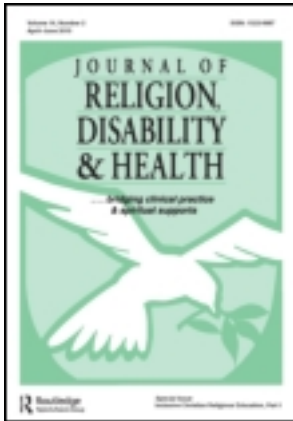


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Language Needs of Deaf and Hard-of-Hearing Infants and Children: Information for Spiritual Leaders and Communities

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Language Needs of Deaf and Hard-of-Hearing Infants and Children: Information for Spiritual Leaders and Communities

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Leaders of spiritual communities should support a family welcoming a deaf or hard-of-hearing child in such a way that the entire community offers the child genuine inclusion. The ideal situation for protecting mental, emotional, and spiritual well-being is to raise the child bilingually. The community leader can guide as the community participates in nourishing the child by providing information and suggestions for action. The community needs to understand deafness as primarily a condition of gaining a culture and language rather than sensory loss, so that family and others evolve from grieving the loss of their expectations of what their child's life might be like to looking forward with hope to the unique contributions that child can bring to the world.

KEYWORDS *deaf, hard-of-hearing, sign language, language access, early intervention*

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The anticipated birth of a child is accompanied by a great deal of preparation as the family rearranges everything from their living environment to their daily routine to welcome the newest member. In addition to these changes, parents find themselves imagining the child's life and projecting their thoughts forward to moments such as the child's first day at school, sports that the child might play, a role in the school play, religious rites of passage, graduation from school, falling in love, and marriage. While these flights of fancy are natural in the anticipation of a new child, they often follow the norms and shared experiences of a parent's own cultural expectations. When a family receives news that a child is different from those norms, they may experience shock and dismay. When this difference is hearing loss, parents often wonder how the hopes and dreams they have envisioned for their newborn can occur without the benefits of verbal and aural communication. Families naturally seek help and information on what to do in this moment when the usual script of life seems disrupted by this significant difference. Medical professionals are typically the first to provide information to families with a newborn with hearing loss. While their information may be helpful in explaining the science of hearing loss and the sorts of medical procedures that are available, the advice of medical professionals seldom satisfies the emotional and spiritual concerns of the family. Families with strong spiritual and religious backgrounds often turn directly to their spiritual communities for support in processing information and deciding what course of action to take. Even those who have become less attached to spiritual and religious traditions may return to such communities when experiencing significant life changes such as the arrival of a child or moments of profound uncertainty (Packer, 2000). The aim of this article is to provide members of spiritual and religious communities and their leaders with helpful information that balances the medical point of view on hearing loss and deafness with perspectives and approaches offered by those who view deafness as primarily a condition of gaining a culture and language rather than sensory loss. In addition, this article outlines a general framework for understanding the role of spiritual communities and their leadership in providing not only an environment of emotional support for the family and their new child but also a forum for ethical deliberation that assists the family in discerning a course of action that is best for their new child.

For this discussion, included under the rubric *deaf and hard-of-hearing (DHH) infants and children* are those who have an auditory impairment, whether permanent or fluctuating, that adversely affects their ability to engage in speech activities without amplification, as well as those who have a severe auditory impairment that adversely affects their processing of speech information with or without amplification. In layperson's terms, these children are frequently referred to as *deaf* or *hard-of-hearing*; this article applies to parents of deaf children and parents of hard-of-hearing children. Most DHH children (perhaps as many as 96%) are born to parents with intact

hearing (Moore, 2001). Most of these parents may initially know little about how to meet the language needs of their children, despite the fact that hearing loss is one of the most common birth disorders in America (Department of Health and Human Services, n.d.). Families, therefore, need advice, and they seek it from many sources, including, increasingly, the Internet (Porter & Edirippulige, 2007), but also primary care physicians (PCP) and religious, pastoral, and spiritual leaders (hereafter termed *spiritual leaders*) (Luterman, 1979; Gregory, 1995). Unfortunately, these sources are often underinformed or misinformed about deafness, Deaf culture, and the language needs of DHH children (Ralston et al., 1996; Meader & Zazove, 2005; Hecht & Staley, 2005); therefore they may give advice to parents that runs counter to the findings of recent research in linguistics, cognitive science, and psychology. Further, the PCPs and spiritual leaders may feel so unsure about the whole area that they hesitate to give follow-up advice at all after hearing loss is detected (Moeller et al., 2006). They often need such information themselves.

