Family Context and Disability Culture Reframing: Through the Looking Glass
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It is estimated that, in the United States, 12% of all children and youth have some form of disability (Garbarino, 1987) and 10.9% of families with children have one or both parents with a disability (La Plante, 1991). Despite the commonality of disability in families, the family therapy field has devoted remarkably little effort to serving or developing theory that is useful for clinical work with such families. The intervention that does occur tends to lack balance regarding the disability issues; it tends to fixate on disability and disregard other issues or to avoid disability issues as if they were unspeakable. The field also tends to pathologize families with disability issues either through the misunderstanding that disability experience consists of unrelenting trauma and loss, or through obliviousness to the degree of trauma and oppression that does exist.

There is a need for acknowledgement of the stressors as well as the day to day negative societal suggestions that have impacted and do impact such families. Without this awareness reactive responses are often interpreted as due to intra-psychic or intergenerational, intrafamilial pathology. Family intervention needs to incorporate, therefore, the societal dimension: an awareness of the resonance of the personal and cultural experience of disability. As in cross-cultural work with families of color, therapy with families with disability issues needs to take into account the oppressive societal context as well as to utilize strengths of the culture. It can draw upon the disability community’s rich cultural antidotes to socially derived problems.

The disability civil rights movement of the early 1970’s (also known as the independent living movement) reacted to the pervasive impact of the medical model on
people with disabilities. Historically, people with disabilities had been grouped into disease and disability categories (e.g., the M.S. Society, United Cerebral Palsy), and language usage reinforced a dehumanizing definition of individuals by pathologies (e.g., “the quadriplegic”, “the C.P.”). In response to being pathologized, the new disability community organizations (such as independent living centers) crossed medically defined disability lines. Instead of patients who were recipients of services, as in the medical model, people with disabilities controlled and staffed most of the organizations, asserting their disability expertise and autonomy. Organizing around common social needs and social change efforts, disability communities, and a sense of culture began to emerge. Like deaf culture, this cultural consciousness was constructed through peer to peer contact, rather than intergenerationally as in ethnic cultures. Culture (albeit with many subgroups and degrees of involvement) developed out of cumulative shared trauma and/or oppression as well as shared experience and coming together in positive coping, social change and creative efforts. A buffering commonality alleviated isolation, but it also countered negative social suggestion and provided a sort of group reframing for disability experience.

MacKinnon and Marlett describe the history of (sub)culture formation among parents of children with disabilities in “A Social Action Perspective: the Disabled and their Families in Context”. This formation occurred particularly in reaction to earlier social pressures for institutionalization of children with disabilities, and, historically, varying degrees of need to band together to combat problems getting appropriate services.

In the 1980’s members of the parent culture started critiquing intervention for children with disabilities for having an excessively “fix it” orientation, focusing on ameliorating deficits or pathologies to such an extent that it seemed to make children feel broken, fragmented and dehumanized. Anne and H. Rutherford Turnbull articulated this issue well in “Stepping Back from Early Intervention: An Ethical Perspective” (1986). The emerging perspective of the disabled adult culture informed this critique, arguing for the importance of valuing the humanity of people with disabilities, whatever their age.
It appeared that the benevolent yet subtly dehumanizing stance toward children as well as adults with disabilities often spread to their families. The result was a distancing and an emphasis on deficit and pathology in the family system, rather than a more empathetic approach.

Disability culture has seemed most consciously defined by individuals who are at its edges, both in and out of the culture, on the verge of entrance, or who have experienced a change in their degree of involvement. Parents of babies with disability and people who are newly disabled often comment on the alien perplexing world they are suddenly forced to enter--a culture they would never have chosen. A person with a disability may feel more culturally identified by marrying another person with a disability, in contrast to a previous relationship with a nondisabled partner. Ablebodied spouses or children of people with disabilities may be on the edge of the culture or in limbo, existing in two realms. Paul Preston (1994) writes eloquently about the cultural status of the hearing children of deaf parents. By articulating the experience of being identified with two cultural realms he deepens our understanding of deaf culture. A well-developed culture, with a rich heritage, its members generally do not self-identify with the general disability community. Families with other disability experience also vary in the degree of their identification with or integration into the (or a) disability community. They may exist almost completely in the nondisabled realm. Or some of the most worrisome families may be isolated from both communities.

