Parents With Physical, Systemic, or Visual Disabilities

Megan Kirshbaum, Ph.D and Rhoda Olkin, Ph.D.

Through the Looking Glass, 2198 Sixth Street, Suite 100, Berkeley, CA 94710.
(800) 644-2666 (voice); (800) 804-1616 (TTY); tlg@berkeley.org; www.lookingglass.org

Original manuscript below was published in*: Sexuality and Disability, Vol. 20, No. 1, Spring 2002*, (pp. 65-80 in the original). The original publication is available at www.springerlink.com

There are over ten million families with children living in the home in which a parent has a disability. This includes over eight million two-parent families and two million single-parent families. [1] Approximately 11% of all American families are parented by one or two parents with disabilities according to the 1993 Survey of Income and Program Participation or SIPP. [2] Despite these numbers data on these families is still relatively sparse. Although there are legions of studies on children with disabilities, the lives of these children as they grow up are less examined, leaving a gap in the knowledge of professionals and in role models for children with disabilities.

When discussing a group as large and heterogeneous as parents with disabilities it is important to keep in mind the diversity of this population. There are varying types of disabilities with tremendous differences in needs, capabilities and limitations. Disabilities can involve physical (e.g., muscular dystrophy), systemic (e.g., lupus), cognitive (e.g., traumatic brain injury), visual (e.g., blindness), hearing (e.g., deafness), developmental (e.g., autism), psychiatric (e.g., bipolar disorder), or multiple manifestations. Research on parents with disabilities often has failed to consider the important distinctions among disabilities and the differences in functional levels even within one category of disability. But the need to more specifically define disability is mandated by the profound distinctions among disabilities and to avoid over-generalizing across differing disabilities. Thus this paper focuses on parents with physical, systemic, or visual disabilities. We will cover three areas, beginning with a discussion of the main problems in previous research on parents with disabilities, so that readers can cast an informed eye over existing research. Secondly we present research in a new key, i.e., from a disability culture and community perspective. This leads to a brief overview of some of the clinical and research work at Through the Looking Glass, a non-profit agency serving families with disabilities since 1982. Finally a summary will describe some of the recurring themes that have emerged from these clinical and research projects.

Problems In Research On Parents With Disabilities

Much of the research on parents with disabilities has been driven by a search for problems in these families. The pathologizing assumptions framing such research presuppose negative effects of the parents' disabilities on their children. The perennial pairing of parents with disabilities and problems in children perpetuates the belief in deleterious effects of parental disability on children. Research "reveals the widespread belief among professionals that disability severely limits parenting ability and often leads to maladjustment in children".[3]

A second problem in the literature is the failure to consider fundamental distinctions among disabilities. Critical distinctions among differing disabilities and levels of functioning are not made, such that a mother unable to get out of bed, an employed mother with a visual impairment, and a mother with an intellectual disability are grouped together and measured against "normal" controls. Often reports on parents with intellectual disabilities are generalized to parents with physical disabilities. For example, an article entitled "Child abuse and neglect by parents with disabilities"[4] is in actuality about only two families, in which the mothers had intellectual disabilities. Similarly, acute episodes (e.g., hospitalization) and chronic disability are lumped together, though the former may be much more of a disruption or crisis for a family.

The third major problem in the literature on parents with disabilities is the confusion of correlation with causation. Thus the presence of both disability in parents and problems in the children are presumed not merely to coexist but to be causally related. But in fact, the correlation is made more likely by the fact that many studies are done on clinical rather than community, samples. Further important contextual factors, particularly known risk factors such as poverty, parent's history of abuse in childhood, substance abuse, or lack of adequate supports, are not enumerated so that all problems found are attributed to disability.

Not surprisingly, many studies which set out to confirm pathologizing hypotheses succeed in doing so. Thus the cycle of negative assumptions about parents with disabilities is perpetuated. We want to emphasize that this is not merely a problem in past literature but quite current. Thus we urge readers to ask many questions about any research on parents with disabilities. In this paper we present research that seeks to circumvent the problems just cited.

