A Disability Culture Perspective on Early Intervention with Parents with Physical or Cognitive Disabilities and Their Infants

This article describes an approach to research, resource development, and early intervention that has evolved in a disability community–based organization—Through the Looking Glass—in response to the unmet needs and obstacles faced by parents with disabilities and their children. Material on parents with physical disabilities is presented first, identifying themes that are embedded in a disability culture perspective: spread and differentiation; contextual, environmental, or social dimensions of disability; adaptation; respect; empowerment and power differential issues; interdependence; and familiarity with disability. Next material on parents with cognitive disabilities is presented in relation to these themes. The integration of infant mental health and family therapy approaches to the disability community themes is discussed. Key words: *adaptation, disability, families, infancy, parents*

Megan Kirshbaum, PhD
Executive Director
Through the Looking Glass
Co-Director
National Resource Center for Parents with Disabilities
Berkeley, California

INTRODUCTION

The intent of this article is twofold: (1) to describe how a disability culture perspective has informed research and early intervention serving parents with physical disabilities and their infants, and (2) to articulate how this perspective is also guiding interventions for parents with cognitive disabilities and their infants. The term *disability culture* refers to the social, civil rights, or minority model of disability: disability as socially constructed, with an emphasis on its social meaning and on social obstacles as the primary problem for people with disabilities and their families. This article identifies themes that have emerged from research and intervention in a disability culture–based organization, Through the Looking Glass (TLG), and that seem particularly salient for improving practice with parents with disabilities and their children.

Differentiating is an appropriate theme to consider initially. There has been a persistent problem in research and practice of blurring distinctions between parents with diverse disabilities. One can

---

Funds for this article come, in part, from the US Department of Education, National Institute of Disability and Rehabilitation Research (NIDRR; #H133A980001). The content and opinions do not necessarily represent the policy of NIDRR, and the reader should not assume endorsement by the federal government.

Inf Young Children 2000; 13(2): 9–20
© 2000 Aspen Publishers, Inc.

consider this overgeneralizing a manifestation of the concept of "spread."[1] Recently Olkin[2] discussed the power of the negatively valenced disability characteristic to spread and evoke inferences about an individual's other characteristics, leading to stereotyping: "A negative value attached to the fact of disability spreads to other unrelated aspects. Thus a person in a wheelchair is assumed to be cognitively impaired; a person with mild mental retardation is viewed as more profoundly retarded; people raise their voices to talk to a person who is blind. A deficit in one characteristic spreads such that similar deficits are ascribed to other characteristics."[2(p56)] The process of spread also affects the perception of families with disabled members.

Negatively valenced spread appears to be one of the processes that has led to pathologizing parents with disabilities and their families in research and practice. That is, most of the overgeneralizing about parents with disabilities has involved pathologic assumptions about them, expressed in the emphases, language, or hypotheses chosen such as "The Mutative Impact of Serious Mental and Physical Illness in a Parent on Family Life"[3] or the hypothesis that children of parents with multiple sclerosis have damaged body images.[4] A more recent article, "Child Abuse and Neglect by Parents with Disabilities,"[5] demonstrates both pathologizing and spread as the article actually concerns only two families with mothers with cognitive disability rather than parents with disabilities in general. Buck and Hohmann,[6] Cohen,[7] Conley-Jung,[8] and Olkin[2] have critiqued the methodology of the research literature that posits maladjustment in the children of parents with disabilities or pathologizes parents.

The pathologic focus in research is a reflection of society's particular stigma about parenthood by individuals with disability; that is, assumptions about disability commonly preclude parenting. Perhaps this attitude explains the persistent and potent tendency for parents with disabilities to be invisible and marginalized in society. Public systems, even in the disability community, do not tend to identify or gather information about parents with disabilities. As a result, these parents are not included in needs assessment, and funds are not earmarked for services for them. Invisibility results in a critical lack of resources for the growing numbers of families in the community. People are often surprised to learn that there are approximately 8 million US families with children under age 18 who have one or both parents with a disability—or almost 11% of families.[9,10]

This article describes an approach to research, resource development, and early intervention that has evolved in response to the unmet needs and obstacles faced by parents with disabilities and their children. Material on parents with physical disabilities is presented first, identifying additional themes that are embedded in a disability culture perspective. Next, material on parents with cognitive disabilities is presented in relation to these themes. The integration of infant mental health and family therapy approaches with disability issues is then discussed.

