Chapter 5
The Role of the Family: A Developmental & Literary Perspective

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Happy families are all alike; each unhappy family is unhappy in its own way.

—Anna Karenina, *Leo Tolstoy*

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All species have ways to protect their young and nurture them until they can fend for themselves. Some build or find protective structures, such as nests, hives or caves, to keep babies away from predators. Others are born with innate behaviors, such as clinging or imprinting, to maintain close proximity until they are mobile and can escape from predators on their own. In our species, the role of the family is to nurture children in an environment adapted to meet their developmental needs until they can adapt independently. When parents hear and have little direct experience with hearing loss, the behavior of the families and knowledge about how to provide an environment that is adaptive and nurturing to their child with hearing loss is not instinctive. And yet, without accessibility to family culture and language, development of a child is at risk.

This chapter is written from the perspective of a practitioner who has worked with families in centers and homes, individually and in groups, in urban and rural settings, mostly in the U.S., for over 40 years. Travel to India, Taiwan, Australia, England, Brazil, and the Middle East (ostensibly to support professionals in their work, but mostly to learn more about families)

added to an understanding of what is the same and different in families around the world.

The scholarly support for this chapter is provided by the work of psychologists who laid a foundation for understanding the growth and development of children in the context of their families. The work of Freud, Erikson, Bowlby, Brazelton, Bronfenbrenner, Skinner, Vygotsky, and Maslow—to name a few—are familiar to teachers who have had courses in human development. These psychologists developed theoretical models—later supported by empirical work—to explain how children ***and*** adults grow and develop, and the synergy and reciprocity that results from the interaction of caregiving.

The chapter addresses three questions:

1	What is known to be true about all families irrespective of variations in culture?
2	What are the inherent developmental risks for children who are deaf and hard of hearing (D/HH) and their hearing parents who adapt the environment to reduce those risks?
3	What can professionals do to support families in their role to aid in the full development of their children?

What do we know to be true about families?

Love and work are the cornerstones of our humanness.

—Signund Freud

Children are born into the culture of a family. Individual family members are understood by their interactions with others. Behavior and development of one family member is connected to others. Actions of an individual family member, therefore, will influence the behavior of others (Corey, 2017).

Parents around the world want their children to grow up to be healthy, independent individuals who can form relationships with others and contribute to their community. They want their children to know about life and culture as ***they*** understand it. Family values and cultural beliefs are conveyed to children formally and informally. Families shepherd their children through rites of passage preparing them for one qualitative shift to the next as they mature and develop into adults. Holiday and anniversary celebrations may be associated with special traditions, songs, rituals, food, or activities passed on in families from one generation to the next. Some rite-of-passage rituals are more formal and require special preparation and instruction from immediate family members, as well as members of an extended community, such as becoming a *bat* or *bar mitzvah* in Jewish communities.

Most cultures have rituals or ceremonies when two partners join for life. This event is a public recognition of the partnership, as well as a celebration of the strength and solidarity of the family. It also acknowledges the joining of two families. When children result from this partnership, their arrival symbolizes life, a sense of hope and future, and a legacy for continuity of the family (Lindbergh, 2012).

The family is the primary culture into which children are born and nurtured. ***Family*** includes the group responsible for raising the children and is best defined by the primary and extended caregivers. With maturation, families provide segue, support, and access to neighborhoods, schools, groups, and institutions that support the community at large.

Children learn about communication in the context of their families. Initially, the communicative message is conveyed nonverbally through sensory experiences associated with acts of caregiving. Feeding, diapering, holding, and soothing a baby provide opportunities for responsiveness and turn-taking that contribute to the reciprocity necessary for a healthy attachment between caregivers and infants. This early experience provides a foundation for future social and emotional relationships, as well as a context for language acquisition.