Parenting has been the last frontier for people with disabilities and an arena in which parents are likely to encounter prejudice. Researchers have found that parents with disabilities experience prejudice about their rights or abilities to parent. [5.6.7.2] In a national survey of almost 1,200 parents with disabilities, about 15% of the parents reported attempts to remove their children.[2] Indeed, about 7% of over 300 undergraduate psychology majors did not think people with disabilities should be parents at all.[8] It seems that the stigma attached to disability encompasses a threat to the right to parent for persons with disabilities. Thus the legal rights of parents with disabilities, especially in custody decisions, is a fundamental issue for all parents with disabilities. [9,10]

This threat underscores the importance of appropriate and culturally sensitive research on parents with disabilities, and of being mindful of how research on parents with disabilities can be misused against this politically vulnerable population. Thus it becomes necessary to demonstrate that parents with disabilities can be adequate parents. One of the earliest studies to address this [3] compared the children of fathers with and without a spinal cord injury (resulting in paraplegia or quadriplegia), matched on sex of child, father's age, and socioeconomic variables. They failed to find any association between fathers' disability and maladjustment in children, or any evidence of difficulties in sex-roles, body image, values, health patterns, interpersonal relationships, or interest in sports (factors often posited to be affected by a parent's disability). In fact, the fathers with spinal cord injury "expressed affection both verbally and physically toward their children significantly more often than did able-bodied fathers" and therefore, not surprisingly, "children with SCI fathers actually reported significantly more positive attitudes toward their fathers than did comparison children (e.g., love, respect, pride)".[3, p. 223]

Despite these positive data, more recent reviews of research on parents with disabilities [5,11, 12] indicate that much of the research is still driven by pathologizing assumptions. Children are seen as victims of parents' disabilities, with "implicit and explicit criticism of disabled parents, their values, their choices and even their right to have children at all".[12]

Research In A New Key

What is an alternative framework? A disability culture perspective underlies the clinical work described by Kirshbaum [13,13,7] of Through the Looking Glass, related to clinical work with parents with disabilities (including developmental disabilities) and their infants, and Olkin's disability-affirmative therapy with families with disabilities. [15] A key aspect of these alternate disability culture-based approaches is the view of disability as socially constructed. This view shifts the emphasis from the differences that reside within the individual to the stigma, prejudice, discrimination, marginalization, and disempowerment experienced by people with disabilities. A specific example can help clarify this distinction. Suppose a study shows that mothers with visual impairments have given the wrong amount of medicine to their young child as a result of difficulties measuring the medication. Traditional research might title this study "The danger of incorrect medication to children of blind mothers" and use it to justify discouraging parenting by women with visual impairments. Alternatively, this study could be used to prompt the federal government to set standards for tactile markings on all bottles of medicine for children. In other words, the same information can be used to further stigmatize mothers with visual impairments or to influence policy to positively affect parents with visual impairments. Thus the purpose of the research and ways in which the research can be used – or misused – are important considerations of those conducting disability research. In the next section we discuss examples of research on parents with disabilities that comes from a disability culture perspective and considers the public policy implications of the research.

Research And Practice At Through The Looking Glass

Through the Looking Glass's founders had provided disability culture-based counseling services to couples and families with older children in the early independent living movement (from 1973-1982) at the Berkeley Center for Independent Living. Through the Looking Glass (TLG) was founded in 1982 to bring a disability culture perspective to earlier preventive intervention with families with disability/medical issues in infant/child or parent. Its primarily home-based clinical model blended infant mental health and family therapy, developmental intervention and disability culture-based adaptations. An attempt was made to utilize aspects of infant mental health and family therapy modalities that were consistent with a non-pathological and disability culture orientation. Staff were considered cultural intermediaries and "peer clinicians,"as they all had personal or family disability experience. Currently more than 80% of TLG staff still have personal or family disability experience.

Synergy between clinical and intervention services and research has been integral to TLG's development throughout the years. Research demonstrated the effectiveness of clinical models, identified the need for practical resources, and led to additional and improved intervention. Clinical experience led to the identification of issues needing research, guided hypotheses and methodology, and identified unserved populations and services gaps.

TLG has had a central role in the national disability community, networking and providing resources, training and technical assistance regarding parents with disabilities and their children; as a result, unmet needs and issues have been identified that could be pursued in research or clinical services. This national networking role evolved through the 1980's and led to the current National Resource Center for Parents with Disabilities, which provides dissemination, professional training, technical assistance, publications, and a national parent-to-parent network for parents with disabilities.