PARENTS WITH PHYSICAL DISABILITIES

The disability community emphasizes identifying and grappling with *contextual, environmental, or social dimensions of disability.* Parents with disabilities face numerous social obstacles, documented in a national survey of parents with disabilities.[10] This national survey, conducted under the aegis of TLG, included more than 1,200 parents, approximately 75% of whom had physical disabilities. Two out of five respondents reported facing attitudinal barriers as disabled parents, with one third reporting being a victim of discrimination as a parent with a disability. Practical obstacles to parenting included transportation (reported by four out of five), housing (40%), recreational access (66%), lack of access to infant care adaptations, and barriers to child care. Fifteen percent reported attempts to take their children away. Other significant issues included parents being told they could not use personal assistants to help with child care and experiencing interference from assistants in their role as parents. More disturbing was the fact that 18 parents reported child abuse by personal assistants.

Cost of resources was another significant concern, even among the predominantly middle-class and well-educated participants in this survey. The average monthly household income for parents with disabilities is $1,000 less than that of parents without disabilities.[10] Poverty is an especially crucial social obstacle among parents with disabilities because of the extra costs that parenthood brings and the lack of public funding for resources such as adaptive equipment and personal assistance for infant care. Unemployment and poverty are common in the disability community, with one out of three households having extremely low incomes.[11]

Despite these social obstacles, parents with physical disabilities have been applying their expertise in problem solving to the realm of parenting for generations. The scant nonpathologically focused research documents positive outcomes for these parents and their children.[6–8,12,13] Usually these outcomes have occurred in the absence of specialized resources or early intervention. Given the social obstacles, these positive outcomes are a testimony to the resilience of parents with physical disabilities and their children. Parents with disabilities have expressed concerns about generalized stigmatization of their families as being particularly needy, and it is important to clarify that many parents with physical disabilities can manage with no intervention or short-term or periodic services. Services or resource requirements for families of parents with physical disabilities would be dramatically reduced if there were fewer social obstacles.

Elsewhere[14] I have described the cumulative effect of repetitive negative social suggestions or messages on our families with disabilities. Social obstacles and lack of adaptations not only exclude our families and complicate our daily lives but also are dismissive and devaluing. They are subtly wounding, reocurring through the course of everyday life. They reify stigma. So it is understandable that a theme in the disability community has been an emphasis on *universal design and access*—the elimination of barriers that are due to attitudinal bias and lack of expertise, as well as barriers that are physical or communicative in nature.

While the disability community advocates for universal access, making life work in the face of obstacles—pragmatic ingenuity regarding adaptation—is another theme. Experiences with disrespectful services and information that connoted inferiority, deficit, or pathology in people with disabilities have led to an emphasis within the disability community on *respect for expertise and adaptations derived from personal disability experience.*

Therefore, as a disability community–based agency approaching the development of services and research with parents with disabilities and their children, TLG emphasizes learning from our community's families, observing and documenting how parenting works. When parents complained that professionals questioned their ability to care competently for their infants, TLG conducted a research project from 1985 through 1988 that videotaped how mothers with physical disabilities cared for their infants and toddlers. Without intervention or infant care adaptations, most mothers developed ingenious solutions to disability obstacles. Infants adapted to their mothers' disabilities as early as 1 month of age (eg, holding still and compact [like a kitten] when lifted). There was a natural reciprocal adaptation process that developed over time.[15]

In subsequent work with particularly stressed families, TLG staff were startled by social services and mental health practice that was pathologic and uninformed about adaptations or disability culture norms. A parent with significant cerebral palsy was videotaped by child protection workers while diapering her infant—without any adaptations being provided and after a long period of out-of-home placement that interfered with the natural reciprocal adaptation process between parent and child. This videotape was cited in court as evidence of her parental incapability, despite the similarity to long diaperings by high-functioning mothers with cerebral palsy in the community.[15,16]

In another instance it was assumed that gaze between an infant and his mother with significant cerebral palsy had not been established because of the (hypothesized) intrapsychic pathology of the mother. Actually the problem was that no one had provided a way to make mutual gaze feasible and comfortable. With adaptive positioning, gaze was promptly established between mother and child. At TLG we concluded that one cannot assess the potential of a relationship between a parent with a significant physical disability and an infant without first providing whatever adaptive techniques and equipment make it possible for interaction to occur and the infant-parent relationship to develop.[16,17]