Many spiritual leaders who have obtained specific training in higher education turn to published reference resources for further information on unfamiliar matters. One common reference resource is the *Dictionary of Pastoral Care and Counseling* (Hunter, 1990), which provides background information on a wide variety of topics. If one looks up “Deafness” in this dictionary, the entry immediately refers the reader to “Handicap and Disability” and “Loss of Function.” In the entry on “Handicap and Disability,” information on pastoral care is given in general terms in an attempt to be applicable to a wide variety of disabilities. The definition of persons with disabilities is broad enough to include, “those whose disability or difference in appearance or behavior creates a problem of mobility, communication, intellectual comprehension, or personal relationships, which interferes with their social activity and/or participation.” (Hunter, 1990, p. 493) Such an extreme case of generalization conflates disparate experiences into one falsely unified category and obscures the distinctiveness of the cultural-linguistic framework that many deaf people use to articulate their being in the world. This conflation is further revealed in the discussion of objectification in language, “Because they have been named by their disability (i.e., the blind, the deaf, the lame, the dumb), rather than their personhood (i.e., persons with a disability or persons with handicapping conditions), they have been viewed as objects or recipients of care” (Hunter, 1990, p. 493).

While the dangers of dehumanizing language are worth consideration, this advice goes against many deaf people’s own descriptions of themselves as Deaf people with Deaf cultures. One simply does not find in the literature of Deaf studies a phrase such as “person with deafness.” Another entry in the *Dictionary of Pastoral Care and Counseling* on “Exceptional Children and their Families” also falls prey to this conflation of Deafness and disability. Included in the rubric for exceptional children are:

children who have social and education needs requiring individualized attention due to cognitive, emotional, or physical impairment or to superior intellectual skills. These include those who are mentally retarded, blind, deaf, crippled, or emotionally disturbed, as well as those who are gifted. (Hunter, 1990, p. 381)

The widely disparate nature of this categorization is unified by the common experience of a family needing to find additional community resources for a child who is notably different from the norms of their own society. Again, the dangers of overgeneralizing apply because, while general advice about seeking resources and challenging prejudices both within their spiritual community and in larger society are valid, no specific information about where to find such resources is offered and there is no intimation of the cultural and linguistic support that Deaf communities and schools can provide. A spiritual leader turning to this resource will not find the information needed to provide a family welcoming a DHH child with a well-rounded and full view of how their child can flourish in the world as a Deaf individual. Today, spiritual leaders may turn to the Internet and discover a vast array of information about Deaf identity and sign language (Table 1 notes useful web-based resources). As with all general Internet searches, the quality and validity of such information can be hard to sort out if one is unfamiliar with the topic. In addition, these resources often do not place the situation of a DHH child in a spiritual or religious context, leaving it up to the spiritual leader to attempt to bridge the gap between their spiritual tradition and an unfamiliar topic. There is a clear need for the development of more accurate and helpful practical information on deafness for spiritual leaders. This article seeks to begin to fill this void.

Kushalnagar, Mathur, et al. (2010) offer recommendations to guide the PCP and other medical advisors in this task. They argue that deaf children need regular and profound exposure to good language models in both visual and auditory modalities from the time hearing loss is detected and continued throughout their education. Not meeting the language needs of these children can have detrimental effects in many areas, including linguistic, cognitive, and educational development, whereas with the use of sign language, these areas can progress properly. Additionally, if DHH children have specific characteristics which correlate positively with the success of hearing aid use or cochlear implants (CI), auditory habilitation may help develop a facility and/or comfort level that can aid in education and open up personal and professional doors (Hanson, 1989; Sterne & Goswami, 2000; Nielsen & Luete-Stahlman, 2002; Luete-Stahlman & Nielsen, 2003; Goldin-Meadow & Mayberry, 2001).

Importantly, not meeting these language needs can also harm the psychosocial health and spiritual development of DHH children (Newport and Meier, 1985; Andrews et al., 2004; Schick et al., 2006; Leigh, 2009). Research

TABLE 1 Useful Websites for Families, for Professionals, and for an Introduction to Sign

For families:

www.clercschildren.com
handsandvoices.org/
www.babyhearing.org/index.asp
idea.ed.gov/
www.wfdeaf.org/
aslthinktank.org/
www.deafchildren.org

For professionals:

www.infanthearing.org/
gri.gallaudet.edu/
www.ahrq.gov/clinic/uspstf08/newbornhear/newbheares.pdf
aappolicy.aappublications.org/cgi/reprint/pediatrics;106/4/798.pdf
aappolicy.aappublications.org/cgi/reprint/pediatrics;120/4/898.pdf

For both families and professionals:

www.nidcd.nih.gov/
www.cdc.gov/ncbddd/ehdi/FAQ/questionsUNHS.htm#programs
www.asha.org/
www.nccusa.org/elmc/specificministries.htm#deafmin
www.nccusa.org/assembly/deaf.htm
www.deafwelcome.org (and write for information to ministries@deafwelcome.org)
www.silentwordministries.org/
deafness.about.com/od/religion/Religion_in_the_deaf_community.htm
www.jdcc.org (Jewish Deaf Community Center)
www.jdrc.org (Jewish Deaf Resource Center, NY)
www.deafhope.org/deafconc.htm
umcsignsofsolidarity.org/
www.millneck.org/
www.icda-us.org/
deafmissions.com/
globaldeafmuslim.org

For introduction to sign:

www.lifeprint.com/
www.aslpro.com/
www.handspeak.com/
www.funbrain.com/signs/index.html
www.asl.ms/

has shown that children with permanent hearing loss whose language needs are not met are at risk for behavioral problems, psychosocial disorders, juvenile delinquency, criminal behavior in later life, and reliance on the social services safety net (Northern & Downs, 2002; American Speech-Language-Hearing Association [ASLHA], 2004; Miller, Vernon, & Capella, 2005). Thus, in regard to the overall mental, emotional, and spiritual well-being of the child, it is important for spiritual leaders to be fully informed as they carry out the responsibility of advising families of DHH newborns and newly deafened small children.