The lack of resources for the growing numbers of parents with disabilities led to a research emphasis on issues that were particularly salient for social change to improve the lives of parents with disabilities and their children. It was considered ethically necessary to incorporate practical resources, services, and dissemination to parents with disabilities and practitioners into each research project. Since 1982 TLG has provided clinical and early intervention services to families in which parents have all categories of disabilities, and conducted numerous research and demonstration projects focused on parents with disabilities and their children, primarily funded by NIDRR, U.S. Department of Education. Only a few of the issues addressed in research and services can be described within the scope of this article.

A chapter on parents with disabilities for a textbook for maternity nurses [16]described results from 32 interviews with parents with physical and visual disabilities and deaf parents were conducted. This articulate and competent group of parents was offended that professionals had questioned their abilities to care for their babies, implying they had never considered the babycare implications of their own disabilities. The literature review conducted for the chapter found that the few studies regarding parents with physical disabilities were pathological in emphases, language, or hypotheses and furthermore results often were over-generalized from data drawn from extremely stressed clinical samples.

These findings led to TLG's disability community-based research to document the spectrum of capability in parents with disabilities. Because of the lack of role models and media images available to parents with disabilities, TLG chose a videotaping analysis for its initial research project. The ground-breaking study of the interaction of mothers with physical disabilities and their babies (funded by the National Easter Seal Research Foundation,1985-88) documented the reciprocal process of adaptation to disability obstacles as it developed between ten mothers and their babies. [17] Basic care (feeding, bathing, lifting, carrying, dressing/diapering) was videotaped from birth through toddlerhood in families with no intervention. This study was intended to provide a descriptive baseline for the development of additional services. Its primary goal was to extend practitioners' working sense of a range of "good enough parenting" to include issues of physical difference in mothers. The study also provided a descriptive baseline and generated hypotheses for subsequent research projects. Videotape analyses mapped the gradual mutual adaptation process as it developed between parent and infant during interaction. In the absence of specialized adaptive parenting equipment or intervention the mothers demonstrated considerable ingenuity in developing their own adaptations in babycare.

Extensive teamwork or work division between couples was identified. Early adaptation in infants and facilitation of the adaptation by mothers was documented. For instance, a one-month old infant would curl up like a kitten and remain very still and compact during lifts by his mother with paraplegia. This adaptation was elicited by the mother positioning the baby on his back and signaling him by tugs on his clothes, pausing to evaluate his readiness before lifting, then lifting by holding on to the front of his clothes with one hand. The mother demonstrated how she had very gradually been working on developing the baby's ability to hold up his head during the lift. One month later, at two months of age, videotaping documented that despite his increased physical ability the baby didn't do his part of the work as effectively when he was drowsy--letting his head fall back more, moving too much and becoming less compact during lifts. His mother explained that he needed to be aware of her signals to cooperate. Other techniques that facilitated cooperation or adaptation in the babies were documented and analyzed as well. For instance, diapering by mothers with significant cerebral palsy could last as long as twenty minutes. The mother/infant dynamics and maternal strategies were identified that enabled babies to remain patient and even enjoy the interactive opportunities of such long diaperings.

Subsequent clinical intervention and evaluation was informed by this documentation of the natural and mutual adaptation process. TLG acquired experience with a wide spectrum of psychosocial functioning in families, from extremely resourceful and attuned parents who were research participants, to parents with multiple stressors who were among those receiving clinical services. The overall strategy was to bring the strengths and strategies of "good enough" parents in the community to families with more stressors and fewer resources, who typically were initially less connected to disability culture and its supports. [13,14]