Building on the solutions of the pioneering disabled parents in our community, TLG conducted a series of research projects to design and provide individualized infant care adaptations in order to ease the number of obstacles at the outset of parenting (Fig 1).[18–22] The disability community's emphasis on empowerment was inherent in this process, as it involved mutual problem solving and brainstorming between parent and occupational therapists (one of whom was a mother with cerebral palsy herself). Another example of the disability community orientation was the nonpathologic emphasis on "environmental mismatch" (ie, "the barriers or physical elements in the environment which fail to match the functional abilities of the parent are seen as the problem rather than the parent's physical limitations"[20(p.72)]). This approach is more respectful and also more conducive to change (ie, one can focus on the problem being how to set up a diapering surface that accommodates a wheelchair rather than the problem being a mother who cannot stand). Our research on the impact of adapted infant care equipment found it to be inherently empowering to decrease environmental barriers and increase parents' functional infant care abilities and involvement and to decrease fatigue and pain and seemingly prevent secondary injury. We observed that as infant care tasks became easier some parents became less focused on the physical demands of the task and engaged in more positive interactions with their infants.[20–22]

Power differential issues and empowerment are key constructs in the disability community. Services, such as personal assistance or assistive technology, are viewed as enhancing independence as long as the individual with disabilities has the decision-making authority to orchestrate them. There is a strong preference for service provision by individuals with personal disability experience. This value is reflected in disability community agencies such as TLG being staffed predominantly by individuals with personal disability experience.

Fig 1. Mother with a physical disability using an adaptive baby carrier. *Source:* © Suzanne C. Levine, Photographer. One time use with permission only. 415-387-0617, P.O. Box 22115, San Francisco, CA 24122-0115 USA.

Disability culture as support is a theme. In *What Psychotherapists Should Know about Disability*,[2] Olkin discusses the power of disability culture inclusion for individuals with disabilities. It is especially informative to consider the role of disability culture for parents with physical disabilities.

Since parenthood by individuals with disabilities is particularly stigmatized, the disability community can provide a buffer and an antidote to social stigma, reframing the meaning of disability. The community carries practical problem-solving strategies (such as infant care adaptations) and is a source of role models for people who were not socialized to expect parenthood.

Interdependence is a related theme. TLG research projects have documented the role of parental teamwork in disability community families.[15,20,23] TLG conducted a second national survey of couples with young children in which one partner was a parent with a physical disability.[23] This study detailed household division of work and decision making, comparing these couples to couples in which both partners were nondisabled. The first analysis (of couples in which only the mother had a disability) found that the able-bodied fathers did a little more housework and the mothers with disabilities did a little more child care. This finding suggests that couples were making satisfactory disability adaptations, as they were more satisfied with their child care role division than were nondisabled couples.

Many parents are sensitive to the stereotype about parents with disabilities overburdening or parentifying their children. A number of TLG studies[7,20,23] suggest that there is a tendency for mothers with physical disabilities to avoid placing their children in helping roles, even the usual household chores. In the absence of infant care adaptations, mothers tend to overuse their own bodies, minimizing their infants' need to adapt.[21–23]

The disability community's familiarity with the patterns and norms of our families enhances the ability to differentiate between situations. In our research[20] the occupational therapist who was a mother with hemiplegic cerebral palsy interpreted a parent's diapering with one hand as the least demanding. The occupational therapist who was the least experienced in observing infant care by parents with disabilities interpreted tasks as more demanding. Adequate familiarity with parents with disabilities helps one to neither exaggerate nor neglect a need for intervention. Drawing from experience with solutions of parents with disabilities, one can identify applicable solutions and tailor them for diverse families. One can differentiate between what is common and readily adjusted to by infants (eg, slow diapering) and what is unusual and worrisome (eg, a toddler purposefully knocking down a parent with balance difficulties). One also can differentiate between characteristics of infants that may present particular challenges for a particular disability situation of a parent. With experience one is less likely to overgeneralize about disability or physical disability in a parent: recognizing subtle differences in functioning; determining crucial distinctions between progressive or relatively stable disabilities; assessing whether disability is long term or recently acquired or worsened; evaluating whether physical disability is complicated by a cognitive or psychiatric component or a trauma history. Moreover, one can differentiate between parents who do not or would not identify as having a disability or being part of disability culture versus parents who would be much more open to a disability culture insider as an intervenor.

INTEGRATING INFANT MENTAL HEALTH AND FAMILY THERAPY APPROACHES

The disability community's emphasis on contextual and environmental factors is consistent with considering the family system and interaction in the relationships between parents and children. Understanding the experience of families of people with disabilities means considering the perspectives and experiences of all family members as they are affected by the social context.

Addressing disability obstacles can clarify and uncover issues in the infant-parent relationship that can benefit from intervention. With one mother, providing a way for her to carry her infant revealed issues with physical closeness, eventually found to be associated with her own history of childhood abuse. Infant care adaptations can produce rapid change; some individuals, couples, or intergenerational families may have difficulty tolerating the sudden increase in functioning, especially at the change-laden time of early parenthood when roles are renegotiated in family systems.[17,24] One mother rejected infant care adaptations when use of them meant that the grandmother felt hurt that her helping role was lessened.[20] Rapid change resulting from adaptive equipment may be especially problematic if there is also a disability change at this point. Adaptive equipment may have an intolerable negative connotation for a parent experiencing a new or worsened disability; for instance, the need for an adapted rather than "normal" crib can represent a painful acknowledgment of loss.

