> famously remarked, "We had the experience but missed the meaning." That is what pragmatic mishaps and challenges are like. They are less about communication breakdowns or struggles to understand what someone says or signs (which might be more formally termed "deficits in functional communication and semantics").<sup>11</sup> Rather, these mishaps tend to be more nuanced. We share common experiences of that feeling of simultaneously understanding but not understanding, not quite "getting it," or becoming aware only after an interaction that something that may have been important was missed. We understood the content of particular communications, yet somehow we missed its intent and meaning. These experiences have consequences for a DHH person's feelings about their interactions with others.

*I recall, as a younger teenager, that a teacher complained in my school report that I was always asking if she was alright. I remember feeling thrown by this comment and trying to work out why I'd been so persistent in asking her about her welfare and came to the conclusion that it was because I was trying so hard to lipread her as well as read her face to interpret the whole message. At times this was incongruent with the "vibe" I was getting so the constant questioning was linked to my struggle to match verbal and emotional cues.*

DHH adult

## WHY DO FAMILIAR EXPERIENCES LIKE THIS HAPPEN?

We fully accept that many of the consequences of deafness can make the development of good pragmatic skills and abilities more challenging. For example, linguistic access to incidental learning is particularly difficult.<sup>12</sup> It is through engagement with a variety of individuals across

numerous contexts that children are exposed to and learn many of the social niceties and cultural norms for social interacting<sup>13,14</sup> as well as gain valuable clues about how others think and feel.<sup>15</sup> This does not work as smoothly for DHH children.<sup>16</sup> From experience, we note that the strong focus of professional services is on DHH children's functional language, which can be to the detriment the development of social communication, which is also vital. One of us, who is a parent, described pragmatics as "[the] missing link for DHH children who otherwise may have language and vocabulary on par with their hearing peers." We are not suggesting that pragmatic development should take precedence over language development, but rather we propose that they should not be separated; formal language and the social use of language are vitally interconnected in supporting the rounded development of DHH children. Unfortunately, in our experience, some kinds of professional interventions are focused on language development in isolation from pragmatic development, which does not serve DHH children and their families well. As one of the parent coauthors pointed out, if a DHH child speaks well yet does not understand the social implications of what is said, this is not a "job well done" unless accompanied by a "deeper social learning." One of the DHH coauthors emphasized that if professionals simplify their sign language when communicating with a DHH child, believing this will ensure clearer communication, they are also simplifying that child's experience of the world. Another pointed out from his experience that if academic achievement comes at the expense of social learning, it is not serving well the DHH adult that child will become.

*Challenges for deaf children in developing pragmatic abilities are underpinned by spoken language limitations—the spoken and the*

*unspoken. I wonder if the lack of exposure to everyday language, banter, teasing, and jokes in signed languages reduces the opportunity to define situations where dialogue can be taken too literally? Deaf people can be susceptible and gullible, more often than not, because the building blocks of pragmatics are not enabled when the language isn't there.*

DHH adult

The significance of pragmatic deficits and delays can come as a shock to parents and caregivers who have been focused on optimizing their DHH children's language development and may have only later started to appreciate this other aspect of their children's development, often through unexpected experiences. Importantly, however, parents can be resilient too, as the following example reminds us:

*I'll never forget sitting around the dinner table one night after my son's first day mainstreamed in the 5th grade. He was using a different communication access technology and could sit anywhere he wanted to in the room. With a bit of smugness, he announced to all of us that HEARING KIDS GET IN TROUBLE, TOO. Then he went on to share a story of a hearing kid who got called out by a teacher for doing something wrong—a typical situation in any classroom. That was when I first realized he regularly missed this common dynamic because he was always "preferentially seated" in the front of the room where he couldn't see or hear well enough to know what was going on behind him where the other students sat. I can tell you I was so shocked by this gap in his experience that I started a vigorous campaign of pointing out how bad hearing kids could be. I might have overdone that, but up 'til then, my son only experienced himself or other deaf kids as the naughty ones. I wanted him to know every kid could be naughty—even hearing kids! Especially hearing kids!!*

Parent

### PRAGMATIC DEVELOPMENT HAS CONSEQUENCES IN ADULTHOOD

One of us, in the process of reading and reacting to the coauthors' reflective responses to the trigger

questions, remarked, "I find I have a pragmatics hangover!" This hangover was an emotional one because of the process of thinking deeply about the topic in the context of her life experience as a DHH person. Involvement in this project made her realize how the challenges of pragmatic development in childhood had persistent effects in adulthood. Such challenges did not arise from misunderstanding the content of what was said but rather from missing its emotional meaning and not quite understanding its social import; even now, this could impact her confidence and sense of self.