The hearing mechanism in a fetus is well developed by 5 months gestation. In utero, it is a stable distance from the mother's larynx for the next 4 months of her pregnancy. The fetus has consistent auditory access to the fundamental frequency of the mother's voice before birth. Expressive language begins with the birth cry. This reflexive sensory-motor act is soon refined and differentiated into vocalization that conveys different states of being, such as hunger, fatigue, pain, pleasure, and contentedness.

As caregivers interpret baby's utterances accurately and respond effectively, a communicative relationship forms, and babies further differentiate their utterances. Children acquire their native language by interacting with fluent users through caregiving and play. The process is natural, informal, and follows the same pattern of learning in all cultures using all languages.

Children who are D/HH, who are born into families in which the parents are also deaf, are born into an environment adapted that meets their sensory needs. Their parents live in an environment adapted to their capacity to hear that is like that of their children. If the parents use American Sign Language (ASL) to communicate, the communication mode is also likely to be adapted to meet their sensory needs. Their fluent native language (e.g., ASL), unlike spoken language, may be one that is entirely accessible through the sense of vision. Linguistic symbols may be adapted to ensure full access of face-to-face communication with the baby (i.e., baby talk), but the meaningful linguistic characteristics of the language are fully accessible to children who cannot hear. A diagnosis of deafness does not shatter any preconceived notion about their children's hearing status. Deafness is part of their identity, values, beliefs, and understanding of the world, and they convey that to their children. Deafness is integrated into the family culture. The developmental trajectory, path, and risks are different than those of children who are D/HH with hearing parents.

What are the risks for children & families when a child is D/HH?

Two or three out of every one thousand children in the U.S. are born with a hearing loss in one or both ears. The majority (90%) of those children have parents who can hear. When the sensory status of the child differs from other family members, full development relies on an adapted family environment and later an adapted community.

Growth and development patterns in early life depend on children's capacity to assimilate sensory experiences and organize them into meaningful patterns that contribute to their ability to adapt to the environment. When the sensory status of the baby is ***different*** from that of the family, the growth and development of the child—and the integrity of the family—are at risk. With little direct experience with hearing loss, it is difficult for hearing parents to imagine the nature of their children's perceptual world. Acoustic events that alert children to transitional activities are inaccessible to children with hearing loss until they have hearing assistive technology that provides access. Spoken language is transmitted through the sense of hearing. The linguistic symbols are not fully accessible to the child who is D/HH if the native language of the family is spoken. In an effort to provide children who are D/HH with an environment to meet their needs, the strain on family resources and integrity of the family structure is at risk.

Loss

If you look for perfection, you'll never be content.

—Anna Karenina, *Leo Tolstoy*

Any time events or information seem to change the imagined course of life, the experience is perceived as one of loss. Hearing parents commonly experience a diagnosis of their child's deafness as loss. Reactions to loss are characterized by grief. Feelings associated with grief include sadness, anxiety, depression, confusion, and a sense of being overwhelmed and disoriented. Unconscious psychological behaviors that protect the self from these feelings may present. Freud called them ***defense mechanisms***. Examples include denial, repression, rationalization, regression, etc.—terms and concepts that have come to have meaning in day-to-day life as individuals adjust to unexpected events and information.

Photo courtesy of NCHAM

Initially these behaviors are adaptive. They allow time to assimilate associated feelings, regroup, and make plans for the next step. These behaviors can become maladaptive, however, if they extend over a long period of time and become the primary mechanisms for dealing with loss. If they proliferate, psychological defense mechanisms can undermine intimacy in family relationships—preventing the acquisition of

knowledge and accessibility to resources that contribute to long-term adaptation for growth and development of both the child and family.

Most early intervention practitioners are aware of the grief associated with a diagnosis of hearing loss and the unevenness with which it is experienced in the family. As parents get to know their children, develop relationships with professionals, make decisions, learn about deafness, and begin to adapt their home environment to meet the needs of their family, behavior associated with grief is less observable.

How will the deafness affect them when they enter school?

Will it affect their ability to learn?

Their friendships?

Their confidence?

Their autonomy?

Their identity?