In the mid-1980’s TLG began providing alternative evaluations when parents with disabilities were involved with child protective services systems. It was startling to discover the degree of pathologizing and the lack of disability expertise in child protection evaluation practice. TLG's research data was promptly channeled into the evaluation and court process. In a number of cases out-of-home placement and inadequate visitation were clearly interfering with the gradual development of mutual adaptation to disability obstacles by mother/infant dyads.[17] One highly publicized situation involved Tiffany Callo.[18] This mother with significant cerebral palsy had had two babies removed to foster care, and a videotape of her slow diapering was being used as evidence of her incompetence as a parent. This videotape was reanalyzed by a TLG clinician in light of research data from the Easter Seal project. Compared to mothers with similar disabilities (and despite inadequate contact with her infant which had interfered with their adaptive process) Callo's diapering was shown to be "good enough," discrediting the videotape as evidence in the case. The lack of mutual gaze between this mother and infant had been interpreted as due to an intrapsychic pathology in the mother. The TLG clinician positioned the baby and mother using a lap tray and pillows, and mutual gaze was promptly established once they were in a comfortable position in which they could see one another's eyes. Prior to TLG involvement in another child protective services situation no one had ever made it possible for a mother with quadriplegia (from a spinal cord injury) to care for or interact with her six month old baby during visitations since his removal at birth. Evaluators and workers had assumed that the mother was disinterested, psychologically incapable of attachment, and that care was physically impossible. In the first session, the TLG clinician showed the mother videotapes of other mothers with significant physical disabilities caring for their babies. The mother immediately asked for help so she could care for her baby. In the next session the clinician made it possible for the mother to hold and feed her baby for the first time, and she immediately engaged lovingly with her baby.

Through these experiences it became clear that one cannot evaluate the capability of a parent with a significant physical disability or the relationship between an infant and such a parent without first providing adaptive babycare equipment and techniques that can make interaction physically possible or less stressful. To do so is only to evaluate the mismatch of the environment with the disability, not the parenting.[7,19] The process of conducting these evaluations also uncovered the lack of babycare adaptations on the market for parents with physical disabilities.

These conclusions fueled the initiation of TLG research to develop and evaluate the impact of babycare adaptations. TLG has conducted three research projects specifically focused on developing and evaluating the effect of babycare adaptations for parents with physical disabilities, [20,21,22, 19, 23] funded by NIDRR. The equipment development was informed by the adaptations which mothers had invented in the Easter Seal study. For instance, in the Easter Seal study several mothers needing to lift with one hand held on to the babies' clothing during lifts. In the babycare equipment development projects TLG designed and used lifting harnesses as a more dependable and secure version of the same adaptation. All three equipment studies used videotaping: analyzing care and interaction prior to and subsequent to provision of babycare adaptive equipment. The first study analyzed infant/parent reciprocity as it was impacted by such equipment. The studies have found that such equipment can have a positive effect on parent/baby interaction, in addition to reducing difficulty, pain and fatigue associated with babycare. By lessening the physical demands of care-giving, the equipment can be instrumental in preventing secondary disability complications. For instance, the equipment may prevent the need for additional rehabilitation services to reduce secondary back or repetitive stress injuries associated with babycare. Reduction of secondary injury became a priority, as there was a strong tendency for parents to over-stress their own bodies in an effort to avoid stressing their babies during care. The equipment has also appeared to have a significant role in preventing or alleviating depression associated with post-natal exacerbations of disability, such as in multiple sclerosis. Clinically these projects documented the profound family systemic effects of barrier removal during babycare.[24]

Experiences in the babycare equipment projects made it clear that it was crucial to get specialized babycare equipment and more universally designed babycare equipment marketed. However, manufacturers were not motivated to develop such equipment without documentation of a market. TLG’s concomitant national networking indicated a critical need for public policy change regarding many obstacles facing parents with disabilities. The next step seemed to be documentation of numbers, or a national needs assessment.

Therefore one of the twelve projects of TLG's Rehabilitation Research and Training Center on Families of Adults with Disabilities (1993-1998) was a national survey of parents with disabilities.[2] Data from the survey was recently reanalyzed to focus on parents of children under age eighteen.[25] This was the largest study on parents with disabilities to date and yields data from a national sample of 1175 parents with disabilities, 879 of whom had children aged eighteen or under living in the home. Most of the sample comprised mothers (76%) who were European American (88%), lived with a partner (71%), and had at least some college education (84%). Most acquired their disability prior to becoming parents. The mean age of respondents was 41 years old, and many were working full- (32%) or part-time (17%). The sample was skewed towards those with more education, employment and income, compared to the total population of people with disabilities in which the unemployment rate is cited as 68%.[26] Nonetheless, it is startling to note that 23% of the sample had household incomes under $15,000 (i.e., below the poverty line for a family of four) and 43% had incomes below $30,000.