*Even as a mature adult, there are times when I am in conversation with hearing peers who do not sign and I have a fluttering, stumbling sensation in the pit of my stomach in case I have missed any emotional contexts within the words that I am lip reading, and I struggle with not being able to fulfill my true self, which is, I hope, quite socially congruent and stable when I fully understand the exchanged dialogue in my own signed language.*

DHH adult

The author above was not alone in appreciating the longer-term impact of pragmatic skills on the adult self. All DHH coauthors, in different ways, established a link between pragmatics and well-being:

*[I]n social situations when someone is missing nuances and subtleties in social communication, it can have an effect on a deaf person.... We know that deaf people are already disadvantaged in terms of poorer mental health and emotional wellbeing, and so if their pragmatics skills are poor, it can mean they feel even more at sea, experience more difficulties, feel embarrassed and perhaps think all the hearing people there are laughing at them. If they "don't get it" they might look at themselves and think, "It's me, I'm the problem," which can adversely affect their self-esteem.*

DHH adult

These examples speak to a legacy, not necessarily of poor mental health (although this can be the case for some DHH children and adults<sup>17,18</sup>), but to the more global experience of

challenges to positive well-being<sup>19</sup> and life satisfaction.<sup>20</sup> Therefore, we wish to emphasize the key importance of developing effective strategies to combat those pragmatic difficulties and maintain positive well-being, what one DHH coauthor described as “a toolkit of compensating behaviours.” Furthermore, strategies can be acquired or taught through young adulthood and beyond.<sup>21</sup> Pragmatic development does not abruptly end at the conclusion of adolescence because the difficulties in reading social cues and appropriately contributing and responding may persist. Empowering oneself as a DHH adult to increase pragmatic skills is also possible.

*As a deaf adult, I feel much better now at “owning” such situations where something has broken down—and finding ways to repair it. This does come with time, but I think I would have welcomed someone saying to me as a deaf teenager that there will be times when you feel awkward or embarrassed in social situations—it’s fine and here’s what you can do about it.*

DHH adult

Parent authors emphasized that although overcoming such difficulties in adulthood could be seen as a work in progress, it would have been far better if those foundations were laid more firmly in childhood.

*I grew up as the sole hard of hearing child in my family, neighbourhood and school. I wish I had met other kids and adults who were like me early on, so I did not have to navigate the world alone and figure it out on my own. It was very important to me that I not appear “stupid.” So, I would often fake it in situations. I wish I was taught some coping strategies early on. This would have gone a long way in helping to develop real relationships. When you are spending a lot of energy trying to look like you fit in, you really do not fit in and have close friends and relationships.*

DHH adult

The insight offered below was from a parent who describes his child as “deaf plus,” meaning deaf with disabilities. In the passage, the child’s

“plus” attributes refer to the aspects of the child’s presentation that are separate from his hearing status alone.

*I wish I had known more practical applications at home. Ways to entice our child to develop this skill on his own as an older child. Link the benefits of mastering this skill to something that would be meaningful to him (increased friendships, better success in volunteer jobs, etc). Part of his “plus” attributes is having an underdeveloped awareness of himself in relation to others.... The importance of this skill...[should be] brought to his attention as JUST AS IMPORTANT in many cases, as his mastery of a class where he got a grade (or some other reward system that was important to him).*

Parent

### DHH CHILDREN AND ADULTS HAVE PRAGMATIC STRENGTHS TOO!

Parent authors and DHH adult authors alike identified key pragmatics advantages and strengths. The majority of these, we contend, derive from enhanced visual attention or attunement to social exchanges, whereby faces and body language are easily read. Discordances in emotional meaning that someone might be seeking to hide are more obvious to DHH individuals in their roles as observers of social interactions or as communication partners.