Research on women with physical disabilities points out how some women with disabilities remain with abusive partners because they are physically dependent on these partners and concerned about losing their children because of their disabilities.[25] This pattern is more common among women who are isolated from the disability community and its resources, and who do not have the benefit of adaptations that can decrease dependency on assistance.

Integrating disability culture expertise and awareness of adaptations with infant mental health and family therapy/family systems knowledge has been effective in intervention with particularly stressed families. A mother with a postnatal exacerbation of multiple sclerosis became extremely depressed. She relied on her able-bodied husband to provide the infant care to such an extent that the child was not forming a relationship with the mother and the father was becoming overwhelmed. Infant care adaptations helped alleviate her depression, increasing a balance of functioning in the couple and allowing the relationship between mother and infant to flourish.

PARENTS WITH COGNITIVE DISABILITIES

There are many clear differences between parents with physical disabilities and parents with cognitive disabilities. For instance, most parents with cognitive disabilities have a need for long-term intervention in which the change process is slow, and these parents are limited in their ability to initiate adaptations. In contrast to parents with physical disabilites, parentification is often an issue for the children of parents with cognitive disabilities. Yet it is informative to apply the previously discussed disability community themes to a consideration of parents with cognitive disabilities. The themes of *spread and differentiation* are particularly relevant. There are significant differences, often blurred in practice and research, between cognitive difficulties associated with disabilities such as head injury, stroke, multiple sclerosis, or developmental disability. This discussion is focused primarily on early intervention issues that are applicable to parents with developmental disabilities. However, "developmental disability" or "mental retardation" are labels that are applied to parents with diverse functional abilities as well. Advocates have alleged discriminatory practice when legal and social services systems presume parental incompetence and the inability to benefit from reunification services based on the categorical diagnosis of "mental retardation" or "developmental disability," rather than on individual functioning and behavior of a parent with his or her child.[26]

The need for *familiarity* is another disability community theme. One needs extensive experience with parents with cognitive disabilities in order to evaluate parental capability. As with parents with physical disabilities one cannot discern the full potential in parents with cognitive disabilities without providing *adaptations* that are individualized to the parent's functioning. Many problems with current practice are related to this issue. For instance, many children's protective services departments send parents with cognitive disabilities to generic parenting classes, which are more likely to undermine their self-esteem than to be helpful. If parents do not benefit from generic intervention, they are typically portrayed as incapable—rather than questioning the appropriateness of the intervention. Even curriculum-based approaches to intervention that are developed specifically for parents with cognitive disabilities are inherently limited in their responsiveness to the wide variations in functioning of this population of parents.

As Jeree Pawl has said, "Pulling together the threads of hope and the evidence of possibility is our task. Often it is not easy. But without real trust, we convey despair—or worse. This undermining message—which parents will apprehend—interferes with whatever positive possibilities we might create."[27(p5)] In the case of parents with disabilities, positive possibilities are enhanced by adaptations.

One needs considerable experience in order to provide effective adaptations for parents with diverse cognitive limitations. Such adaptations are often neglected and, instead, the parent is characterized as noncompliant or unable to benefit from services. In contrast to parents with physical disabilities, parents with cognitive disabilities are much less likely to self-initiate adaptations. Thus, there is a far greater need for adaptations to be introduced by intervenors. Yet professionals lack training and information regarding adaptive strategies, and this deficit is reflected in current problems in evaluation and intervention. The misuse of generic unadapted parenting classes is one example of such poor practice. Evaluation of parenting capability often relies on measures that have not been normed with parents with cognitive disability or that preclude success by those without high verbal and cognitive functioning. Observation of actual parent-child interaction during evaluation may be limited, absent, or in an inappropriate setting such as an office. Contextual approaches, such as observation in the home and community, are often neglected. Too often evaluations are conducted by professionals with inadequate familiarity with parents with cognitive disability.

Social stigma and obstacles are issues emphasized in a disability culture perspective. Poverty is a common stressor in the lives of parents with cognitive disabilities, and over the years a number of researchers have examined its impact.[28–32]

Expertise and adaptation during evaluation and intervention are especially crucial to counteract the social stigmatization regarding cognitive disabilities affecting parents as well as professionals. In comparison to physical or sensory disabilities, cognitive impairments tend to be particularly stigmatized or ranked as less acceptable.[2] The qualitative "life narrative" research of Tim and Wendy Booth[28,29] documents the ongoing, intense, and pervasive effect of stigma and discrimination on the lives of parents with cognitive limitations and their children.