It can present again as their children move to a new stage of development. The effects of grief for parents at later stages in their child's development are usually more subtle and less influential in terms of parenting and caregiving.

What kind of sensory aids will their children use?

What kind of language will they learn?

What's the best way for them to learn in school?

In childhood, it is the parents who make decisions to manage the risks that hearing loss can impose on their children's development. These responsibilities begin to be shouldered by adolescents as they separate from their parents and develop an adult identity that includes deafness. The grief and loss experienced by parents early in their children's development can be experienced later in young adolescents as they begin to internalize the effects of deafness on their adult life. Just as the parents' grief diminishes as their children grow, so does it recede in young adults, especially as they form satisfying social relationships and find work that is fulfilling.

Erikson asked Freud . . .

"What is essential for a human being to have a happy life?"

Freud answered . . .

"*Lieben und arbeiten*—love and work." And the first of these, is love.

There is a story that comes from the field of human development about a conversation that took place between Erik Erikson and Sigmund Freud late in Freud's life.

Attachment

Bonding refers to the initial, intense relationship between a mother and newborn infant. Fueled by hormones and sensory experiences, it is an emotionally charged, overwhelming experience of affiliation between two individuals who have limited knowledge of each other—analogous to falling in love. Two people meet, are smitten, inexplicably drawn to each and in a state of temporary emotional insanity until they can learn more about each other and navigate the relationship to a steadier course.

Development, it turns out, occurs through this process of progressively more complex exchange between a child and somebody else—especially somebody who's crazy about that child.

—Urie Bronfenbrenner

As a result of Universal Newborn Hearing Screening (UNHS), newborns in the U.S. are screened for hearing loss before they leave the hospital. This timing is expedient for a public health effort to reach the greatest number of infants. Results of "referral" or a failure to pass the screening test, however, can be a distraction to initial bonding. It is probably not the best time for parents—who are just becoming acquainted with their infant—to receive information that undermines their trust in how they will get to know their baby.

Attachment refers to the enduring, long-term relationship that develops between a baby and caregiver over time. It relies on sensory feedback for each to adapt to the other's behavior and accommodate the change that takes place as babies develop and become more competent. Above all, the attachment relationship is characterized by trust, reciprocity, joy, and mutual satisfaction. T. Berry Brazelton—a pediatrician who applied attachment theory with the families and graduate students with whom he worked—provides an operational definition of ***reciprocity*** characteristic of attachment in caregiving relationships:

Reciprocity Characteristic of Attachment

"The ability to adjust to the goals and personality of others while retaining one's own identity is basic to reciprocity. This implies the ability to control or influence others with effective but nonviolating strategies and to be reasonably influenced by the other without being totally overcome or dominated."

Reciprocity is a characteristic of most working, intimate relationships.

An early, passionate start to an intimate relationship is exciting, a pleasure to experience, and gives the relationship a little boost. With attention, care, and commitment, however, relationships characterized by secure attachment can develop and eventually flourish in the absence of an initial bonding experience. And it is a good thing, especially for premature infants whose survival depends on being separated from their caregivers at birth and for those diagnosed with conditions that put babies at risk for long-term full development.

The early (Erik Erikson, 1950; Winnicott 1945, 1957) and later writings (Brazelton, 1983; Tronick, 2007) on caregiver-infant attachment refer to the importance of sensory-motor development in the beginning stages of the relationship. It is the sensory information from both caregivers and infants that provide feedback, so that the pair can adapt behavior for a more satisfying relationship characterized by reciprocity and trust. Caregivers trust their babies will provide them with information regarding their needs and state of being, and babies trust their parents to meet those physical and emotional needs.

Photo courtesy of NCHAM

The role of sight and vision is important at the early stages of attachment relationships when caregivers and babies are in close proximity and engaged in face-to-face interaction. Vision is directional, requires light, and is only possible when the baby has a clear view of the caregiver. Unlike vision, hearing provides omnipresent, omnidirectional information about the proximity of a caregiver. Even when out of sight, an infant or toddler has access to information about the whereabouts and availability of a caregiver that contributes to developing trust. So while UNHS may interrupt the initial bonding experience, early amplification can provide an infant with access to a caregiver's accessibility and reassurance even when not in view.