Further, some of the decisions that parents must make regarding language for their child are time-sensitive and irreversible—since the linguistic mechanism in the child's brain needs to be nourished by 5 years old

or linguistic deprivation is risked (Lenneberg, 1964, 1967; Mayberry, 1994, 1998)—and these decisions come at a moment of emotional turmoil and vulnerability, when some parents grieve the loss of their expectation of having a normally hearing child (Kurtzer-White & Luterman, 2003; Steinberg et al., 2007). As a result, the parents may rely particularly heavily on a spiritual counselor in that moment. In fact, extremely strong reliance on spiritual leaders may continue for a prolonged period; depression is not uncommon among parents of deaf children, often for years, and research suggests that parental depression can worsen the deaf child's (often already poor) communication skills (Kushalnagar et al., 2007).

Parents of DHH newborns or newly deafened children need hope. Yet many medical advisors facing patients or parents of patients to whom they must deliver disturbing news hesitate to delve into the question of hope because they see the very discussion as stirring emotions and perhaps engendering false hopes, which may then actually impair the decision-making process on the part of those patients or their parents (Feudtner, 2009). As Feudtner argues, this hesitation may well be founded on the idea that hope is monolithic, and that if patients or their parents are asked what they hope for, the answer will be a miraculous cure. Instead, Feudtner has found that when a clinical advisor probes further about what the patient or family might hope for, when that advisor poses the question, "Given what you are now up against, what are you hoping for?" and then waits for an answer, other answers will tumble out, ranging from the miraculous to the mundane (Feudtner, 2009, p. 2307). Probe the parent of a DHH newborn or newly deafened child; parents do not just hope that their child will suddenly be able to hear. They also hope that the child will be able to communicate with others; will develop into a happy, healthy person; will be able to have a productive, satisfying place in society; and will have the joys of having friends, spouse, children—in other words, will have the same chances as hearing children. If patients and families are led to examine the breadth of their hopes and to understand that many of them are, indeed, realistic and well within reach given appropriate action, then a discussion of hope not only supports the patient and family in making difficult decisions, but also helps fortify their motivation to carry out those decisions (Feudtner, 2009, p. 2307).

Who better than the spiritual advisor to do this? Hope is certainly within the realm of spiritual and religious vocabulary. Nearly every spiritual tradition places a premium on the search for right relationships and a good life. While some religious traditions project hope into the future as something one works toward, others place hope in the context of discovering a balance between people, powers, and influences that allows one's full potential to flourish. In any circumstance, the anxious family's question of "What should we do?" about a DHH child can be met by spiritual advisors with a hopefulness that allows a family to adjust their hopes from one set

of norms to a new horizon of norms that allows them to seek a healthy and happy life for their DHH child. Who better than a spiritual advisor to help the patient and family see deafness not simply as an auditory state, but as a gateway into another language and culture and all the richness that follows? Certainly such a positive future requires positive action on the part of the family. In the context of open discussion of all aspects of the issue, including all emotional aspects, the importance of giving reliable, up-to-date, timely, comprehensible, complete, and unbiased information to support parents as they make these decisions is critical to the overall well-being of both the child and the family as a whole (Kurtzer-White & Luterman, 2003).

BACKGROUND

Readers are referred to the references cited in the article by Kushalnagar, Mathur, et al. (2010) and to Winefield (1987) for justification of the historical claims made in this section. For many decades now, parents have generally been advised to make an exclusive choice in raising and educating their DHH children: either a signing environment or an oral environment (including assistive technology, speechreading, and voicing). Most parents choose an exclusively oral environment. This is no surprise given that the parents are, for the most part, hearing (and thus familiar with hearing cultures but not so much with Deaf cultures) and that they trust the advice they get. The American Academy of Pediatrics has published several policy statements recommending early screening and intervention, accompanied by monitoring of the child's communicative, language, motor, cognitive, and social-emotional development, heavily concentrating on audiological input via habilitation and vocal output. Throughout, they stress protection of infant and family rights through informed choice. These policies consistently emphasize the importance of family decision-making regarding raising the child orally versus raising the child with a sign language, where the physician gives information, then steps to the side as the family decides what to do.