Families come to disability experience with connotations regarding disability that are the result of intergenerational disability experience impacted by past social messages and conditions. Society’s current negative suggestions and influences then enlarge the personal and intrafamily sense of loss and isolation in the present. This is unfortunate since the personal grief and disorientation is difficult enough in the face of disability loss, without being socially accentuated. For example in my own family, after 4 years of rapid progression of her father’s longterm and previously mild multiple sclerosis, at age 18 our daughter wrote:
MS

You didn’t know that morning
how I watched you from behind the locked glass doors
your back turned away from my young stare
your fingers searching through the drawer for socks
you didn’t know daddy
how I saw your foot slip
out of your hands like soap
or how I saw you lift it up again
and cradle it like a baby in your arms
trying to soothe it or show it how to move
to remind yourself it was not yet dead
and still needed to be touched

I watched your hands struggle
to cover your feet with the socks
one brown one rusty green and wondered why you wore them
when you couldn’t even feel what warmth they might lend
It seemed I stood forever
wanting more than anything to break through the doors
pull the socks easily over your feet
as you once had done for me
before I had grown and you had shrunk
but instead I held my breath and watched
not so much afraid that you might discover my presence
but afraid that you might not get the socks on straight

Struggling to cope with disability loss and disequilibrium within your own family
means you are in a particularly vulnerable state. The onset of disability—whether the birth of
a baby with a disability, or a disabling event in a parent, or a significant exacerbation of a
disability—usually is experienced as a traumatic change. Even in families with stable and
longterm disabilities, developmental transitions or life cycle points (such as childbearing)
can trigger earlier trauma and also create family disequilibrium and vulnerability.

As discussed in family systems literature (Levinson (1978, 1986), (Carter and
McGoldrick (1980) it is as if family life structure is reevaluated during transitional life cycle
periods. In regard to chronic illness Rolland (1989) identifies transitional periods as
“potentially the most vulnerable because previous individual, family, and illness life
structures are reappraised in the face of new developmental tasks that may require discontinuous change rather than minor alterations.” (p. 447). He describes how the evolution of family adaptation during key transitions reveals organizational shifts and coping strategies of the system in response to past stressors. Intrafamily patterns relevant to illness, loss and crisis, transmitted across generations, impact current family coping with disability. Rolland’s analysis is clinically astute and practical, but it would be strengthened and depathologized by a recognition of the social, cultural context of these family processes.

Just at these “life-structure changing (transitional) periods”, when families are the least armored with defenses or coping mechanisms, they are particularly bombarded with negative societal messages—potent multiple suggestions—regarding the disability. Some messages come from within the immediate and extended family and are historical, having been absorbed by the family in relation to disability experiences and social suggestions in the past. I believe that the intrafamily, intergenerational connotations of disability are carried using a process like that described (in relation to other issues), in Ritterman’s *Using Hypnosis in Family Therapy.* She delineates what is seemingly a normal process, in which families unconsciously utilize positive or negative hypnotic suggestion techniques with their members. Using family therapy transcripts she documents the family induction of symptoms (such as hopelessness), the transmitting of indirect or unconscious messages, which attain cumulative potency, e.g., through repetition from different sources.

Families with disabilities vary as to the degree of intergenerational negative suggestion regarding disability; however, bombardment with negative messages from the social sphere is the norm. The frequency and interspersed nature of these messages seems to create negative social induction that is particularly potent during vulnerable transitional periods.

*As soon as my husband started using a wheelchair people began behaving dramatically different. People stare and act ill at ease. Strangers touch him a lot like you do with children. Instead of being wary of a man who’s a stranger, women smile and initiate conversations on the street. Is the message that he is supposedly*
neutered? Waiters address me when we’re together, as if he’s no longer capable of ordering food. At social events when we’re among strangers they tend to be avoidant of us as a couple. He notices most people who do approach talk to him just about disability. We have a continual hassle with access. It makes me feel like our family doesn’t count or belong--like a curtailed existence is OK for us now. Somehow having fun together as a family has gotten more depleting than refueling. We just aren’t going out so much anymore. We can manage everything so much better at home. There aren’t the kind of uncertainties as to how everything will work. Like when we went cross country and a motel that claimed disability access had steps to every room. Or a tourist spot that considered disability access to be their willingness to carry someone up the stairs. Or the movies that are set up so we can’t sit together as a couple or as a family.