During a recent home visit, a hearing mother was asked if she noticed any changes in behavior when her 5-month-old daughter wore her hearing aids.

The mother replied . . .

"She makes more noise when she wears her hearing aids. But I also notice that she seems a lot calmer when I'm in the room with her, and she cannot see me. And she can follow her very active 3-year-old brother when he's running around the room!"

—Home Visit, February 22, 2017

Hearing caregivers talk and sing to their babies as they provide basic care of feeding, diapering, and comforting them. They do this without immediate feedback from the baby. With experience, babies respond to their voice, turn of phrase, or musical melodies. When parents believe that their children cannot hear, they are less likely to talk and sing to them (Gregory, 1995).

In a recent memoir, a mother of a child who is deaf ***and*** hard of hearing, who had professional training as singer, said at first it was difficult for her to sing to her children, knowing they couldn't hear her voice (Rosner, 2010). After getting to know and observing her children, she sang to them in her beautiful voice. Later both children developed an interest in music and singing.

Language & Cultural Access

For the purposes of this discussion, ***language*** is defined as a set of symbols that stand for concepts and a set of rules for selecting, combining, and ordering these symbols to convey meaning. Changing the order of the symbols changes the meaning conveyed. Language is used in a social context that reflects the cultural milieu of the people that are using it. A ***native*** language refers to the language used in the home ***or*** the surrounding home culture or community.

To speak a language is to take on a world, a culture.

—Frantz Fanon

There are some obvious conditions necessary for successful language acquisition. The linguistic symbols must be accessible to the user. In spoken language, the person must hear well enough to differentiate the sounds of speech patterns. The people using the language must be *fluent* users. There should be a comfort and ease associated with the use of language. Temperament and aptitude can be contributing factors in an ability to acquire and use language. Some people have a talent for it.

The greatest risk for children who are deaf born into hearing families is that of learning language. Incomplete sensory access to spoken language puts acquiring language of the family at risk. The elements of spoken language are not entirely accessible through vision. Children cannot learn to understand spoken language if they cannot hear the melody or discriminate the elements of speech. Critical movements of the speech mechanism are not visible. Speech production requires hearing to gain control of the speech mechanism and produce clear speech.

This makes a very good case for providing children with a language that is accessible through the sense of vision. It is manageable for hearing parents to acquire some basic signs early in their child's life to support their spoken language with visual symbols. Sign-supported spoken language, however, does not have the same characteristics of a language like ASL. ASL, with its own semantics, morphology, and syntax, changes over time to reflect the way it's used in different communities—usually deaf communities. For families seeking an ASL approach to communication for their child to have access to the nuances of and acquire fluency in ASL, parents need interaction with communities of adults who are deaf who use ASL for a richer, fuller linguistic experience in ASL. Early intervention professionals can provide connections to these communities. Extended family members who wish to communicate directly with the children who are deaf need similar experience with fluent users of ASL. The prospect of finding that sort of group is more likely in densely populated urban settings but less likely in rural settings.

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During much of the 20th century, families sent their children away to live in residential schools for the deaf, so that they could learn language, literacy, and academic skills. Some used sign language; others use spoken language. Irrespective of mode of communication, these self-contained communities were adapted to meet the sensory, linguistic, and learning needs of children who were D/HH. With limited technology and a low incidence of deafness demographically, this was often the best choice families could make for the future of their children who were deaf. The choice of mode of communication may have been limited depending on the philosophy of the schools for the deaf in their region. And in all cases, families forfeited involvement in the day-to-day lives of their children.