This emphasis on family choice reveals an underlying misconception about the nature of the relevant decisions; in particular, the decisions are not purely cultural, but involve important biological matters. Small children need frequent and regular exposure to accessible language; around the age of five the brain changes, becoming less plastic, and any child who has not had considerable language experience prior to that time will almost assuredly never reach a native level of proficiency in any language (Lenneberg, 1964; 1967; Mayberry, 1994; 1998). The language mechanism in the brain is biological, and the child whose language mechanism has not been nurtured with accessible language will experience linguistic deprivation, with profound socio-psychological effects. Preventing linguistic deprivation is as much a medical concern as treating diabetes is. No PCP would tell a family they had

a choice as to whether or not to give their diabetic child insulin; the child who does not get insulin has a great chance of experiencing mood swings (sometimes drastic), irritability, depression, and a range of physical maladies from blurred vision and high blood pressure to kidney failure. Likewise, a PCP should not tell a family they have a choice as to whether or not to give their child accessible language; that is, the biological language mechanism in the brain needs to be nourished—and not nourishing it causes biological harm. The child who does not get accessible language has a great chance of experiencing psychological isolation, irritability, depression, and a range of biological damages to their cognitive abilities, including poor memory and inability to organize information, gain literacy, or perform mathematical calculations—cognitive disabilities that could so easily be avoided (Brueggemann, 2008; Ronnberg, 2003; MacSweeney, 1998; Courtin, 2000; Courtin & Melot, 2005; Courtin et al., 2008; Morgan & Kegl, 2006; Rimmel & Peters, 2009; Russel et al., 1998; Schick et al., 2007; Figueras et al., 2008). Linguistic deprivation is a medical issue; physicians need not only to recognize this issue but also to actively promote early exposure to signed and spoken languages for DHH children. An early language access guideline has been created for these physicians (Kushalnagar, Mathur, et al., 2010).

The same is true regarding advice from spiritual leaders. If a spiritual leader were to see parents abusing a child, whether on purpose or from ignorance, it would be irresponsible to adopt the attitude that such behavior was family prerogative. After all, abused children disproportionately experience mental illness and/or feelings of worthlessness, and often engage in criminal activity as adults (Briere & Runtz, 1988; Bryer et al., 1987; Carmen et al., 1984; Favazza, 1989; van derKolk, 1989; Rimsza et al., 1988)—behavior that clearly indicates a lack of proper nourishment of the psychosocial-spiritual self. As such, this situation is exactly the kind in which spiritual leaders should regard it their responsibility to become involved. Just so with linguistic deprivation. Linguistic deprivation is not simply tantamount to abuse; it is abuse. It disrupts the proper psychosocial-spiritual development of the child, as well as the biological development of the language mechanism in the brain and, thus, the biological development of other cognitive mechanisms in the brain that rely on proper linguistic development. In addition, linguistic deprivation can disproportionately lead to the same range of aberrant behavior to which other kinds of abuse lead. The spiritual leader should assume the important role and responsibility of providing support to parents of DHH infants and children so as to ensure early language opportunities are made available to the children.

In many cases, a spiritual leader may be mandated by civil law to report suspected or witnessed abuses of children. While the legal standing of linguistic deprivation as abuse may not hold up under investigations initiated by such a reporting, the ethical judgment of linguistic deprivation as a form of abuse remains a legitimate concern. The various degrees and techniques

of intervention, reporting, and counseling available to spiritual leaders in any abuse situation are available, as well, in the situation of a deaf child facing potential linguistic deprivation. When caringly confronted with the consequences of linguistic deprivation, most families will naturally opt for reasonable solutions. At times, these solutions may not be apparent to them, or to spiritual advisors, because of the inadequacy of present policies aimed at ensuring that DHH infants and children have full access to language early in life.

The strongest piece of evidence that the present policies are inadequate—that is, the policies of urging the parent to choose just one modality of language for the deaf child and, in particular, the oral modality—comes from the extremely limited success America has had in meeting the language and educational needs of deaf children in the past century. The first school of the deaf in America was founded in 1817 (the Connecticut Asylum at Harford for the Education or Instruction of Deaf and Dumb Persons, which later came to be known as the American School for the Deaf), and the students at that school were educated in sign language (Sacks, 1989). Over the next several decades, similar schools of the deaf sprang up around the country, and deaf people who received an education at these schools achieved levels of literacy comparable to their hearing peers (VanCleve & Crouch, 1989). But in 1880, the Second International Congress on Education of the Deaf met in Milan, Italy, and promoted *oralism* (that is, the exclusive use of spoken language to educate deaf people) so strongly that sign was forbidden in many schools of the deaf. The results were catastrophic; most deaf Americans who went to school in the twentieth century never gained basic literacy to the point where they moved from learning-to-read to reading-to-learn. Part of this failure is due to late detection of hearing loss, a shortage of habilitation professionals, and lack of funding for appropriate programs and technology (Winefield, 1987), but even without such problems, deaf children have a high rate of communicative and educational problems (Marschark et al., 2007). The assertion in this discussion is that the general tendency in America of using only one modality of language with deaf children is not adequate (Padden & Ramsey, 2000; Strong & Prinz, 2000; Mayer & Akamatsu, 2003; Paul, 2003; Schick, 2003; Marschark et al., 2007; Wilbur, 2008; Chamberlain & Mayberry, 2008), and the general tendency in America of leaving the choice up to the family as though all modalities are equally advantageous with respect to protecting the child's ability to acquire language is pernicious. These parents will benefit from inclusion of family advisors with informed and strong advice.