The transition to parenthood can trigger vulnerability to negative social suggestion at a time when there is an increase in the number of such messages. Disrespectful comments or behavior of strangers can undermine a parent’s self-esteem before birthing a child, or the authority or image of the parent in the eyes of their child. For instance, a stranger told a noticeably pregnant woman with cerebral palsy that she couldn’t be pregnant, and a blind pregnant woman was asked, “how could you do this to your child”!? Strangers sometimes make comments that imply a child must belong to someone else--not his or her parent with a disability.

Parents of babies and children with disabilities report numerous problems with public reactions to appearance or behavioral differences. They frequently need to learn to strategize about how to handle cruel and stigmatizing comments or actions, as well as social awkwardness.

A mother goes to a ballgame with her other children, and finds herself constantly repositioning herself to block a girl’s hostile and persistent staring at her daughter with retardation. She associates this with the reluctance of special education to mainstream her daughter; in many ways they also convey an underlying sense of repulsion and rejection. It takes so much mobilizing and energy to protect her daughter from negativity coming from so many sources, and with such frequency.

When the negative suggestions occur at the most vulnerable transition points they can be remarkably powerful and enduring in their traumatic impact.
When my baby was first born with medical problems I felt like I was in an altered state. Because I had experienced hypnotherapy I thought I was often in a trance state. This was particularly true when I was in the most stressful medical situations with my baby. The things that people said to me about him at those points have stuck for years, in this vivid concrete way, whether they were positive or felt like an assault on my relationship with my baby.

Medical procedures are a frequent source of cumulative trauma in families with disability issues. Women with disabilities have been particularly eloquent in explaining the impact of experiences during medical procedures, sometimes likening the long term emotional effects to the impact of abuse. Victoria Thornton, in “Growing up with cerebral palsy” (Bullard & Knight, 1981) describes dissociation and compromised body image caused by recurrent objectifying clinical procedures and public exposure during exams.

The cumulative effect of such pervasive and repetitive negative social messages is that we construct a personal framework of meaning regarding disability. This frame can, in turn, have a profound effect on individual family members’ self-esteem, sense of defeat, and depletion. It can narrow our families’ sense of the range of what we can do together, of who we can be together.

Family theorists and practitioners may inadvertently contribute to the pathologizing of families by underestimating the degree and impact of negative social suggestion. For example, Rolland (1989) describes how disability transitions “exert a centripetal pull on the family system”, as if the disability element, like a new family member, sets off a systems level of inner absorption and withdrawal while “socialization to illness” or restructuring occurs. The question is how much is a family’s social withdrawal a consolidating coping mechanism because of intrafamilial structural changes, and how much is withdrawal a response to social suggestions.

Taking another example, the parents of a child with a disability may be pathologically labeled as over-protective when such behavior may be functional considering the impact of bombardment by social suggestions and stigmatizing events by the public and service system.
Within a social pathology paradigm, the family factors that impede separation may be conceptualized as overinvolvement of the mother, personality traits of the parents that inhibit the natural separation, or a marriage that is maintained by the disabled person’s involvement. The fact that the family’s rigid external boundary and the parents’ overinvolvement” were functional and necessary for the era in which the handicapped child was born is not always recognized (MacKinnon & Marlett, p. 117).

In *Trauma and Recovery*, Herman says that “trauma is resolved only when the survivor develops a new mental ‘schema’ for understanding what has happened.” Shazer and Lipchik describe the “looking glass” or interactional nature of frames and their labels:

*The client saw other people seeing her as crippled, adopted the label, and started to behave as if crippled. The more she behaved as crippled...the more people would see her as crippled, and the vicious cycle continued to maintain itself. When she started to exhibit stronger behavior...others saw her as strong, and she started to see them see her as strong, and the virtuous cycle began to maintain itself. Importantly, the change in labels can ‘start’ anywhere in the system...If others had started to see her as strong before she had seen herself in such a way, then they might have initiated the ‘strong frame’ for her (Shazer & Lipchik, 1984)*

In our experience a therapeutic reframe here and there won’t usually do, because of the ubiquitousness, the ongoing nature of the negative social suggestions. Reframing needs to be potent and continuing enough to counteract this onslaught.