The Booths' study of adult children of parents with cognitive disability identified the effects of social exclusion as a major problem in the lives of these families. They suggested that this argued for the applicability of the social model of disability to this population of people with disabilities: "When problems are seen as rooted in people's personal deficits and limitations they may seem intractable and out of reach. Shifting the focus onto features of people's lives that can and should be changed challenges the negative stereotypes that inform such thinking and opens up possibilities of social action in support of families."[29(p38)]

Issues of *power differential and empowerment* are key concerns in the disability culture; they are issues that arise in the face of social stigmatization and exclusion. Parents with cognitive disabilities often have a lifetime of being "one down," of feeling powerless. Intervenors are inherently "one up" in a power position relative to them. So, it can be effective to intervene in such a way that the power differential is softened or counteracted rather than accentuated. A very respectful approach, eliciting the parent's goals and ideas and acknowledging one's own limitations, mistakes, or problem-solving process, can be helpful.

Teaching needs to be handled very sensitively with many parents, particularly those with mild cognitive limitations and long-term issues of "passing" as nondisabled. Many parents have been scarred by disrespectful treatment, including teaching or behavioral intervention that has felt demeaning. Parenthood may be one of the first experiences that has implied normalcy—and teaching that challenges their competence as parents is likely to mobilize resistance or opposition.[33] Defenses are manifest in a variety of ways, including a tendency to withhold problems or questions, a hypersensitivity to any intervention implying deficits, a rejection of even critically needed supports, and polarizing or withdrawing in reaction to didactic approaches.

Adaptation has been described as a central issue in disability culture, related to expectations of a full life despite social obstacles. A respectful orientation is particularly crucial for intervenors working with parents with cognitive disabilities; it is an underlying adaptation needed in the face of pervasive stigmatization. A gradual process of attunement allows one to discern how direct or indirect one needs to be at a particular point in the relationship with a parent. That is, some parents can tolerate teaching from the outset; others accept it only after a respectful working relationship has been established. An effective approach has been a slow process of observing and building on concrete moments that emerge from the parent and parent-child interactions in the home setting. In an ongoing way, one can evaluate the interaction between parent and child as well as the impact of one's interventions on the parent and on parent-child interaction. Over time, the intervenor must adjust to the parent's particular abilities and limitations in order to be effective, yet avoid being patronizing. With experience one learns to discern intuitively and attune to the individual's sense of time, short- and long-term memory (and for what), whether reading is a workable modality for conveying information, processing abilities regarding lengths of sentences, pauses between sentences, series of questions, sequencing, etc. This attunement process involves trial and error, missteps, and repair. Particularly around issues of protection, one must sometimes intervene in direct ways that predictably may offend and necessitate repair of the working relationship. One needs to voice concerns along the way and not collude with hazardous or hurtful behavior toward a child. One might decide to facilitate a safety scenario such as "what would you do if your infant started choking on some food?" and find that the parent feels disrespected by it. Eliciting parental problem solving around safety, when possible, is less likely to mobilize resistance and more likely to result in the parent owning the solutions. Over time, as limitations are clarified, one needs to explore openness to setting up the environment to enhance functioning, such as offering or suggesting concrete adaptations to bypass problems like digital clocks, digital thermometers, a premeasured dose of acetaminophen, calendars with appointments, watches with alarms, feeding or medication charts, or premixed formula. The need for repetition and problems with generalization can be dealt with, without nagging or being demeaning, by presenting concepts via multiple modalities in varied situations (eg, videotapes, books, charts, and varied ways of talking about the issue from the perspectives of different intervenors). When parents have intense polarizing or oppositional patterns it can be effective to intersperse important suggestions into other comments, sandwich critical or sensitive material with positive comments, or use a "lightning rod" preface to the suggestion such as "This may seem like a dumb idea but. . . ." It can be helpful to even the power differential by normalizing not knowing (eg, "I used to do this with my infant until my neighbor gave me this idea").