DEAF IN A HEARING WORLD

Humphries (2008) traces the development of self-perception of the Deaf community (that is, the cultural community that uses sign as its most

comfortable language) in the United States. Humphries argues that two events allowed the Deaf Pride movement to form and thrive. One was the scholarly recognition of American Sign Language as a natural human language with systematic complexity typical of natural languages (which started in the 1960s and blossomed as of the 1980s). The other was the recognition by both d/Deaf and hearing people of the very existence as well as the richness of a culture founded on that language. Indeed, that movement can claim credit for laying the foundation for the recent (October 18, 2009) appointment of T. Alan Hurwitz, born deaf to d/Deaf parents, as president of Gallaudet University in Washington, DC, the most prestigious university for the Deaf in the world.

While the Deaf community, as “a group of people who live embedded within a much larger population of dominant others” has undergone “re-organization of the self” (Humphries, 2008, p. 4) in a thorough and highly promising way, the situation of the individual deaf person is a separate matter, as Leigh (2008; 2009) so clearly demonstrates. Social identity and personal identity are two different things (Cross, 1987). The 96% of deaf children born to hearing parents tend to be in a home environment without sign for several years at least (and sometimes forever), and receive their education in mainstream settings (Karchmer & Mitchell, 2011). Increasingly more of them are receiving cochlear implants CIs rather than hearing aids at a young age (Christiansen & Leigh, 2005). These children rarely are exposed to deaf peers and Deaf culture until they become old enough to seek such exposure on their own (if ever) (Andrews et al., 2004). Their attitudes toward their own deafness are strongly influenced by the attitudes of the particular professionals they come in contact with who specialize in working with the deaf (Mertens et al., 2000), and can range from viewing deafness “as a miniscule difference (not hearing), a stigmatized concept to be minimized, or as a significant core identity” (Leigh, 2008, p. 23).

Glickman (1996) talks about four ways a deaf person may view herself, originally proposing these as developmental stages in the formation of identity, although, in fact, deaf people may not go through all these stages and not necessarily in this particular order (Leigh, 2008). In one, the person is culturally hearing, avails herself of auditory rehabilitation techniques, and tries to be fully integrated into hearing society. In another, the person feels marginalized in hearing culture but is equally marginalized among deaf people, since communicating with either is extremely difficult in the absence of both a comfortable spoken language and adequate knowledge of a sign language. In a third, the person immerses herself in Deaf World and eschews anything to do with hearing culture. In a fourth, the person tries to find a viable way to interact with both hearing and Deaf cultures, essentially becoming bicultural.

Four identity categories are adopted by Maxwell-McCaw (2001) in the discussion of the psychological identification of deaf people in the United

States, looking at people who were born deaf or became deaf early in life. Maxwell-McCaw developed the Deaf Acculturation Scale (DAS) to measure the degree of acculturation of deaf people with both Deaf and hearing cultures, posing four types of acculturation—hearing acculturated, marginal, deaf acculturated, and bicultural (parallel to Glickman's [1996] four categories)—and found correlations between acculturation and psychological well-being. Deaf people who perceived themselves as Deaf acculturated and bicultural were more likely to report a higher sense of well-being than deaf people who are hearing acculturated. The group with the least psychological well-being was the marginal one (Phinney, 1992). The correlation between higher self-esteem and Deaf acculturated people, compared with all three other groups, was confirmed in Jambor and Elliot (2005).

Once more, language is the crux. Deaf acculturated and bicultural individuals—members of the two groups most psychologically healthy—are comfortable with sign. Hearing acculturated individuals are not comfortable with sign and show varying degrees of comfort with spoken language (specifically meaning speech, not written language). And marginal individuals—who show the most psychological problems—are not comfortable with any language.

The interaction between language, identity, self-esteem, and a sense of belonging also interact with spiritual and religious aspects of life. Dr. Mary Weir, a Deaf Canadian Christian theologian, became deaf at the age of 7 years and calls her current state of being, “God’s amazing gift of deafness” (International Ecumenical Working Group [IEWG], 1996). Rather than describing her deafness as a loss of hearing, she describes it as a gain. In fact, Bauman and Murray (2009; 2010) have coined the term *deaf-gain* to challenge the traditional understanding of d/Deaf people as defined by *hearing-loss* and to raise the question, “What do people gain from being d/Deaf?” Such an idea may seem odd to someone unfamiliar with Deaf cultures but may prove to be very beneficial in readjusting the perspective of a family welcoming a DHH child from one of grieving the loss of their expectations of what their child’s life might be like to one of hope for the unique contributions that child can bring to the world. Weir’s attitude goes beyond acceptance of her deafness and celebrates it when she states (IEWG, 1996, p. 2),

It has been in my adulthood that I have come to claim my deafness as a banner over my life and a blessing which I am called to honour and use for God’s greater glory. I chose and choose to be deaf, even though this particular gift of God has not always been to my liking. Deaf is who I am, and where I come from, deaf is more than not hearing—it is being a person of vision and touch. Perhaps it is that all deaf people need to come to choose their deafness—as a calling, a gift, and as essentially good creation.