In the 21st century, families have ***real*** options in the communication choices they make for their children. Technology is not perfect and does not restore hearing, but most children in industrial countries can have reasonable, early, consistent access to sound that is adequate enough to provide them with the sensory feedback necessary to learn spoken language. When sensory aids are appropriate, and children have auditory access early in their development, the process of language acquisition can mirror that of hearing children.

A number of laws were passed in the later part of the 20th century (e.g., Chapter 766 in Massachusetts, P.L 94-142 nationally) leading to the Individuals with Disabilities Education Act (IDEA), which is directed to providing educational services to all children near their home communities. The advantage is that ***all*** children can go to school near enough to home, so that they can be part of daily family life. The risk is that finding well-trained, experienced teachers of the deaf to serve potentially every school district in the country is difficult. Teachers of the deaf are teachers of language. Some specialize in sign language, some in listening and spoken language. But the goal is for them to continue what families have started in the early years, so that children become literate and academically competent in school. With the decentralization of education of the deaf, the responsibility for ensuring an appropriate educational program falls heavily on the parents.

Language and culture are interdependent, inextricably entwined. Linguistic dialects of a particular region reflect the differing cultural nuances of the area. Sometimes families decide to use a language with their children that is different from one used in mainstream culture. Many give intellectual consideration to this decision. Nurturing children, providing them with support and reassurance, however, is not an intellectual activity. Making an intellectual choice to use a language with which they are not intimate and fluent usually means impoverished communication (with regard to language) and reduces the access children will have to the culture that is important to their parents.

Integrity of the Family

Families need families. Parents need to be parented. Grandparents, aunts, and uncles are necessary. Stresses on many families are out of proportion to anything two parents can handle.

—T. Berry Brazelton

In this statement, Brazelton is referring to the stress of raising typically developing children. The stress increases dramatically when a child has a hearing loss. As families make adjustments and accommodations to ensure accessibility for their child who is D/HH, resources may be strained—putting the family itself at risk. There is additional emotional strain. A diagnosis of hearing loss can throw a family into a world of unfamiliar concepts, terminology, technology, opinions about sensory aids, approaches to communication, and political and ethnocentric arenas that tug at the fiber of what it means to be human.

There are financial burdens. Hearing aids and cochlear implants are expensive, require maintenance, and clinical support, and technological advances dictate replacement and ongoing costs. And finally there is the logistical and physical strain of getting to appointments, support services, and ensuring that results become available to extended family members and the educational team.

The support of extended family members at all levels helps greatly to reduce the stress on the nuclear family. Grandparents, aunts, uncles, cousins, and family-like friends can provide material and emotional support that reduces the burden that otherwise would fall solely on primary caregivers. As parents meet other parents of children who are D/HH, they too can support each other as they travel through a similar emotional space and experience in raising children who are D/HH in a hearing culture. Contact with other deaf adults helps them learn about their own children in the context of their hearing loss.

As education of the deaf has become decentralized, and early work with families is practiced in a "naturalistic environment," usually the home, opportunities to meet other families who have children who are D/HH, and gaining access to deaf communities is more challenging. Both of these groups—in addition to extended family—are helpful in terms of providing support, affiliation, and sometimes material care of children and adults.

These are some of the risks for hearing families raising children who are D/HH in a hearing world. What can professionals do to help families manage the risks and fulfill their role to nurture their children in an environment adapted to meet their needs?

What can professionals do to support families in their role?

Relationships within families are intimate, close, and private—the nuances of which are seldom completely accessible to individuals and communities outside of the family. The developmental risks imposed by hearing loss are significant enough to warrant intrusion by outsiders—with specialized knowledge and expertise—to support the family.

Photo courtesy of NCHAM

Effective practitioners join the family system as they are received and begin a partnership of counseling, coaching, teaching, and learning together in the context of the family system. In the beginning, some professionals may work with families in their homes. It is important to respect and honor an invitation to participate in the intimacy of their family.