Identifying parent qualities that you admire or can learn from is especially conducive to respectful and effective intervention. Activities that the parent particularly enjoys can be focused on to enhance the role of the parent in interactions with the child. Videotaping can be used to reinforce the strengths of a parent and to enhance the ability of the parent to observe the infant and wonder about his or her inner experience. It also can be used to enhance the parent's ability to be assertive, in this case about reactions to the intervenor's actions—as a way of discussing their working relationship. The parent can observe the videotaped mistakes or insensitivities of the intervenor and these can be discussed and repaired.[31] The continuity of this intervenor-parent relationship in the face of negative moments provides a model for the relationship between parent and child. Jeree Pawl said:

> We learn over time that everything we think we know is a hypothesis; that we have ideas, but that we don't have

truth. We learn that those with whom we work have all the information we need, and that this is what we will work with. When we know this, our attitude conveys it; and the child and the parent sense themselves as sources, not objects. . . . In this context, they become aware of a mutual effort—one in which a sense of partnership can be maintained much of the time. They do not feel weighed, measured, or judged. They do feel listened to, seen, and appreciated."[28(p5)]

INTEGRATING INFANT MENTAL HEALTH APPROACHES

The literature on parents with cognitive disabilities is seldom informed by current mental health perspectives. This is ironic given the degree of trauma in the past and current lives of so many women labeled with developmental disability.[35] Programs serving mothers with cognitive disabilities report a startling prevalence of trauma histories.[33] In 1999, 77% of the parents in TLG's program for parents with cognitive disabilities had personal histories of trauma or abuse.

Infant mental health knowledge has been particularly salient, with its expertise about helping parents develop new models of attachment in which others are experienced as caring and reliable and themselves experienced as worthy of care and capable of nurturing.[36] Identifying and eliciting the "ghosts in the nursery"[37] have been effective with many parents with cognitive limitations. Eliciting the meaning of behavior is often effective in producing change that is not achieved by more educative or behavioral approaches. One mother adamantly refused to allow her toddler to attend a child care center until early memories of school maltreatment and taunting were surfaced. Another mother curtailed the mobility of her infant for long hours while she fastidiously cleaned, continuing this practice until she was helped to re-process the removal of other children from the home that she had incorrectly attributed to her messy household. Understanding the meaning and history of behavior can lessen an intervenor's tendency to judge behavior and therefore enhance his or her ability to form a positive relationship with the parent in which more positive parental behaviors can be elicited.

Cognitive limitation can mean that the verbal working through of past trauma is less feasible than it is with other parents. The nature of the containing relationship with the parent becomes even more important because it enacts and puts into practice concretely and understandably what we want to be reflected in the infant-parent relationship (ie, kindness, consistency, responsiveness, respect, handling of change and transitions, limit setting, exerting influence, negotiating, problem solving, tolerance of different perspectives, awareness of others' experience, etc). This kind of relationship between parent and intervenor provides a model for secure attachment for parents who often did not have this experience in their own early childhoods. Unfortunately, parents with cognitive limits are especially likely to have multiple superficial and short-term relationships with service providers—the exact opposite of what they need.

Early intervention practitioners are often taught to use role modeling to teach parenting skills. Infant mental health experience suggests that this approach should be used cautiously and selectively. Modeling skills may "outparent the parent" and undermine vulnerable parental self-esteem. They may contribute to the more pervasive problem of the infant being drawn to the practitioner during home-based intervention. A more appropriate stance is to be the intervenor for the relationship between the parent and infant, facilitating and reinforcing positive aspects of the relationship. Recent infant mental health discussions[38] describe this as "inclusive interaction." It appears to be even more important to establish inclusive work from the outset with this population of parents, primarily due to the parental performance anxiety issues that arise when the intervenor is too centrally involved with the child. The sort of therapeutic relationship inspired by infant mental health ideas provides modeling at a deeper level than that of skills; one's relationship with a parent is a model for the infant-parent relationship and is a laboratory for developing abilities that contribute to that relationship.

Infant mental health experience conveys a need for modest goals and a belief that even modest improvements in a infant-parent relationship can have a profound and lasting impact on a child. Intervention with these families can require considerable patience and necessitates supervision and support for workers so they can support the parent and the parent, in turn, can nurture the infant. One needs to provide models for attachment on all levels.

CONSIDERING THE FAMILY CONTEXT

An inclusive approach should not only focus on the infant-parent dyad but also on the family system needs. One must consider the family's ambivalence about an increased role for the parent with a cognitive limitation. Birth is a developmental point in the family life cycle when roles are renegotiated and an outsider facilitating even more change may not be well received. A respectful orientation to the family, not just the parent, can be crucial. There is evidence[39] of improved outcome when families provide consistent support that complements the abilities of the parent. Yet the ongoing need for family support can be wearing for families. Particular tensions tend to arise in intergenerational households. Family therapy expertise can be an essential part of intervention and can help the family system sustain positive and respectful support. This is especially crucial because of the social exclusion experienced by adults with cognitive disabilities and the centrality of the family in their social life.[40]