Recall that the adult disability culture is inherently a reframe or a complex of reframes. Different forms of contact with such a culture can help achieve the development of a new “schema”. People in disability transitions can experience profound shifts in meaning from contacts with individuals with longterm disability experience and disability community involvement. This can occur through peer to peer networking whether formalized through support groups or programs, through joint social change efforts, or simply through informal socializing in the community or interaction among colleagues in the workplace.
When we as a couple became involved with the early disability independent living movement we were confronting our future, should my husband’s MS progress to severity. Our first teacher there regarding peer counseling was a social worker with quadriplegia who was a father of several children. He was an attractive, compelling man, powerful enough so I had difficulty holding my own as his co-therapist. His being was profoundly reassuring about the future possibilities for us as a couple.

Being involved in the adult disability community is likely to expose one to a cultural perspective that values disability. For instance, one may know a deaf person who, out of cultural pride and a desire for full communication, hopes to have a baby who is deaf. One encounters the belief by some people with disabilities that the genetic counseling field is genocidal. One listens while a woman rejects the usually acceptable description of her as “a woman with a disability”: she prefers calling herself “a disabled woman” out of pride about her identity, pointing out the analogy to an Afro-American woman. Cultural participation reveals that disability can be celebrated and valued and not just be a source of grief and loss. One may end up wondering what it would mean to families’ disability experiences to have been for generations in a society that is not oppressive and pathologizing about disability.

We are given a glimpse of the de-stigmatizing impact of the intergenerational integration of people with disabilities in Groce’s *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha’s Vineyard* (1985).

At Through the Looking Glass, in Berkeley, California we have chosen to pursue a conscious depathologizing process, where we bring the perspectives of the disability culture(s) to clinical intervention with families that have disability issues in parent or child. An attempt is made to focus on aspects of infant mental health and family therapy modalities which are consistent with the depathologizing process. Staff “peer clinicians” (psychotherapists with personal disability experience) frequently function as cultural intermediaries and reframing agents. A peer clinician has a profound advantage for beginning to reframe the cluster of connotations associated with disability; their beings
present a reframe: a disability peer who is a survivor, a provider, a person with authority, etc. Negative suggestions can be counteracted. Isolation can begin to be alleviated.

A Samoan mother received services five years after her head injury. She was concerned about how she could take care of her newborn baby, given her hemiplegia and her view of herself as quite helpless. She was unnecessarily dependent on her ablebodied husband, and their family unit was isolated both from their ethnic community as well as from the disability culture. A Hawaiian-Japanese clinician with post-polio provided the home visit services to the family. A dual cultural intermediary, her services resulted in the gradual integration of the woman into both cultures and, by increments, a dramatic increase in functioning that has been maintained for years.

Our early research (Kirshbaum, 1988) documented the interaction of mothers with physical disabilities and their babies: “good enough” or mentor mothers coping with disability obstacles during babycare. The resultant videotape and research data has informed clinical intervention with more stressed families, sometimes directly by using the videotapes with anxious expectant or new parents. A current research project (funded by NIDRR) builds further upon the ideas generated in the community, developing many items of adaptive parenting equipment for physically disabled parents, e.g., a babycare tray to attach to a motorized wheelchair, a playcenter at wheelchair level, accessible cribs, etc. These projects use expertise from within disability culture to develop pragmatic solutions regarding disability obstacles.

A young African-American woman with moderate cerebral palsy called Through the Looking Glass. She was pregnant and frantic with anxiety, because she and her partner wanted very much to have the baby, but her parents were intensely pressuring her to abort. They were maintaining that she was physically incapable of taking care of a baby, and her own uncertainty about this was all that made her consider discontinuing the pregnancy. She had been living independently in an apartment with her partner for several years and had a computer programming job.