Although this specific example is from a Christian context, Weir's idea of choosing to be deaf and understanding it as a blessing and a gift rather than a curse or infirmity can be sought in many spiritual and religious contexts. And this understanding can provide spiritual leaders a way to help families envision a healthy, vibrant, and socially connected range of identities for their DHH children rather than the imagined life of isolation and struggle that arises from the questions of how a deaf child will manage in a strictly hearing environment.

Every human being needs a language in which to feel comfortable:

... for it is only through language that we enter fully into our human estate and culture, communicate freely with our fellows, acquire and share information. If we cannot do this, we will be bizarrely disabled and cut off—whatever our desires, or endeavors, or native capacities.” (Sacks, 1989, p. 8)

To deny a deaf child the use of sign language is, in most cases, denying them a language in which they can be comfortable—a language to make friends in and tell jokes in and fall in love in. That child is often isolated.

Isolation can be extreme. As Brueggemann (2008), a scholar of Deaf Studies, noted:

I come to Deaf studies as a hard-of-hearing (the only term my family could use) girl from the extremely rural region of western Kansas; there are still less than twenty-five people per square mile in Greeley County, Kansas. I come as someone who didn't even know that sign language or, say, Gallaudet University existed (let alone a single sign or the idea of deaf education) until the age of 29. (p. 41)

But even deaf children born to signing deaf parents can experience isolation if they are thrust into a hearing environment without the proper support. T. Alan Hurwitz, the new President of Gallaudet University, was such a child. For 10 years he attended a residential school for the Deaf. Then he transferred to his family's local school system and was mainstreamed in a school that gave him no appropriate supports. He says,

How did I get through school? It remains a mystery. I admit I did not learn from class; instead my learning occurred outside the classroom where strong study habits and a passion for mathematics helped me through my high school years. I also believe my interest in athletics and sports helped me 'survive' public schools.

It is not a complaint, but rather a fact that I did not have many friends in school. Most relationships with my peers were superficial, like saying, "Hi. How are you? It's nice outside, etc." There were no meaningful dialogues with my peers, all of whom were hearing. (Hurwitz, 2009)

Imagine. Simply imagine.

Both of these people are talented with numerous skills and had loving and supportive families, and perhaps that is why they came through so well. But what about individuals with fewer natural and environmental supports who face such isolation? Siegel (2000, pp. 32–33) reports on how many mainstreamed deaf children are neglected “sometimes to the point of mental and emotional abuse” (quoting from Dr. Larry Stewart’s testimony before the U.S. House of Representatives, Sub-Committee on Select Education in 1989, reported in Siegel, 2000, pp. 32–33). Alternatively, hearing teachers sometimes “pity” their deaf students and are “flexible” with them to the point where the deaf students are not required to put out effort in their own education (Fisher & Mattiacci, 2008), a situation that does a disservice to the deaf students’ education and identity. Mainstreaming does not in any way guarantee membership of a deaf child in a classroom either academically or socially—what is needed is interaction that genuinely includes the deaf child—and that is, unfortunately, too rare in a mainstreamed classroom (Stinson, 2008). This demonstrated need for genuine inclusion in the classroom motivates some of the comments in the final section of this discussion addressing what the spiritual leader can do.

The alternative of sending deaf children to a bilingual-bicultural educational program, where classroom discussion can occur in sign language but readings can be done in the ambient spoken language (English, for example), would ensure educational opportunity and protect the right of the deaf child to have a comfortable language allowing full self-expression and full understanding of others—a language in which to simply be a social being (Fisher & Mattiacci, 2008; Lane, 1992).

Parents often balk at such a suggestion, particularly parents of children with a CI. Those raising their DHH child exclusively orally may assess their child’s progress as age-suitable, and decide that spoken language is the appropriate comfortable language for their own child. Research, however, shows findings contrary to this decision. Among children with CIs, those who receive no linguistic benefits (instead perceiving only noise) amount to approximately 21% (O’Reilly et al., 2008; Uziel et al., 2007). For the 79% of children with CIs who range from receiving minimal to substantial linguistic input (from being able to recognize alarm bells and fire engine sirens but not speech sounds, to being able to use the telephone), the device still neither restores nor effects normal hearing. No CI recipient gets benefit when the implant malfunctions or when the external apparatus must be removed, such as for sports events or sleeping (which can be interrupted by an emergency requiring communication). Without a doubt, their communication abilities need to be supplemented by contextual clues and speechreading, which makes language a constant task requiring focused attention and substantial effort. All these children need and deserve a language they can use with ease, just as hearing children do. So when parents judge spoken language to be enough for their child, they are overlooking a range of important information.