Several themes emerged from the parents in this sample. Transportation was cited by 83% as a problem for them as parents with disabilities. Accessibility of housing was another key area; 69% of the respondents reported making at least one housing modification to increase access**.** Despite the relatively low income of the sample, fully 84% paid for housing modifications out of pocket and/or loans (21%); only 8% of modifications were covered by Medicaid or insurance. Further, 62% reported that they were unable to do some housing modifications due to lack of funds. We would argue that this presented a significant barrier to parenting in the early years when babies and toddlers require much physical care. Another access problem was identified regarding adaptive parenting equipment. This equipment is still essentially unavailable on the market and is seldom reimbursed by public or private health or disability funding systems. In this survey out of the 396 parents responding to a question regarding payment for such equipment, 67% had used their own money. Out of the 240 parents answering what prevented them from obtaining parenting equipment, 50% had no way to pay for it, and 48% didn't know how to find it. Yet parents who answered how adaptive parenting equipment could have improved their lives (n=717) most said it would have made them more independent or less tired (53% each), made things take less time (51%), made them feel more secure about child's safety (49%), or that it would have caused less pain (42%).

A significant portion of the sample experienced difficulties during pregnancy or childbirth. For example, 24% cited physical or communication access barriers, and 62% found a lack of disability expertise on the part of professionals, attitudinal problems, and/or interference in the right to become a parent (e.g., pressure to have an abortion or tubal ligation, efforts to remove children). Of particular concern was that 16% reported efforts to remove the children from their custody. This theme – that even more educated parents experience threats to this most basic parenting right, of keeping one's children – reemerges in other studies reported in this paper.

Two further RRTC projects examined parents with disabilities (dissertations with the second author as chair). One study was on new mothers with visual impairments [6] and the other on mothers with physical or visual impairments with latency age children.[5] Both studies included an examination of the issue of family role flexibility, i.e., ways in which the family adapts to the rhythm and requirements of a disability. Although disability was not in itself a problem, it was of course relevant and did impact parenting. Mothers gave examples of how the disability was incorporated into the family's ways of doing things. For example, a mother with a visual impairment who walked her child everywhere used the time for them to discuss their day. This echoes the enjoyable parent/infant interaction during long diaperings documented in the Easter Seal study. Both later studies demonstrate the absence of ill effects of a parent's disability per se: disability alone was not a predictor of problems or difficulties in the children. Predictors of problem parenting were the same as those for non-disabled mothers – history of physical, sexual, or substance abuse in the mother's family of origin. Thus research on parents with disabilities must collect data on the background of the parents, to avoid confusing disability with history of trauma.

Cohen[5] was able to directly address one specific stereotype, namely that the children of parents with disabilities will be parentified, i.e., forced to attend to parents' physical and emotional needs at too young an age. Generally Cohen found the opposite to be true: parents often were reluctant to ask their children to do tasks common to children of non-disabled parents (e.g., taking out the garbage) if the parent felt this was in any way necessitated by the parent's disability. In most cases mothers took any increased disability-related difficulties onto themselves. As shown in previous TLG studies of mothers with disabilities and their babies [20,21,22,19,23] mothers will do this even at the peril of their own bodies, risking injury to themselves before making demands of the baby.

Previous TLG research had focused on parents with disabilities whose children were under three. The Cohen[5] study of mothers of older children was a logical extension of this work and contributes to a description of a baseline of "good enough" parenting for latency-age children of mothers with disabilities. This kind of normative work is essential to combat the pervasive negative presumptions of parents with disabilities.

Two more key findings emerge from these two studies. [5,11] The first, which echoes findings from the national sample cited above, is that approximately 10% of these mostly middle to upper-class moms experienced active interference in their parenting (e.g., steps to remove the child, pressure to have an abortion, unauthorized efforts to find absent fathers). We want to underscore the need to include questions about this in any research on parents with disabilities. A second finding was related to the absence of disability norms. Because parents with disabilities usually lack role models, their images of how to parent would be based on non-disabled parents. Thus those parents with with some residual sight would first try things "the sighted way" and only when that failed would they find their own method. In contrast, mothers with greater degrees of visual impairments would assume that sighted ways would not work for them, and would move directly to finding their own way. As more information about the variety and flexibility of ways to parent with a disability become available, parents will have more models and examples from which to choose.