Clinicians and teachers are trained to ***do*** things to change the behavior of the children with whom they work. They learn to demonstrate, model, rehearse, intervene, give feedback, and provide didactic instruction to promote learning behavior. Success is measured by the children's progress. In working with families, the goal is similar—to advance the behavior and skills of the children, so their development in all areas is synchronous.

The locus of control, however, is different—it is the caregivers who are responsible for the change in the children's behavior. The practitioners/professionals support and coach them, so they can provide an environment for their children that is perceptually and linguistically accessible to ensure full development. Practitioners mediate the children's growth and progress through the relationships they form with the primary caregivers.

Teacher-student relationships are inherently authoritative in nature. One member of the dyad is more knowledgeable, skilled, experienced, and more powerful than the other. There must, however, be some level of parity in the relationship that allows students to take risks and grow. Erik Erikson in his theory of development called this ***trust***. T. Berry Brazelton calls it ***reciprocity***. Brazelton's definition of reciprocity in an attachment relationship is also basic to a successful partnership, like the one that develops between a practitioner and parent.

Good, succeeding relationships between two individuals require each participant to observe, organize, evaluate, and respond to the behavior of the other. Participants make adjustments in their own behavior based on observations and how they interpret the behavior of others.

The behavior . . .

- Is the evidence that we have to make a judgment about our effectiveness in influencing the other person in the relationship.
- Is the evidence that allows us to make adjustments in our behavior, so that we can continue to influence the other positively.
- Permits us to make inferences about how a human being is changing and developing in response to our interaction with them.

So what can professionals ***do*** to support families in their role? They can listen, learn, love, coach, and enjoy their work and the families.

Listen

At heart, we are grief workers.

—David Luterman

Teachers or clinicians who prepare professionally to work with children who are D/HH are acquiring skills and a scope of practice to reduce the risks that hearing loss can have on the development of children and their families. They are not preparing to be "grief workers."

David Luterman originally trained as a diagnostic and rehabilitation audiologist, but his enduring contribution to the field of deafness and communication disorders has been to help practitioners understand and be present with the loss families feel at a diagnosis of deafness. He worked with parent groups around the world and found that "grief is not culture bound or disability specific. It is endemic to disability" (Luterman, 2011).

In a hearing family and culture, deafness is a disability. Parents struggle mightily to reconcile the loss often with feelings of guilt, sorrow, and shame—all of which may go unnoticed and unacknowledged by practitioners. These feelings are important in adults coming to know themselves in relationship to their children, but when they are new and unfamiliar, academic learning and knowledge is difficult to hear and assimilate.

Professionals can help by listening. Relationships are formed and maintained by listening. Listening is an active process requiring the listener to be attentive to the speaker's nonverbal and verbal behavior without judgment. Listening allows one to form a relationship characterized by reciprocity with another person—the kind of relationship in which an individual can effectively influence the behavior of another without violating or compromising that individual's autonomy.

A goal of practitioners is to support families in making informed choices about their children. This situation seems like it calls for providing information, evidence, data, talking, and lecturing. Effective, confident professionals are less controlling of the learner's behavior in their interactive style. They ***listen***. By listening, the practitioner has an understanding of when and what the parent is ready to learn. Listening helps the parent to figure out what is important in terms of

decision-making. It is, after all, the family that lives with the long-term benefits or consequences of the decision, not the practitioner.

Listening is a powerful clinical and pedagogical tool. Listening elicits a sense of power and confidence in the speaker, because it requires the listener to be submissive and available. It supports parents who may feel anxious and lack confidence in their abilities to meet the needs of their children. Listening reduces distractions for the speaker who may be overwhelmed or confused. It provides an opportunity for marshaling inner resources that will fuel them in caring for their children. An active listener pays attention to the congruity between verbal and nonverbal behavior and looks for patterns in conversation that may reveal underlying concerns or questions that prevent a parent from moving forward. Active listening is work. It's working when the listener (practitioner) is tired, and the speaker (parent) is energized and ready to take action.

Love

Respect was invented to cover the empty place where love should be.

