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Language, Identity, and Belonging: Deaf Cultural and Narrative Perspectives

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ABSTRACT

By acquiring an understanding of the cultural meaning of deafness and acting as a bridge to resources and opportunities, clinicians may better serve children and parents.

Hearing parents who learn that their child has hearing loss — especially those who are not familiar with deaf people and Deaf culture — may, in their shock and grief over the diagnosis, feel that a barrier has fallen between them and their child. Not knowing what life is like without hearing and not knowing how good a life it might be, parents may imagine only a profound and grave loss of the goodness that hearing constitutes in their lives. They may also find it difficult to imagine an easy and satisfying means of communicating with their child, and this lack of information and a complex imaginary of life with deafness may suggest to them that the very parental bond has been weakened or even broken. Understandably, depression sometimes follows the shock of a diagnosis of deafness. Kushalnagar and colleagues point out that this depression may isolate the child further: "A deaf child's poor communication skills may be made worse by increased level of parental depression."¹ Emmanuelle Laborit, born in France in 1972, wrote a narrative account of being deaf in a hearing family² and describes this initial shock and sense of separation: "My mother says she didn't know what to do with me. . . . She stopped talking to me. What was going through her head was, 'I can't even tell her I love her any more because she can't hear.' She was in a state of shock, stunned."³ Laborit's mother had no imaginary of deafness with which to embark on a relationship with a deaf child.

At the time of the diagnosis of deafness — and, in many cases, until parents begin to do research and to develop relationships with speech therapists, educators, and people who are deaf — the family's doctor is the primary, or perhaps even sole, source of information about deafness. Thus deafness is often viewed, as Kushalnagar and colleagues point out, "as a medical condition that has a technological solution." However, in contrast to this medical model, a social model of deafness (like the social model of disability) posits that deafness also has cultural and social meaning and that the negative effects of deafness are due to socio-cultural obstacles, such as discrimination and barriers to access, as well as physiological disorders. (Clinicians and medical organizations increasingly recognize the salience of social factors in disability and deafness.⁴) Clinicians can be a resource to patients and families in providing insights into these socio-cultural issues. Recent research suggests that parents would like healthcare professionals to provide a broader range of options and understandings of cochlear implants;⁵ it is also likely that parents would like the same sort of range of information regarding social and cultural understandings of deafness. Deaf people are not highly visible in our society, and representations of culturally Deaf people in popular culture are rare. This concept

of cultural Deafness — signified by the capital *D* in the term *Deaf people* — describes those who use sign language, identify with Deaf culture and history, and share in a rich social network. Those who are culturally Deaf tend to share an understanding of deafness as cultural difference rather than as disability. They see disability as an effect, not of hearing loss in individuals (the medical model), but rather of society's failure or refusal to accommodate their difference (the social model). Kushalnagar and colleagues reflect this understanding when they argue that choosing not to educate a deaf child bilingually "can create disability where none need be." Parents and physicians may not have ever considered deafness as a positive, or at least neutral, form of human variation rather than as a tragic disability. Viewing deafness as a tragedy, that is, purely in terms of loss, could have profoundly negative effects on the child. It is understandable that hearing parents with little or no knowledge of deafness might initially respond this way. However, alternative conceptions of deafness are available and can help both hearing parents and deaf children to adjust positively to the diagnosis and subsequent therapeutic and educational approaches.

Thomas Spradley's narrative about raising a deaf child in the 1960s offers insight into a perception of deafness as a tragic and disabling condition: "*DEAF!* The word hit me with unexpected force, as if someone had hurled an iron bar through a plate-glass window, shattering the protective screen of explanations I had erected for Lynn's perplexing lack of response to sound. . . . *DEAF-AND-DUMB! DEAF-MUTE!* The words came uninvited, set off like a chain reaction. I didn't know anything about deafness."⁶ Like many parents, Spradley and his wife, Louise, search for the best ways to communicate with and educate their daughter. Spradley describes the long route to learning about Deaf people and their culture, and his book powerfully advocates sign language as the ideal form of communication for deaf people. The title of his book, *Deaf Like Me*, quotes Lynn's initial, signed response when meeting other Deaf people for the first time, and reflects Spradley's emphasis on Deafness as a cultural identity as well as a physiological state. Spradley argues that, for him and his wife, "accepting Lynn meant more than communicating in her language, more than hoping that someday she might learn ours and become bilingual. It meant a personal involvement in that world which would surely become hers in the future — the world of deaf people."⁷ Spradley and his wife struggled to find the resources and opportunities they needed to learn about and from Deaf people. Clinicians may be a bridge to those resources and opportunities. They may better serve patients and families if they understand and can explain cultural Deafness to parents and represent not only arguments for the advantages of sign language, but also the potential for goodness in a life with deafness.