We often see the parents of independent and high functioning people with disabilities question the ability of these competent adult children to become parents. A crisis may ensue, in which an expectant or new parent with a disability--vulnerable to suggestion during this
transitional period-- can feel undermined and abandoned. At these points of developmental change interactional rules regarding roles and functions are renegotiated, and expertise from within disability culture can facilitate the process:

In this situation, initially videotapes of parents with comparable disabilities taking care of their babies were shown, to give the expectant mother and her partner a realistic idea of both difficulties and possibilities. She subsequently chose to have the baby. Mother/daughter therapy was provided, integrating again the use of the videotapes. With the help of our adaptive parenting equipment, provided by an occupational therapist who was herself a mother with cerebral palsy, the new mother gradually proved her abilities, and asserted herself regarding excessive help postnatally from the grandmother. The couple regained their independence. A subsequent birth was calmly accepted by the grandmother, and the whole family is thriving.

In the course of clinical work we were asked to assess and intervene with families that were multiply stressed, isolated, and receiving treatment by systems without disability expertise. We were startled by the degree to which professionals were pathologizing many of these families. We therefore began to conceive of our work as involving a depathologizing process through familiarity with cultural norms as well as culturally derived expertise about solutions to disability obstacles.

A young African-American mother with quadriplegia, whose baby was in foster care, was said to be uncooperative with substance abuse treatment, and to have formed no bond with her baby despite visitations. Up to the point of TLG involvement, her workers’ referrals to services had not taken into account her disability: she was asked to go to inaccessible programs, which would not do urine samples because she was catheterized, and she was expected to get there without disability transportation. She was pathologized as having no attachment to her baby. Yet in six months, no one had made it possible for the mother to hold, feed, or play with her baby during visitations--all of which TLG established by the second visit.

An African-American mother of a child with severe cerebral palsy was reported to CPS for medical neglect due to the child’s slow weight gain. Practical or supportive in-home intervention was not provided at this point, and the mother had had minimal contact with other parents of children with disabilities when the child was removed to foster care. In out of home placement the child continued to gain poorly and, additionally, became depressed at the separation. A TLG peer clinician, the mother of a child with a comparable disability, provided the first facilitation of the mother/child relationship, and mediated between the mother and the services system. She taught the mother systems navigation skills. It was determined that the weight
gain problem had been due to the child’s need for a gastrostomy. The child returned home and child protective services monitoring was no longer necessary.

A depathologizing effort can also be applied in situations where there is need to heal trauma induced by the medical realm. Many parents of babies with disabilities feel traumatized by recurrent experiences that seem to dehumanize their babies.

A team of dysmorphologists examined a newborn baby and his parents to discern whether the baby had a syndrome involving retardation and multiple anomalies. Then a written report was sent to the parents enumerating the baby’s normal and abnormal body parts. To the parents this conveyed a message that the baby was a kind of specimen, a thing, a sum of his parts. For weeks the mother would be cuddling her baby and shift to their pathologizing view, fixating on an abnormal part of his body. The TLG clinician, offering an alternative frame, facilitated their perception of the baby as a little person, as a unique individual. Later, the parents felt it necessary to pursue a followup diagnostic session with the dysmorphologist team. The clinician had the parents note the behavior of the physicians and write these in a description that would be incorporated into sensitivity training for medical personnel to be offered by the parent community. The family weathered the appointment well and reported the dysmorphologist behavior with humor and insight.

A “streetwise” parent clinician was able to prevent additional family trauma and impotence, reframing their experience into a powerful stance: transforming what were previously specimen analysts into the specimens to be analyzed, and in the process contributing to the continuing education of these physicians by the parent community. This was a mischievous enterprise, a cultural in-joke that consolidated the parents’ entry into the parent culture.

There has been a reluctance to reveal our most painful stories to those outside of disability cultures, because of the history of pathologizing our families, fixating on trauma and despair. It is a kind of dehumanizing and distancing from our families, conceiving of us as alien beings. Because we are much more like than unlike your own family. We need to be able to safely share the total spectrum of this experience without wariness. The depths of its despair and the degree of its trauma cannot be understood without an awareness of its wisdom, resilient beauty and playfulness. Our families are profoundly ordinary.
REFERENCES


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