Service systems instead of disability culture

The disability culture has seldom functioned as a support or buffer for this population of families. In the absence of a positive, ongoing disability culture or family support it is especially crucial that services simulate nurturing and practical assistance provided by long-term family involvement. Unfortunately service systems may carry their own stigma or even be abusive, disempowering, or otherwise contribute to the problems of parents.[28] There tends to be inadequate training and supervision, poor reimbursement, and high turnover of providers working with this population. Lack of continuity, patterns of excessive rescuing and subsequent burnout, judgmental and negative approaches, and interference with the infant-parent relationship are all too common. Family or individual emotional patterns can be reflected in the service system (eg, "splitting") and workers can get in conflicts that reflect and perpetuate clients' difficulties. There is a strong need for coordinated efforts and interagency teamwork. Though home-based intervention is crucial, services offering peer contact such as parent support groups need to be more available.

Interdependence

Research on adult children of parents with cognitive limitations found that the strength of the parents' support system was important to their children's experience.[29] Current research at TLG is investigating the perceptions of mothers with cognitive disabilities regarding the nurturing versus interfering aspects of their family, community, and therapeutic support systems.[41] The Booths are particularly eloquent about the problematic aspects in the support networks of parents with cognitive disabilities and present a normalized view of their interdependence during parenthood: "Competence may more properly be seen as a feature of parents' social network rather than as an individual attribute. The notion of what might be termed 'distributed competence' underlines the fact that parenting is mostly a shared activity and acknowledges the interdependencies that comprise the parenting task.[30(p37)] This is consistent with the disability culture's contextual view of parenting that refocuses on the elements in the social network and environment that are compensatory and nurturing versus undermining and stressful.

We as intervenors need to be self-reflective and vigilant about our own roles in the lives of these parents, ensuring that we are truly contributing to positive outcomes. As respectful intervenors we need to recognize the commonalities as well as the differences between our families. It is hoped that this discussion has increased familiarity with disability culture perspectives and has helped practitioners who are crossing the "lines of difference" presented by parental disability.

REFERENCES

1. Wright BA. *Physical Disability: A Psychosocial Approach*. 2nd ed. New York: Harper & Row; 1983.
2. Olkin R. *What Psychotherapists Should Know about Disability*. New York: Guilford Press; 1999.
3. Anthony EJ. The mutative impact of serious mental and physical illness in a parent on family life. In: Koupernick A, Koupernick C, eds. *The Child in His Family*. New York: John Wiley & Sons; 1970; 1.
4. Olgas M. The relationship between parents' health status and body-image of their children. *Nurs Res*. 1974;23:319–324.
5. Greene BF, Norman R, Searle M, Daniels M, Lubeck R. Child abuse and neglect by parents with disabilities: a tale of two families. *J Appl Behav Anal*. 1995;28(4):417–434.
6. Buck FM, Hohmann GW. Parental disability and children's adjustment. *Annu Rev Rehabil*. 1983;3:203–241.
7. Cohen L. *Mothers' Perceptions of the Influence of Their Physical Disabilities on the Developmental Tasks of Children*. Alameda, CA: California School of Professional Psychology; 1998. Unpublished doctoral dissertation.
8. Conley-Jung C. *The Early Parenting Experiences of Mothers with Visual Impairments and Blindness*. Alameda, CA: California School of Professional Psychology; 1996. Unpublished doctoral dissertation.
9. LaPlante M, Miller S, Miller K. People with work disability. In: *US Disability Statistics Abstracts*. No. 4. Washington, DC: National Institute on Disability and Rehabilitation Research; 1992.
10. Toms Barker L, Maralani V. *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities*. Berkeley, CA: Through the Looking Glass; 1997.
11. Risher L, Amorosi S. *The 1998 N.O.D./Harris Survey of Americans with Disabilities*. New York: Louis Harris & Associates; 1998.
12. Buck FM. The influence of parental disability on children: an exploratory investigation of the adult children of spinal-cord–injured fathers. *Dissertation Abstracts International*. 1980;41(5):1905.
13. Rintala DH, Herson L, Hudler-Hull T, Dupre D. *Parenting Styles of Individuals with Spinal Cord Injury Compared to Individuals with No Physical Disability*. Houston, TX: Baylor College of Medicine, Department of Physical Medicine and Rehabilitation; 1998. Unpublished report.
14. Kirshbaum M. Family context and disability culture reframing: Through the Looking Glass. *Fam Psychol*. 1994;10(4):8–12.
15. Kirshbaum M. Parents with physical disabilities and their babies. *Zero Three* 1988;8(5):8–15.
16. Matthews J. *A Mother's Touch: The Tiffany Callo Story*. New York: Henry Holt; 1992.
17. Kirshbaum M. Babycare assistive technology for parents with physical disabilities: relational, systems, and cultural perspectives. *Am Fam Ther Acad Newsletter*. 1997;(67):20–26.
18. DeMoss A, Rogers J, Tuleja C, Kirshbaum M. *Adaptive Parenting Equipment: Idea Book 1*. Berkeley, CA: Through the Looking Glass; 1995.
19. Vensand K, Tuleja C, Rogers J, DeMoss A. *Adaptive Baby Care Equipment: Guidelines, Prototypes & Resources*. Berkeley, CA: Through the Looking Glass; 2000.
20. Tuleja C, DeMoss A. Baby care assistive technology. *Technol Disability*. 1999;11(1,2):71–78.
21. Through the Looking Glass. *Developing Adaptive Equipment and Adaptive Techniques for Physically Disabled Parents and Their Babies within the Context of Psychosocial Services*. Berkeley, CA: Author; 1995.
22. Tuleja C, Rogers J, Vensand K, DeMoss A. *Continuation of Adaptive Parenting Equipment Development*. Berkeley, CA: Through the Looking Glass; 1998.
23. DeMoss A, Jans L, Kirshbaum M. *Assistive Technology and Parenting: Teamwork Component. The Parenting with a Disability Couples Survey*. Berkeley, CA: Through the Looking Glass; 1995.
24. Rolland JS. *Families, Illness, and Disability: An Integrative Treatment Model*. New York: Basic Books; 1994.
25. Nosek MA, Howland CA, Rintala DH, Young ME, Chanpong GF. *National Study of Women with Physical Disabilities: Final Report*. Houston, TX: Center for Research on Women with Disabilities, Baylor College of Medicine; 1997.

