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Serving Parents with Disabilities
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Adaptations Supporting Relationships Between Parents With Physical Disabilities and Their Infants and Toddlers

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Through the Looking Glass
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At least 6.1 million children, 9.1% of children in the United States, have parents with disabilities. More than 4.1 million parents with children less than 18 years old, 6.2% of parents, have reported they have at least one disability (Kaye, 2012). In addition, there are many parents and primary caregivers who do not identify as disabled although they experience functional difficulties that affect baby care such as pain and fatigue. There has been a rapid increase in the number of grandparents in parenting roles, cited as 2.6 million for 2008–09 and estimates of disability in these parenting grandparents has ranged from 25% to 50% (Kaye, 2012; Minkler & Fuller-Thomson, 1999).

This prevalence of parenting with a disability is obscured because systems at the local, state, and national levels seldom identify parents with disabilities in their data collection. The resultant lack of identification of need has limited the development of resources, expertise, and systems change to support families.

As the newly released report *Rocking the Cradle: Ensuring the Rights of Parents With Disabilities and Their Families* by the National Council on Disability (2012) pointed out, parents with disabilities and their children face ongoing multisystem social obstacles,

including housing, transportation, personal assistance, custody, and assistive technology. They frequently have to pay out-of-pocket for extra expenses associated with being a parent with a disability despite family incomes that are approximately half those of parents without disabilities (DeNavas-Walt, Proctor, & Smith, 2012; Kaye, 2012).

A Disability Culture Perspective

DISABILITY CULTURE'S CONTEXTUAL view of disability as socially constructed shifts the emphasis from the differences that reside within the individual

to an emphasis on social and environmental obstacles. A social or cultural perspective regarding disability focuses on transcending obstacles through access: the elimination of barriers whether due to attitudinal bias, lack of expertise, lack of resources, communication, environment, or public policy (Kirshbaum, 1994; Olkin, 1999).

Abstract

This article focuses on a disability culture-based organization's process of addressing baby care adaptation issues of parents with physical disabilities and their babies and toddlers. The author describes the role of teamwork between infant mental health specialists and occupational therapists, application in custody situations, and public policy change efforts relevant to baby care adaptation. Baby care adaptations can have a profound effect on the relationships between parents with physical disabilities and their young children.

Speaking from the perspective of people with disabilities and their family members, pragmatic ingenuity about adaptation is needed to achieve access—to make family life work in the face of everyday obstacles (Kirshbaum, 2000).

Through the Looking Glass

Through the Looking Glass (TLG) grew out of the independent living or civil rights movement for people with disabilities. As such, the organization has had a cultural rather than a medical model of disability—with a commitment to decreasing social obstacles through supporting better practice and more resources nationally, through adapting services, and through developing parenting adaptations to reduce functional obstacles associated with disability. Since its founding in 1982 TLG has served families with disability in parent or child, combining infant mental health, family therapy, and early developmental intervention with practical adaptive disability solutions. TLG has been the primary organization, nationally and internationally, focused on baby care adaptations for parents with physical disabilities and their young children, serving thousands of these diverse families. Over the years TLG has found that baby care adaptations can have a profound effect on the relationships between parents with physical disabilities and their babies and can impact the outcomes of child custody cases.

This article focuses on the process of addressing baby care adaptation issues of parents with physical disabilities and their babies and toddlers, including the role of teamwork between infant mental health specialists and occupational therapists, application in custody situations, and public policy change efforts relevant to adaptation.

Documenting Natural Infant–Parent Adaptation

AS INITIALLY DESCRIBED IN *Zero to Three* (Kirshbaum, 1988) TLG conducted a groundbreaking research project from 1985 to 1988 that sought to expand the working sense of the range of “good-enough parenting” to include physical difference in parents. The project videotaped, monthly, how mothers with physical disabilities cared for their babies from birth through toddlerhood in basic areas of care (e.g., feeding, bathing, diapering and dressing, lifting, carrying, and moving). Without intervention or adaptations being introduced by service providers, most mothers developed ingenious solutions to disability obstacles. A natural reciprocal adaptation process unfolded over time in the mother–infant dyads. Videotape analyses mapped this gradual mutual adaptation process as it developed between parent and infant during interaction. Babies adapted to their mothers’



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disabilities as early as 1 month old.