Proficiency in both expressive and receptive language, or access to appropriate accommodation, is necessary for full participation in a community. Children with hearing aids or CIs may speak proficiently (for CI users, the ones at the top end of the highly variable scale, see O'Reilly et al., 2008) but still struggle in the receptive end; they have to work hard to understand the conversation in the classroom. Even children with mild hearing loss experience such great cognitive demand in listening to others that they can get fatigued and be unable to sustain attention or process information at peer level, with detrimental effects on learning, and often, on behavior (Hicks & Tharpe, 2002). Further, the language gains of children implanted early are not maintained; soon implanted children fall behind their hearing peers (Marschark et al., 2007; Geers et al., 2008). (This contrasts with the situation of DHH children who sign, as noted in the next paragraph.) Additionally, a teacher faced with a CI user may assume the child needs no additional help and, so, may not offer it. Instead, in fact, the child may be experiencing cognitive overload at processing the abstractions, technicalities, and complexities of academic language and classroom discussions, thus the risk of underachievement is high (Baker, 1997). As Herbert (2008), an early CI user, explains, "... we [the mainstreamed deaf students] had to work harder to communicate and access information, compared to our hearing peers" (p. 133).

The deaf child who is asked to use spoken language exclusively is being taxed severely—and for what gain? Many studies show that deaf children who sign achieve better in school than those who do not sign, regardless of other factors (such as whether their parents are deaf or hearing and whether or not they have assistive hearing devices and/or oral training) (Wilbur, 2008; Allen et al., 2007; Schick, 2003; Paul, 2003; Mayer & Akamatsu, 2003; Padden & Ramsey, 2000; Strong & Prinz, 2000). Indeed, American Sign Language skill above other possible factors correlates strongly with reading achievement (Chamberlain & Mayberry, 2008).

Crucially, the child who is taxed in this way risks being cheated psychosocially and spiritually. DHH children need friendship and membership in a community in order to build a healthy identity and self esteem, just as hearing children do (Gaustad, 1999). But hearing children often reject the mainstreamed deaf child as lazy or stupid (Stinson & Liu, 1999) or express other negative attitudes toward these deaf children (Cappelli et al., 1995; Weisel, 1988; Gaustad, 1999). Certainly, appropriate activities and training of the relevant participants can help the situation (Antia et al., 2002; Foster & Walter, 1992; Gaustad, 1999; Kluwin & Stinson, 1993; Stinson & Liu, 1999), but such activities are not commonly undertaken. DHH children find themselves in an environment in which it is difficult to develop a healthy self-esteem, risking depression. Bringing deaf children into frequent and varied contact with deaf peers and adults and exposing them to good models in sign language so that they can become fluent signers is critical (Stinson,

2008). The child without a comfortable language, who has to struggle constantly merely to communicate, is at a disadvantage in terms of developing equanimity, inner harmony, love of both self and others, and the kind of openness that allows for spiritual development (Steiner & Von Arnim, 2008; Roehlkepartain et al., 2006; Yust et al., 2006).

The ideal situation is to have the child be raised bilingually. That means both signing and using the written form of the ambient spoken language. Additionally, the child should be exposed to spoken language, and, if the child shows good progress in both receptive and expressive spoken language, the child should receive auditory rehabilitation training. Bilingualism has great benefits for the deaf child in cognitive, social, and educational areas (Christiansen & Leigh, 2005; Wilbur, 2001). In fact, both the sign language and the spoken language of bilingual deaf children display more syntactic complexity than that of their monolingual peers (Klatter-Folmer et al., 2006). And the evidence that high proficiency in two or more languages results in more creative thinking in problem solving, and better mental flexibility and cognitive control that persists through late adulthood is firm (Bialystok, Craik, & Freedman, 2007; Bialystok, Craig, Klein, & Viswanathan, 2004; Baker, 2006; Prinz & Strong, 1998; Cummins & Gultstan, 1974; Kushalnagar, Hannay, & Hernandez, 2010; Lightbown & Spada 2006). All around the world children are raised multilingually, and the bilingual-bicultural trend for deaf education is a mega-trend (Kushalnagar, Mathur, et al., 2010). Dual proficiency in sign language and English affords the deaf child the benefit of adapting to both signing and non-signing peer groups with greater ease, resulting in better overall socio-emotional and behavioral development (Marschark, 1998).

WHAT THE SPIRITUAL LEADER CAN DO

The primary task of a spiritual leader in any context is to provide meaningful and practical support to the family welcoming a DHH child into their midst. To do that, a spiritual leader must be prepared to develop cultural competency in understanding and conveying the cultural and linguistic nature of Deaf lives. An entry on Cultural and Ethnic Factors in Pastoral Care from the Dictionary of Pastoral Care and Counseling suggests that, “the culturally fluent counselor will be aware of personal cultural biases, the cultural inclusiveness of operative theoretical framework, and the need for a repertoire of resources and skills to invite and sustain a working counseling relationship and communication process that is congruent with the client’s world” (Hunter 1990, p. 254). What makes this cultural fluency uniquely challenging in the situation of a family welcoming a DHH child is that, unlike a situation where a spiritual leader is providing care to an entire family from a culture other than his or her own, they are providing care to a family who is just emerging

into an awareness that they will now need to be a multi-lingual and multi-cultural family. Furthermore, they may find themselves struggling alongside this family with misperceptions and competing ideas both inside the spiritual community and in larger society about how this DHH child is to be viewed and what is best for this child's well-being. Therefore, it is vital that spiritual care be viewed as going beyond mere presence, prayer, and emotional support to provide a place where learning, growth, and change can occur; the spiritual leader must work to ensure that this community and society can be the best environment possible for this family and their DHH child.