Couple Teamwork in Families with Young Children

Issues of family roles, work division and teamwork, originally identified in the Easter Seal project, were the focus in one of the projects of TLG's RRTC on Families of Adults with Disabilities: the Teamwork Component of the Assistive Technology and Parenting Project. [22] This project developed the TLG Parenting with a Disabilities Couples Survey, adapted from the "Who Does What?" survey.[27] Couples with children age 10 or younger participated. Data was analyzed for 59 couples in which mothers had disabilities (98% physical disabilities) and fathers were non-disabled. Kessler Institute, which was given permission to use the survey, later submitted data that included 30 additional couples in which mothers had physical disabilities (spinal cord injuries) and a non-disabled comparison group of 18 couples--both with children 10 years or younger. A recent re-analysis of the data, [28]including the Kessler material, found that severity of disability did not influence marital happiness. In fact, couples, regardless of disability, on average reported happy marital relationships and high satisfaction with their division of family labor, e.g., with the division of childcare, household tasks, and family decisions. In addition, division of family labor was found to be more equal in couples where the wife had a disability. That is, husbands tended to contribute to the childcare and household tasks that their wives were physically unable to do. Despite the common assumption that husbands of women with severe disabilities might feel burdened by childcare and household tasks, these men directly reported being quite satisfied with their role arrangements. A majority of the mothers with disabilities, however, rated improved availability of funding for adaptive equipment and disability-related assistance services, as well as improved accessibility in housing, as likely to increase their satisfaction with the division of family labor.

Parents with Disabilities and their Teenage Children

A current TLG study, Parents with Disabilities and their Teenage Children, also funded by NIDRR, continues the interest in work and role division within families with parental disability. A logical extension of the work on parents with disabilities and their babies, toddlers, and latency age children was to turn to parents with disabilities who have teenage children. An obvious advantage of studying this population is the opportunity to gather the perspectives of the teenage children. It also allows for a more systemic perspective on the family. This is important because disability in a parent impacts the entire family, and small changes in disability status (e.g., the introduction of an electric wheelchair to a mom with MS who previously used a manual wheelchair) can have profound repercussions across the system. The main focus of this research is on how disability issues are manifest during this developmental phase of the family, i.e., when there are adolescents. One research question relates to "parentification" – the reliance on children for tasks that are age-inappropriate. Because it is such a pervasive assumption in the literature that children of parents with disabilities are overburdened and inappropriately engaged in care-giving, we find it necessary to seek data to shed light on this, but to collect data in a way that doesn't impose preconceived notions of family roles. Further, this question can be examined through the dual perspectives of the parent and the teen, and these perspectives can be compared for families in which a parent does or does not have a disability, since so little is known about what kinds of household and family tasks teens in general engage in.

An additional focus of this current study is on what it means to make research truly accessible to people with varying types of disabilities. For example, we are conducting a national survey of parents with disabilities and of their teens. However, this paper-and-pencil method requires modification for parents with some types of disabilities. For parents with visual impairments we are utilizing a phone version of the survey and an on-line version that allows respondents to use their own computer modifications (e.g., screen enlargers, voice programs). For parents with developmental disabilities we are engaging in an in-person interview with parents who already have a positive relationship with our agency. For Deaf parents we have developed a different questionnaire, to make questions more relevant to this population, deleting items some might find offensive (e.g., items concerning personal care which question physical ability), and ensuring that the reading level is accessible to this population. We are also conducting in-person interviews as this is generally the preferred format for a Deaf population. This kind of tailoring of approach is mandated by the profound distinctions among disabilities, yet allows for examination of core questions that cut across all disabilities. However, this kind of research across types of disabilities necessitates tremendous cross-fertilization among staff (e.g., with expertise in particular disability types) and across disciplines (e.g., psychology and occupational therapy). It is important that researchers and granting agencies not underestimate the requirements of this kind of cultural competence in disability. Without this awareness and expertise, the complexity of disabilities and the boundaries among disabilities are overlooked.