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. (Kirshbaum & Olkin, 2002, p. 72)

Subsequent work with families involved with the child welfare system revealed interruption of the mutual infant–parent adaptation process associated with out-of-home placement and infrequent visitation. It became clear that

families in these situations had a heightened need for assessment and intervention regarding baby care adaptations.

A parent with significant cerebral palsy was videotaped by child protection workers while diapering her baby—without any adaptations being provided and after a long period of out-of-home placement which interfered with the natural reciprocal adaptation process between parent and child. This tape was cited in court as evidence for her parental incapability, despite the similarity to long diaperings by high functioning mothers with cerebral palsy in the community. (Kirshbaum & Olkin, 2002, p. 74)

In response, the TLG infant mental health therapist, familiar with disability adaptations, began introducing parenting adaptation as part of her evaluations in child welfare cases.

For example, in a child welfare case involving a mother with significant cerebral palsy, the psychologist conducting the evaluation speculated that the lack of mutual gaze between mother and baby was likely due to the intrapsychic pathology of the mother. However, no one had set up a physical situation in which the

PHOTO: HUNTER LEWIS WIMMER

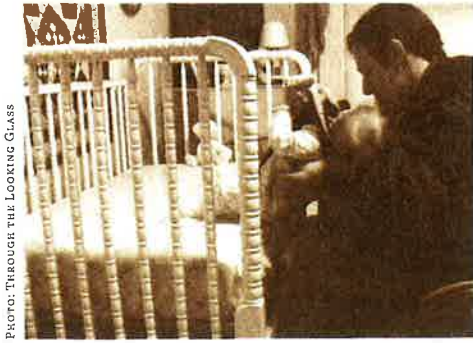


PHOTO: THROUGH THE LOOKING GLASS

Parents with disabilities and their children face ongoing multisystem social obstacles, including housing, transportation, personal assistance, custody, and assistive technology.

mother and baby were comfortably located face-to-face at an appropriate distance from one another to allow mutual gaze to develop. The disability specialist simply attached a lap-top tray to the mother's motorized wheelchair and positioned the baby on a pillow on the tray (with pillow and baby secured by a wide Velcro strap); mutual gaze between mother and baby began immediately. (National Council on Disability, 2012, p. 175)

Such situations led to the conclusion that one cannot evaluate parental capability and the potential of a relationship between a parent with a significant physical disability and a baby without first providing whatever adaptive techniques and equipment reduce stress during parenting or even make it possible for interaction to occur and the infant-parent relationship to develop. Without doing so one is evaluating the mismatch of the environment with the parental disability, not the parenting.

Baby Care Adaptation Research and Development

THESE EXPERIENCES MOTIVATED the addition of occupational therapists to TLG's infant mental health staff, so that baby care adaptation development could be a focus. TLG began a series of three research and development projects funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and conducted by a team of infant-family mental health specialists and occupational therapists. These projects designed, fabricated, and provided individualized baby care adaptations to parents with physical disabilities and their babies in order to reduce obstacles at the outset of parenting. The equipment was informed by the inventions of mothers documented in the 1985-1988 study. For instance, several of those mothers who needed to lift with one hand grasped their babies' clothing during lifts. Lifting harnesses were

developed as a more dependable and secure version of that strategy. The adaptations also included accessible cribs; baby care trays and seats for wheelchairs; four-wheeled walkers with baby seats; accessible diapering surfaces and high chairs; positioning supports for breastfeeding, holding, and carrying; as well as accessible childproofing. Adaptive techniques (e.g., one-handed diapering and dressing) and facilitation of cooperation in the infant (e.g., teaching them to lift their bottoms during diapering) that were based on the solutions of parents with disabilities were included in the intervention. Illustrations were provided through publications with photographs (DeMoss, Rogers, Tuleja, & Kirshbaum, 1995; Vensand, Rogers, Tuleja, & DeMoss, 2000) and a videotape.

The disability cultural perspective was reflected in the emphasis on *environmental mismatch*, "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" (Tuleja & DeMoss, 1999, p. 72). Focusing on what is conducive to change is the point—changing a diapering surface to accommodate a wheelchair—rather than focusing on a mother who can't stand as the problem.