—Anna Karenina, *Leo Tolstoy*

Respect and understanding is a basic requirement for a working relationship in any realm—at school or work, in social groups, among friends, in neighborhoods and communities, and within families. Respect allows us to feel safe, open, and transparent in our interactions with others. It allows us to take risks and accept criticism necessary for learning and growth. Respect is a minimal requirement in a relationship. It is not love.

Teachers—recognized for how well their students learn—love their students. They take pleasure in their talents and curiosity, acknowledge and accept their frailties, and are committed to helping them fulfill their potential as learners. Supporting families to reach their potential as providers of nurturing environments for their children requires love—selfless, unconditional, positive regard for and belief that the family has or can reasonably acquire the resources necessary for the job at hand. Rescuing families from great distress is not usually possible, at best provides only short-term relief, and engenders a sense of powerlessness when the next crisis arises. Confidence and belief in a family's potential to nurture their children—and listening to them with acceptance and support—engenders feelings of capability to care for their children. It is that care that leads the children to grow and thrive at all age levels.

Brazelton talks about the effects on infants . . .

"Every time you give a parent a sense of success or empowerment, you're offering it to the baby indirectly. Because every time a parent looks at that baby and says, 'Oh, you're so wonderful,' that baby just bursts with feeling good about themselves."

It is fairly easy for teachers and pediatric clinicians to love children. Often it is their puerile nature that draws practitioners to the work. It is more challenging to love adult caregivers in distress—feeling overwhelmed, inadequate, and struggling with their role in their family.

Norman Fischer (2014)—a Zen Buddhist priest and poet—talks about love and the difficulty of practice in work and real life . . .

"This [love] doesn't happen by itself. It takes attention. It takes commitment, continuity, and effort. It won't come automatically. It won't come from wishing or believing or assuming. You are going to have to figure out how to not get distracted by your personal problems, by your success, or your lack of success, by your needs, your desires, your suffering, your various interests, and keep your eye on the ball of love, even as inevitably you juggle all the rest of it."

Love is the catalyst that ignites teaching and clinical skills to elicit empowerment, change, and learning in families who are gathering their resources to care for their children.

Learn

One learns about a culture or family by listening and observing behavior. The more a practitioner considers the values of the family culture, the more they can support parents in the role of nurturing their children.

I think . . . if it is true that there are as many minds as there are heads, then there are as many kinds of love as there are hearts.

—Anna Karenina, *Leo Tolstoy*

Initially . . .

How does the family relate to the practitioner?
How do they communicate about logistical, practical aspects of the relationship?
How easy is it to plan jointly?
Are appointments canceled or rescheduled regularly?
Who attends or meets with the practitioner?
Do the participants vary?
Is extended family included?
How open, revealing, and genuine are caregivers with the practitioner?

This information begins to accrue as the relationship develops.

Then . . .

What is important in family life?
Who are the primary players in the day-to-day life of the children?
How do they interact and communicate with each other?
How are basic family needs met?
What seems to be the priority of need?
Are parents available to care for the child, or does that responsibility fall to someone else?
What are the daily stressors for a particular family?
What are the resources?

In assessing the truth about family culture, it is better to observe than survey the family for information. What family members say or feel has relevance but can be affected by transient, episodic events external to family life. What family members ***do*** and how they behave provides a truer picture of family culture. Observing patterns of behavior, the division of labor, who fulfills particular roles, the communication lines and medium among family members may help families identify resources that they might otherwise overlook. In learning about a family, the goal is to find out what they want for their children. Only then can the practitioner coach parents effectively towards that end.

Coach

A failure is not always a mistake. It may simply be the best one can do under the circumstances. The real mistake is to stop trying.