Continuing the Improvement of Practice

Additional current work at TLG pursues the early goal of improving and depathologizing parenting evaluation practice. The National Resource Center for Parents with Disabilities had been compiling information on marital custody (often involving parents with physical disabilities) and child protection services practice. Psychological evaluations of parents with cognitive disabilities involved with child protection systems are being analyzed, and guidelines for practice are being developed.

A new three-year research project has just been funded by NIDRR, which will use TLG's research measures for babycare adaptive equipment in order to develop clinical babycare evaluation tools for occupational therapists. The new evaluation tools are expected to encourage nonpathological and informed intervention for parents with physical disabilities and their babies. There are currently very few occupational therapists with the expertise to intervene regarding babycare adaptations and there are no appropriate evaluation tools to guide their intervention. This lack of expertise has been an obstacle for parents seeking assistance in babycare. Training occupational therapists in the use of the tool is therefore expected to increase the availability of babycare equipment assistance for parents.

Lack of funding for babycare adaptations remains a key public policy problem in the U.S. TLG is currently channeling technical assistance, based on its babycare research data, into public policy change so that babycare adaptive equipment evaluation and provision can be funded under Medi Cal or Medicaid.[29]

Conclusion: Themes Emerging From Research And Practice

We have stressed the pervasive pathologizing lens through which parents with disabilities are viewed, and how this perspective has shaped much of the existing research on this population. In contrast we have presented an alternate disability culture-based approach that has been used in clinical work, evaluation and research at TLG. A disability culture orientation has been delineated, emphasizing disability as socially constructed and thereby shifting the emphasis from differences within individuals to social obstacles and contextual factors. Assessing parental disability in context has been contrasted with attributing difficulties to disability while ignoring confounding risk factors in parents, such as childhood histories of trauma. There has been an emphasis on the importance of experience with families that are diverse in terms of disability and psychosocial functioning and history, so that one can discern differences and avoid over-generalization. The complexity of acquiring cultural competence regarding diverse disability in families should not be underestimated.

The extreme lack of supports for parents with disabilities led to the synergy between research, resource development, and social change efforts described at TLG. The underlying question has been: what would parental disability mean in families with appropriate supports and without social obstacles due to discrimination and lack of access? And, in the meantime, how are our families navigating disability and social obstacles? TLG's research has been documenting this process through the course of the parenting life cycle, beginning with infant/parent adaptation to disability obstacles, then family role division and teamwork between couples with latency-aged children, and currently the evolution of such issues in adolescence. Given the absence of disability norms and role models the intent has been to bring the strengths and strategies of "good enough" parents in the disability community, documented through research, to families with fewer resources and more stressors.

With the focus in the literature on negative effects on children of parents with disabilities, it has been important to counter this by acknowledging the positive aspects. This is not to minimize the difficulties encountered or to paint an overly rosy view, but rather to provide balance and to help clinicians and researchers consider strengths, not just deficits. Anecdotally, and in at least three studies, [3,5,30] positive outcomes for older children of parents with disabilities have been cited. These include learning early the value of family and friends, displaying greater flexibility in family roles, finding humor even in dark situations, and putting quotidian problems in perspective. As children of parents with stigmatized conditions, they tend to learn about oppression, empowerment, and civil rights from an insider perspective and at an early age. Furthermore, children of parents with disabilities share in the disability experience and through it a connection to the disability community, a source of possible enrichment. But in focusing on the differences between parents with and without disabilities it is easy to lose sight of the similarities. Ultimately parenting is about loving, guiding, caring, and nurturing, disability status aside.

References

1. Seelman, K: National Institute on Disability and Rehabilitation Research five year plan. Federal Register: 64(234): 68575-68614, 1999.

2. Toms Barker LT, Maralani V: Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities. Oakland, CA, Berkeley Planning Associates, 1997.

3. Buck F, Hohmann G: Personality, behavior, values, and family relations of children of fathers with spinal cord injury. Archives of Physical Medicine and Rehabilitation 62: 432-438, 1981.

4. Greene BF, Norman R, Searle M, Daniels M, Lubeck R: Child abuse and neglect by parents with disabilities: A tale of two families. Journal of Applied Behavior Analysis 28(4): 417-434, 1995.