Kushalnagar and colleagues note many PCPs have "very limited experience in caring for children with hearing loss, and probably received little to no training in deaf issues," resulting in "advice that is based on misperceptions about deafness and deaf people," and that "information given to families is often inaccurate, incomplete, and/or equivocal." Clinicians who educate themselves and their patients via resources such as narratives,⁸ films,⁹ and encounters with Deaf people can offer a deeper understanding of "deaf issues." They can help parents develop a more complex imaginary of life with deafness and perhaps recognize the potential for "Deaf Gain" rather than hearing loss. Deaf Gain posits that deafness has the "potential to contribute to the greater good of humanity."¹⁰ Bauman and Murray say it reflects the goodness of life Deaf people experience and how deafness can be integral to a positive individual identity and community: "For most parents, the birth of a deaf baby conjures up anxious thoughts of isolation, limited communication, and myriad other difficulties for their child. But that is the old frame. The new frame, the frame of Deaf Gain, sees the baby not as a problem but as an asset. A family with a deaf baby benefits by being exposed to a new language and culture and to new people, ideas, and experiences."¹¹

This need to assert Deaf Gain and thus deliberately reframe the negative construction (for example, "a child with hearing loss") in a positive way (for example, "a visual child") reflects the assumption and social reality of deafness as a condition that makes life significantly more difficult. Deaf culture has a long history of oppression and marginalization; its strength as a social network derives from deaf people having been systematically excluded from hearing culture, from education and professions. In Deaf schools and social clubs, Deaf people shared resources, provided mutual support, and taught each other sign language. The core Deaf cultural value of interdependence derives from the need to compensate for a lack of accommodation by

hearing culture — discrimination and barriers to access persist today (for example, in healthcare¹²). Despite the obstacles, the disabling aspect of deafness disappears when a deaf person is fluent in sign and in the context of others who sign fluently. In this context, where Deafness is a social relation rather than a deviation from normalcy, Deaf people embrace the richness of their shared culture and language. Clinicians who recognize the deep socio-cultural value of Deafness, as well as the challenges of being deaf in a society that does not yet fully accommodate such difference, will help parents to consider whether their negative perceptions of deafness might drive them to make a child as "normal" as possible by focusing on oral communication and excluding sign language. Learning about Deaf culture and Deaf people may help clinicians and parents regard sign language — and life with deafness — more positively.

Here I will interject that my observations on Deaf culture are from an outsider's perspective. I am not d/Deaf. Thus I share the position of hearing clinicians and other experts who make judgments and recommendations about and for d/Deaf people, a position that evades the ethical imperative of self-advocacy and self-representation. This assertion, that one either has a Deaf cultural identity or does not, calls attention to the potential for cultural difference within a family. Hearing parents and clinicians may wish to avoid or ignore this difference in identity and experience.¹³ Nonetheless, it exists physiologically (as Kushalnagar and colleagues note, "the device still neither restores nor effects normal hearing") and thus in terms of identity. Knowing about cultural Deafness can help clinicians advise hearing parents about their deaf child's possible future, including communication through sign language.

An analogy may help clinicians understand the difference this cultural knowledge can make and how it can be implemented. Parents may respond with deep anxiety and fear upon learning their child has Type 2 diabetes. They may worry that the child will be isolated from family, the familial and broader culture, and from peers in school because of dietary requirements and the need for medication, monitoring blood sugar, and managing food intake and activity. Clinicians can reassure parents about their child's ability to adjust to the condition through education and support, and perhaps also by meeting others with diabetes. Clinicians can provide parents and children with resources — books and other literature, videos, meetings with patient educators — so parents and young patients can learn more about living with diabetes. Similarly, clinicians can reassure parents that their child will adjust to deafness and that there is a range of resources available. Clinicians who have educated themselves (and/or received training) in Deaf culture in healthcare (an area of "cultural competence" akin to those based on ethnicity) can represent to parents not only therapeutic resources, but also social and cultural resources: books and films, social service agencies, community Deaf self-advocacy organizations and social groups. Through such agencies and organizations, parents can meet with hearing parents of Deaf children as well as older Deaf children with and without cochlear implants who sign. Through such encounters, as well as through books and films that represent the lives of Deaf people, parents begin the "personal involvement" in Deaf culture that Spradley found so critical to his and his wife's acceptance of Lynn's deafness.

Spradley's narrative offers a way for parents to imagine combining sign and speech in a bilingual approach to education. For the first five years of their daughter's life, Thomas and Louise Spradley followed the advice of audiologists and educators to use a strictly oral method of communication and education. By age five, however, their daughter could recognize only a few spoken words and could not make herself understood to her parents. When Thomas Spradley first encountered sign language and Deaf people, he felt excluded by his lack of understanding: "A curious feeling came over me, as if I were in a foreign country, unable to speak the native language."¹⁴ Spradley and his wife worked through their discomfort, however, and, through friendships with Deaf people, they learned about sign language.