Videotapes of interaction were analyzed before and after provision of baby care adaptations to assess outcomes. These research projects found the baby care adaptations to be inherently empowering, decreasing environmental barriers and increasing parents' functional baby care abilities and involvement, decreasing fatigue and pain. By reducing the physical demands of care the equipment appeared to prevent secondary injury. Occupational therapists had observed mothers, without baby care adaptations, overstressing their own bodies and developing repetitive stress or back problems, in an effort to avoid stressing their babies during care. In some situations, the equipment helped resolve maternal depression that was associated with postnatal exacerbations of disability, such as in multiple sclerosis. As baby care tasks became easier, parents tended to be less preoccupied with the physical demands of the task and engaged in more positive interactions with their babies (Tuleja & DeMoss, 1999; Tuleja, Rogers, Vensand, & DeMoss, 1998).

Next, a national survey of 1,175 parents with disabilities was conducted for TLG's National Center for Parents With Disabilities, documenting the many social obstacles these parents experienced (Toms-Barker & Maralani, 1997). Parents noted the unavailability of adaptive parenting equipment or information about it and the lack of public or private health funding for it, necessitating

out-of-pocket payment. Of the 717 parents who answered how adaptive parenting equipment could have improved their lives 53% said it would have made them more independent or less tired, 51% said it would have made things take less time, 49% said it would have made them feel more secure about their child's safety, and 42% said it would have caused less pain.

A subsequent survey of 89 couples in which mothers had disabilities and nondisabled partners documented happy marital relationships and high satisfaction with their division of child care, household tasks, and family decisions. However, a majority of the mothers with disabilities rated improved availability of funding for adaptive equipment as likely to increase their satisfaction with the division of family labor (Abrams, Jans, & Kirshbaum, 2001; DeMoss, Jans, & Kirshbaum, 1998).

Encouraging National Baby Care Adaptation Practice

SINCE THE ESTABLISHMENT of TLG's NIDRR-funded national centers for parents with disabilities and their families in 1993, requests for technical assistance and information have indicated an unmet need for occupational therapy services for parents with physical disabilities and a related need for occupational therapist training regarding baby care adaptations. TLG responded by developing a curriculum to train occupational therapists in academic settings (Tuleja, Rogers, & Kirshbaum, 2002). TLG is currently developing an online course regarding baby care adaptations to meet the needs of practicing occupational therapists.

Developing Tools to Support Baby Care Adaptation Practice

During the national centers' technical assistance and training, a need had been identified for tools to guide baby care assessment and intervention practice. TLG completed the *Baby Care Assessment for Parents With Physical Limitations or Disabilities: An Occupational Therapy Evaluation* (BCA; Tuleja, Rogers, Kirshbaum, & Abrams) in 2005 as a NIDRR Field-Initiated Development Project. It has been primarily used to guide intervention and to train occupational therapists since then. The breadth of the assessment has also proved to be very effective for clarifying the physical functioning of parents involved in custody cases.

The BCA tool (Tuleja et al., 2005) was based on extensive clinical experience assessing and addressing parents' baby care strengths and challenges, analysis of existing performance measures, and TLG's research projects involving development and analysis of the impact of baby care adaptations. The tool reflects development by a team of

infant–family mental health specialists and occupational therapists, including those with personal and family disability experience. The BCA includes a Parent Baby Care Self-Assessment, Occupational Therapy Baby Care Performance Analysis, and Parent–Child Relationship Referral Guide. The domains included in the Baby Care Performance Analysis are:

1. Holding,
2. Positional Changes,
3. Carrying and Moving,
4. Nursing,
5. Bottle Feeding and “Sippy” Cup,
6. Spoon Feeding,
7. Diapering,
8. Dressing,
9. Nap and Bedtime Routines,
10. Bathing,
11. Hygiene,
12. Going Places,
13. Comforting,
14. Interactive Play,
15. Providing Developmental Experiences, and
16. Discipline/Limit Setting/Cooperation.

TLG has already established that the BCA (Tuleja et al., 2005) performance analysis ratings have strong content validity and high inter-rater reliability among TLG occupational therapists. External content validity was established through training and use by occupational therapists in several institutions. Current research focuses on whether performance ratings made by occupational therapists who were not involved in the development of the tool are adequately correlated with TLG ratings, to ensure that the BCA has sufficient inter-rater reliability when used with occupational therapists outside of TLG.