5. Cohen L: Mothers' perception of the influence of their physical disabilities on the developmental tasks of children. Unpublished doctoral dissertation, California School of Professional Psychology, Alameda, CA, 1998.

6. Conley-Jung C, Olkin R: Mothers with visual impairments or blindness raising young children. Journal of Visual Impairment and Blindness 91(1): 14-29, 2001.

7. Kirshbaum M: A disability culture perspective on early intervention with parents with physical or cognitive disabilities and their infants. Infants and Young Children 13(2): 9-20, 2000.

8. Patterson JB, Witten B: Myths concerning persons with disabilities. Journal of Applied Rehabilitation Counseling 18: 42-44, 1987.

9. Kerr S: The application of the Americans with Disabilities Act to the termination of the parental rights of individuals with mental disabilities. Journal of Contemporary Health Law and Policy 16: 387-426, 2000.

10. Odegard J: The American with disabilities act: Creating "family values" for physically disabled parents. Law and Inequality 11: 533-563, 1993.

11. Conley-Jung C: The early parenting experiences of mothers with visual impairments and blindness. Unpublished doctoral dissertation, California School of Professional Psychology, Alameda, CA, 1996.

12. Olsen R: Young carers: Challenging the facts and politics of research into children and caring. Disability and Society 11(1): 41-54, 1996.

13. Kirshbaum, M: Family context and disability culture reframing: Through the Looking Glass.

The Family Psychologist 10(Fall):8-12 ,1994.

14. Kirshbaum M: Serving families with disability issues: Through the looking glass. Marriage and Family Review 21(Winter 1/2):9-28,1995.

15. Olkin R: What Psychotherapists Should Know about Disability. New York, Guilford Publications, 1999.

16. Kirshbaum M, Rinne, G: Parents with physical disabilities. *In* Maternity Nursing: Dimensions of Change, M Enriquez, M Auvenshine (eds). Wadsworth Press:645-669, 1985

17. Kirshbaum M: Parents with physical disabilities and their babies. Zero to Three 8 (5) : 8-15,1988, June.

18. Matthews J: A Mother's Touch: The Tiffany Callo Story. New York: Henry Holt & Co. 1992.

19. Tuleja C, DeMoss A: Baby care assistive technology. Technology and Disability 11(1,2): 71-78, 1999.

20. 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: Through the Looking Glass, 1995.

21. Tuleja,C, Rogers,J, Vensand, K & DeMoss,A: Continuation of Adaptive Parenting Equipment Development. Berkeley, CA: Through the Looking Glass, 1998.

22. DeMoss A, Jans L, Kirshbaum, M: Assistive technology & parenting: Teamwork component--The parenting with a disability couples survey. Berkeley, CA: Through the Looking Glass, 1998.

23. DeMoss A, Kirshbaum,M, Tuleja, C, Roger, J & Vensand, K: Adaptive Parenting Equipment: Evaluation, Development, Dissemination and Marketing. Berkeley, CA: Through the Looking Glass, 2000.

24. Kirshbaum M: Baby care assistive technology for parents with physical disabilities: Relational, systems and cultural perspectives. American Family Therapy Academy Newsletter, 20-26. Spring1997.

25. Abrams K: Parents with disabilities raising children under 18: A re-analysis of a national survey of parents with disabilities. Unpublished manuscript, 2001.

26. National Organization on Disability/Louis Harris and Associates, Inc: 2000 N.O.D./Harris Survey of Americans with Disabilities, 2000.

27. CowanPA, Cowan CP: Becoming a family: Research and intervention. *In* Family Research,

Vol. 1, I Sigel, G Brody (eds). Hillsdale, NJ, Lawrence Erlbaum Associates, 1990.

28. Abrams K, Jans L, Kirshbaum M: Marriage and disability: A look at couple relationships and division of family labor between mothers with disabilities and their partners. Unpublished manuscript, 2001.

29. Kirshbaum M: Tales from the frontlines: A practitioner's first experiences in public policy advocacy. Zero to Three 21(6):26-28, 2001.

30. Preston P: Mother Father Deaf: Living between Sound and Silence. Cambridge, MA, Harvard University Press, 1994.