—B. F. Skinner

A practitioner who works with a family at home in an early intervention model or a teacher of the deaf on an educational team that supports students in inclusive settings functions in the role of consultant and coach. The actual time spent in direct contact with the infant, toddler, family, or student is a very small percentage of their waking, active hours at home or at school. In the case of early intervention, it may consist of a home visit with a family and child, one to two hours per week. To be effective, caregivers must partner with the practitioners. With guidance and support from the professional, the caregivers lead the charge. Shelden and Rush (2005, 2006, 2010, 2011) have some excellent practical, accessible information and guides for coaching families. The first step in a coaching model is to help families describe outcomes they wish for their children. Together practitioners and caregivers construct goals that will lead to that outcome.

The next step is to coach caregivers in addressing the goals. Parents and practitioners jointly plan activities that address behaviors related to the goals. Practitioners observe parents during the activity. They ask caregivers to reflect on what happened while they were interacting with the child. What worked? What did not work? What would they change (i.e., how would they do it differently next time)?

Practitioners provide feedback to enhance the caregiver's reflections and call attention to what may be important in terms of a qualitative shift in behavior. They may add observational insight based on their skill and professional training. Then both practitioner and caregiver jointly plan the next step or strategy to refine, enhance, or rehearse a particular behavioral pattern.

Coaching is an active, dynamic process characterized by dyadic exchange and reciprocity and is not hierarchical in structure. As children advance, and their capacity for developmental potential becomes clearer, it may be necessary to revisit the validity of the original goals. Based on their training and expertise, professionals may observe these qualitative changes in behavior sooner than the caregivers. It is incumbent on them to lead caregivers in their observations, so that they can make adjustments in their vision for their children.

The goals and expectations for the children and families must be established and embraced by the caregivers. When the goals of the practitioner are misaligned with those of the family, everyone fails. The children cannot thrive without the support of the family, the family feels bad about their ability to fulfill their role, and the professionals feel like they have fallen short of their responsibility. Listening, acting, reflection, feedback, and joint planning keep everyone in step. When hurdles present, or there is a clearing in the developmental path, the family and coach can move forward together.

You have to enjoy what you're doing. You won't be good if you don't.

—Mihaly Csikszentmihalyi

Enjoy

Working with families is layered, complicated, dynamic, and can be quite challenging, depending on the needs of the family. It is also creative, exhilarating, purposeful, and can be a source of professional joy and fulfillment. The practitioner who works with families with children who are D/HH must have knowledge and skills in human and language development, speech and hearing science, and psychology and sociology of deafness. To enjoy and succeed at this work, knowledge of self is equally important.

Boothroyd & Gatty (2012, p. 220) observe . . .

"Entering into family relationships requires an interesting mixture of arrogance and humility . . . the best advice for professional preparation is to make sure your own emotional house is in order before trying to intervene in someone else's."

Practitioners need to be genuine, authentic, and real in their interactions with families to develop collaborative, trusting relationships. The relationship requires both participants to be interested, engaged, and available, so it is important for practitioners to model that behavior with the families with whom they work. Values root us in our own history of family life and influence how one works with families. Practitioners need to be aware of their own biases, attitudes, and develop an awareness of their values and cultural beliefs, so they are free to welcome and learn about those the family has to offer (Corey, 2017).

Self-care in working with families is not a luxury—it is an ethical mandate. One needs vitality to maintain relationships that require availability, support, and compassionate coaching. Self-care includes regular exercise, eating and sleeping well, and recreation. Some families manage more than a reasonable amount of stress with limited resources. It is good to know when a situation calls for professional reinforcement, collaboration, and supervision, so that practitioners can continue to maintain their availability to the family.

Families are the best resource in protecting and nurturing children until they can adapt on their own. Working with families to help them fulfill their role as caregivers is helpful, purposeful, and meaningful. The work is related and connected to engagement in the difficulties as well as the joys of family life, and the work itself is fun. It includes playing, eating, creative problem solving, and sharing moments of despair and ones of hope and celebration. It is a pleasure and privilege to contribute to and witness the growth, confidence, and autonomy acquired by primary caregivers, extended family, and of course the children. Enjoy the experience. The outcome is better for everyone.

Photo courtesy of NCHAM

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