There is a common trope in narratives by Deaf people who learn sign language after years of a strictly oral method and who find sociality and community through sign: that the experience is transformative, life-changing, and the accounts at times resemble conversion narratives, expressing the profound depths of psychic re-orientation, and above all, a sense of belonging. Spradley's narrative reflects the parental perspective on this experience. In one evening, Spradley and his wife learned a few signs and how to finger spell, and, the next day, Louise began to sign to their daughter, "I love you." By the end of the day, Lynn had

learned to sign it back to them. Spradley describes his and Louise's tears of happiness as they share a phrase their daughter has never been able to speak to them and could not hear: "She had found her voice!"¹⁵ And through sign, their daughter first learned her name: "Of all the injuries that oralism had inflicted on Lynn, the most insidious had been to rob her of a name. We had unwittingly told her, 'You are not a person until you can see "Lynn" on our lips, until you can say "Lynn" with your voice. Lacking a name and a language to give it life, she could not say, 'I am someone. I am Lynn.'"¹⁶

Laborit's narrative describes a child's perspective on the profoundly transformative experience of learning sign, particularly the moment of claiming a signed name and identity. In her first parent-child sign language workshop, Laborit develops a signed name for herself, "Sun-Coming-From-the-Heart": "I finally understood that I had an identity. I, Emmanuelle. Until then, when I talked about myself, it was like talking about someone else. . . . There was no 'I.' 'I' was 'she.' . . . She discovered it with sign language, and now she knew. . . . It was like being born again. My life was just beginning."¹⁷ Laborit thus describes a Deaf person's self-realization through sign language. While this is only one account, it may help clinicians and parents recognize the benefits of sign language as well as oral education.

Spradley's account represents one initial response of hearing people to Deaf culture and signing: they feel excluded, as if in a foreign country without a language phrase book. Hearing parents may worry that if their child learns sign, they will become part of a foreign culture, apart from their child. But by learning sign — "out in front" of their deaf child, as Kushalnagar and colleagues recommend — parents can build a deeper bond with their child and enable connection to family and community and self-realization. Clinicians can offer hearing parents references to Deaf community groups, so that parents might, like the Spradleys, come to be comfortable with what at first seems like a foreign language and culture. Thus clinicians can move beyond a medical paradigm of deafness — as a medical condition with a technological solution — to an understanding of the value of cultural Deafness and of sign language as critical part of bilingual communication.

NOTES

1. P. Kushalnagar et al., "Infants and Children with Hearing Loss Need Early Language Access," in this issue of *The Journal of Clinical Ethics*.

2. Laborit wrote the book with hearing parents of deaf children in mind: "There are hearing parents who have deaf children and who don't know what to do with them. They have never read anything by a deaf person in terms of information." E. Laborit, "Writing My Life," *Sign Language Studies* 7, no. 2 (Winter 2007): 242-52, p. 242.

3. E. Laborit, *The Cry of the Gull*, trans. C. Mitchell and P.R. Côté (Washington, D.C.: Gallaudet University Press, 2002), 7.

4. L.I. Iezzoni and V.A. Freedman, "Turning the Disability Tide: The Importance of Definitions," *Journal of the American Medical Association* 299, no. 3 (23 January 2008): 332-4; R. Garden, "Disability and Narrative: New Directions for Medicine and the Medical Humanities," *Medical Humanities* (forthcoming, December 2010).

5. J.B. Christiansen and I.W. Leigh, "Children with Cochlear Implants: Changing Parent and Deaf Community Perspectives," *Archives of Otolaryngology — Head and Neck Surgery* 130, no. 5 (May 2004): 673-7, p. 677.

6. T.S. Spradley and J.P. Spradley, *Deaf Like Me* (Washington, D.C.: Gallaudet University Press, 1987), 19-20.

7. *Ibid.*, 261.

8. B. Bragg and E. Bergman, *Lessons in Laughter* (Washington, DC: Gallaudet University, 1989); H. Lager Cohen, *Train Go Sorry: Inside a Deaf World* (Boston, Houghton Mifflin, 1994); P.G. Jacobs, *Neither-Nor: A Young Australian's Experience with Deafness* (Washington, D.C.: Gallaudet University Press, 2007); and the narratives here.

9. D. Garey and L.R. Hott, *Through Deaf Eyes*, WETA-TV, 21 March 2007; B.J. Bahan, H-D.L. Bauman and F. Montenegro, *Audism Unveiled* (San Diego, Calif.: Dawn Sign Press, 2008).

10. H.-D.L. Bauman and J.M. Murray, "Reframing: From Hearing Loss to Deaf Gain," trans. F. Brizendine and E. Schenker, *Deaf Studies Digital Journal* 1 (Fall 2009).

11. *Ibid.*, 9.

12. L.I. Iezzoni, B. L. O'Day, M. Killeen, and H. Harker, "Communicating about Health Care: Observations from Persons Who Are Hard of Hearing or Deaf," *Annals of Internal Medicine* 140, no. 5 (2 March 2004): 356-62.

13. In a recent study, more than half of the parents interviewed saw their child as being deaf after the child received a cochlear implant; a significant number of parents of children with cochlear implants do not identify their child as either physiologically or culturally deaf. Parents thus assign deaf identity to their children, at least until the child is autonomous enough to do so her- or himself. See note 5 above, p. 675.

14. See note 6 above, p. 213.

15. *Ibid.*, 246.

16. *Ibid.*, 248.

17. See note 3 above, p. 34.