26. Watkins C. Beyond status: the Americans with Disabilities Act and the parental rights of people labeled developmentally disabled or mentally retarded. *California Law Rev.* 1995;83(6):1415–1475.
27. Pawl JH. The interpersonal center of the work that we do. *Zero Three.* 2000;20(4):5–7.
28. Booth T, Booth W. *Parenting under Pressure: Mothers and Fathers with Learning Difficulties.* Buckingham, England: Open University Press; 1994.
29. Booth T, Booth W. *Exceptional Childhoods, Unexceptional Children: Growing Up with Parents Who Have Learning Difficulties.* London, England: Family Policy Studies Centre; 1997.
30. Feldman MA, Walton-Allen N. Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children. *Am J Ment Retard.* 1997;101(4):352–364.
31. Crittenden PM, Bonvillian JD. The relationship between maternal risk status and maternal sensitivity. *Am J Orthopsychiatry.* 1984;54:250–260.
32. Mickelson P. The feebleminded parent: a study of 90 family cases. *Am J Ment Defic.* 1947;51:644–653.
33. Hansen S. Serving parents with cognitive disabilities. *Parenting Disability.* 1994;3(2):4–6.
34. Hansen S, Corbus K. Adaptations and strategies in working with parents with developmental disabilities. Presented at the Tri-Cities Children's Center Infant Development Program; March 2000; Fremont, CA.
35. Sobsey D. *Violence and Abuse in the Lives of People with Disabilities.* Baltimore: Paul H. Brookes; 1994.
36. Leifer M, Smith S. Preventive intervention with a depressed mother with mental retardation and her infant: a quantitative case study. *Inf Ment Health J.* 1990;11(3):301–314.
37. Fraiberg S, Adelson E, Shapiro V. Ghosts in the nursery: a psychoanalytic approach to the problems of impaired infant-mother relationships. *J Am Acad Child Psychiatry.* 1975;14:387–422.
38. Pawl JH, Ahern C, Grandison C, Johnston K, St. John M, Waldstein A. Responding to infant and parents: inclusive interaction in assessment, consultation, and treatment in infant/family practice. *Zero Three.* 2000;20(4):11–32.
39. Zetlin AG, Wisner TS, Gallimore R. Diversity, shared functioning and the role of benefactors: a study of parenting by retarded parents. In: Thurman SK, ed. *Children of Handicapped Parents: Research and Clinical Perspectives.* Orlando, FL: Academic Press; 1985.
40. Krauss MW, Seltzer MM, Goodman SJ. Social support networks of adults with mental retardation who live at home. *Am J Ment Retard.* 1992;96(4):432–441.
41. Ehlers-Flint ML. *Perceptions of Parenting and Social Supports of Mothers with Cognitive Disabilities.* Alameda, CA: California School of Professional Psychology; 2000. Unpublished dissertation.