*My son’s greatest strength is...this super-human ability to grasp the emotional heft of a situation—always calling me out when he senses anxiety or sadness or some discomfort in me or others. And he’s always right. I assume it’s his visual acuity...scanning the room or group to see what’s happening and who is feeling what.*

Parent

These advantages, although perceived as gifts are, in part, a result of struggle. We see them as the hard-won gains arising from the effort, concentration, and relentless alertness required of DHH people in most social situations to check and double-check that they are understanding what is going on around them, what is being said, and what is intended.

### WHAT COULD BE DONE TO AMELIORATE PRAGMATIC DIFFICULTIES FOR DHH CHILDREN?

In our experience, pragmatic development is not a problem that requires attention only when clinically significant thresholds of delay and deficit have been reached. It is a focus that should be integral to how DHH children and their families are supported throughout childhood. Our experience is that this aspect of support and development is only rarely and inconsistently attended to; looking back, we wish it had been otherwise.

We identify good pragmatic skills as one of the most essential keys for DHH people to successfully navigate a world that confronts them with many challenges, many discriminations and, often, reduced opportunities. We believe that good pragmatics aids good relationships (within the family, at work, and in other settings) and makes the multiple routes to self-fulfillment easier to achieve. One parent author reflected on what she would say now to new parents of DHH children:

*Immerse your child in different opportunities and many different people. Don’t shelter them—let them explore the world and let them make mistakes. Ask open-ended questions of your child and help your child use language for different purposes. Respond to your child’s intended language and don’t try to fix their message. Set up role play activities that mirror situations your child may struggle with. Talk about feelings—a lot! Show interest in what your child is interested in and add language to what they see. Encourage lots of opportunities for turn taking activities and activities that encourage theory of mind development—don’t let your child always win and encourage lots of discussions about differing points of view.*

Parent

### CONCLUSIONS

In authoring together this contribution, we have become acutely aware as DHH adults and parents of

DHH children that this topic (pragmatics) is so rarely discussed among us and has been poorly understood. As an international community and through organizations such as the World Federation of the Deaf, the Deaf Leadership International Alliance, the Global Coalition of Parents of Children Who Are Deaf and Hard of Hearing, and Hands & Voices, we have the channels to open up this conversation and work alongside those researching and practicing in this field.

Our message to medical providers, allied health providers, and researchers working with DHH children and their families or with DHH adults is this: Use us! Work with us! Ask us! Our contribution is unique. It is not more or less special than that of any other interested parties, but it is different because we have lived this experience. Our knowledge, insights, reflections, contacts, and experiences can be put to good use in expanding this field of clinical practice and research to ensure that the needs of DHH children and their families are met. Collectively, we offer the following priorities for research and practice in this field:

1. In producing information on pragmatics for parents and DHH adults, remember we are great moderators of information aimed at us. We can easily recognize language or forms of expression that may be common in medical communications yet not readily understood by many parents or DHH adults. In addition, we know the vocabulary that we are accustomed to using and/or seeing and that resonates with us (eg, "hearing impairment" is not one of them). When we are involved in informing the content as well as the design of information, whether in a written or signed language, we are able to help facilitate information reaching its intended

target and being effective. Forms of knowledge codesigned by parents, for parents and by DHH people, for DHH people brings additional relevance and validity.

2. In the design of new assessments, tools, or interventions, parents and DHH adults also have relevant roles to play. Just as in this article, we are able to draw from our lived experiences to contribute to content, expression of ideas, and the design of the tool or intervention with valuable perspectives as the end users of those resources. Parents have grounding in the detailed practicalities of raising DHH children that enable us to contribute a view on whether a prototype assessment, tool, or intervention is likely to actually be used or be effective. This is important, for example, in the development of home-based interventions.
3. Our potential contributions to research studies include the use of our networks for recruitment of participants, the codesign of means of data collection to match participants' ways of knowing and understanding, contributions to data analysis when an insider perspective is useful, and dissemination and promotion of the results of research to user communities (ie, collaborating with parents of DHH children and with DHH adults throughout means that results are accessible and address their concerns).
4. Finally, we would like to see an extension of the kind of work we have showcased in this article. We wish to see more parents and DHH adults engaged in conversations about pragmatic development that can enable the research community to identify a range of issues and opportunities about this topic, leading to the formation of a repository of knowledge, ideas, and experience. This would

inform the development of information, assessments, interventions, and study designs as well as be of direct value to parents of DHH children and to DHH communities.

#### ABBREVIATION

DHH: deaf and hard of hearing

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