Extending the action domain of spiritual care beyond the duties of the spiritual leader empowers an entire community to enter into learning, discovering, and discerning their spiritual-ethical approach to the issues this family and child will encounter. This broadened approach to the role of the entire community in spiritual care is complementary with Francis Schussler Fiorenza's (1992) depiction of Christian congregations as an ideal setting for the type of discourse ethics proposed by Jürgen Habermas (1983 [1990]), ethics not limited to only Christian environments. Habermas argues that money and power, rather than the meanings and values created through public discourse, are increasingly driving public policy. He proposes a discursive approach to ethics as a solution to this dilemma. Rather than basing societal justice on religious foundations or conceptions of the good life, Habermas envisions an arena of public and practical argumentation to establish moral norms (Fiorenza, 1992). The apparent rejection of religious foundations for defining justice is based on Habermas' view of religion as outdated worldviews based in authoritarian traditions that do not lend themselves to public discussion and critique. While such approaches to religion remain a part of public life in many parts of the world, Fiorenza (1992, p. 74) notes that in modern societies those who base their actions on religious beliefs are more likely to hold these beliefs because they have come to personally accept them as correct actions on their own reasoning rather than accepting them uncritically as a result of traditional authority. Fiorenza therefore sees spiritual communities as an ideal place for Habermasian discourse ethics. The normative functions of communal religious life that bring forth caring deliberations about what is just and good can provide a hedge against the domination of strictly money and power considerations.

Such a conception of spiritual communities can empower those communities and their leaders to become not only places where families welcoming a DHH child can find emotional and material support, but also forums for social discourse. In this manner, spiritual communities become a site where competing ideas about policies with profound implications can be discussed and modified in an environment that considers the full value of Deaf lives rather than being driven solely by economic and socio-political concerns. With such an approach, spiritual care is not solely the task of an individual spiritual leader advising a single family but, instead, involves the entire

congregation in transforming their community to discern what is just for a DHH child's upbringing and putting into practice what their vision for a better society entails. What follows are some practical steps that can be taken to embody a more just society. The practical steps extend from the information in this article about Deaf lives and from research on the role of accessible language in a deaf child's cognitive development.

First, disseminate information that becoming fluent in a sign language is crucial to the overall well-being of the child, from academic to personal matters. Second, promote bilingualism on the grounds of its extensive cognitive and social benefits. Let people know that if deaf children are raised with good linguistic models in both signed and spoken languages, they will have:

- 1) The assurance of acquiring language and thus being able to participate in all those things we call "humanity";
- 2) At least one language in which to feel at ease when communicating: one language that does not place undue cognitive load resulting from constant special effort;
- 3) The benefit of exposure to two cultures and expanded social opportunities;
- 4) Maximal advantage of visual clues in learning language skills, both receptive and expressive;
- 5) The potential to do better at school and to develop superior visuospatial cognition; and
- 6) The benefits of bilingualism for higher-order cognition and mental flexibility.

Other key actions in this regard are:

- Encourage families (parents and siblings alike) to begin learning sign language as soon as they find out their child has a hearing loss. It is not sufficient to learn sign language along with the child; the families should be out in front.
- Encourage families to expose the DHH child regularly and frequently to good signing models from birth on by taking them to Deaf events and bringing them in contact with Deaf peers and Deaf adults.
- Be proactive. Arrange events where Deaf and hearing can come together for the benefit of the children.

Some families may opt to join a religious group that has signing deaf participants, judging that their child will benefit more from getting spiritual education in a setting with other deaf people; some may not. In the case of families that choose to stay within their original spiritual community, encourage members of that community to learn sign language. Point out the benefits to the community as a whole of having a DHH child or children

among them, how the entire community's faith deepens when they open their hearts to new members of diverse needs and backgrounds. Make opportunities for DHH children to be included in a profound and meaningful way in the spiritual community through activities that fully engage them. Develop ongoing relationships with other religious groups that have DHH members. See to it that leaders of the relevant activities get the proper training to be able to ensure this, probably through working with a local deaf and hearing community service group. Find out whether any organizations supporting DHH members already exist in your religious or spiritual community, and work with them to the benefit of the DHH children.

Let the families of DHH children know that the breadth of their hopes can, in fact, be realized: their child can have a productive, satisfying, rich life. They are not helpless. The way to ensure that the child has the same opportunity for a good present and future as any other child is to ensure a firm linguistic foundation—and that is within the reach of any family.

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