Ensuring validity of the tool is particularly important because it is increasingly being used to generate evidence in child welfare and family court custody cases when the physical functioning of a parent with a disability is alleged to negatively impact the well-being of their child. A TLG vignette included in the National Council on Disability report on parents with disabilities and their children illustrates such use:

Paul’s story demonstrates the gravity of the situation faced by many parents with disabilities who are involved in the family law system. Paul was a father with quadriplegia and a stay-at-home parent for his three-year-old son Leo. He had spent 20 years as a police officer and became quadriplegic when he was shot on the job.



PHOTO: THROUGH THE LOOKING GLASS

Baby care adaptations can have a profound effect on the relationships between parents with physical disabilities and their babies.

Although Paul used walking canes, his active son was safe in his care. He had door alarms on the doors and bookcases in case Leo tried to climb or leave the house. An ingeniously installed alarm system triggered if Leo tried to leave the yard. Leo had never been hurt or gotten away as a result of Paul’s disability. Then Leo’s mother filed for divorce, moved out, and filed for full physical custody. She asserted that quadriplegia rendered Paul unable to care for Leo.

Despite uncontested testimony that Paul had always been the primary parent, the Georgia family law court awarded temporary custody to the mother, with severely limited visitation to Paul. Twenty-four-hour supervision was required during the visitation periods, and Paul was ordered to hire a professional nanny to supervise visitations. Over the next two years of litigation, Paul went through a significant portion of his disability retirement fund paying for attorneys, private nannies, interim child support, and assessments.

He and his attorney concluded that the only way to show parental capacity was with an Adapted Baby Care Assessment. No occupational therapist was able to do the assessment in their area, so a therapist from TLG flew to Georgia, conducted the assessment, completed and submitted a court report, and appeared in court to defend it at trial. Paul won half custody of Leo with no requirement of supervision. While grateful, he was sad that he had missed a great deal of his son’s life. Both he and Leo experienced tremendous grief during the long periods of court-ordered separation. (National Council on Disability, 2012, p. 148)

TLG has also been modifying the BCA (Tuleja et al., 2005) for use to predict adaptation needs and potential functioning when current performance in baby care cannot yet be observed. One example of this is use of the BCA in home studies that precede adoption. Another TLG vignette from the National Council on Disability’s report regarding parents with disabilities and their children illustrates this:

For instance, a woman with a physical disability experienced difficulty during the home study required for adoption. The social worker said she had serious reservations about the woman’s ability to parent, especially that she might drop a baby or be unable to catch a toddler who ran off. The woman—a leader in the independent living community—assumed that it would not be wise to express her dismay about the social worker’s speculations. Rather, she contacted a national center that provides technical assistance regarding custody issues of parents with disabilities. The center conducted a baby care adaptation assessment, using weighted dolls and adaptations that have proved helpful to other parents with disabilities. The mother provided the adoption agency with the assessment report, documenting capabilities and solutions to potential difficulties, as well as the center’s video and publication illustrating such adaptations in use by other parents. She successfully adopted a baby. (National Council on Disability, 2012, p. 179)



PHOTO: THROUGH THE LOOKING GLASS

Once parents experience the use of the adaptations, they have voiced that the “can-do” attitude implicit in the baby care solutions opens up hope and possibilities.

As a disability culture-based tool, the BCA (Tuleja et al., 2005) has an empowerment orientation; the development of adaptations is guided by the parent’s expertise and choices about role and care options. Teamwork between parents and occupational therapists is integral to the process.

Teamwork Between Infant Mental Health and Occupational Therapy Practitioners

Teamwork and mutual support between infant mental health and occupational therapists is crucial when serving the most stressed and vulnerable families. Parents with disabilities are not immune to the problems that are familiar in infant mental health practice and that complicate the formation and course of the infant–parent relationship. They may have had childhood histories of abuse and neglect and may have had multiple out of home placements. Having grown up in an era of inadequate support for families of children with disabilities, their relationships with their own parents may have been affected by unaddressed parental grief and depression.

In addition, women with disabilities are more vulnerable to abuse and violence than women without disabilities. Social isolation and dependence on others for personal and household assistance increases this risk. Research documents that some women with disabilities stay with partners who are potentially dangerous to themselves and their children when the women depend on the partners for care and are concerned they will lose custody of their children without this assistance (Millberger et al., 2002; Nosek, Robinson-Whelan, & Hughes, 2006). Recall that TLG’s research indicated that baby care adaptations can increase the parenting role; therefore they can reduce dependency on assistance.

Parents with disabilities may be vulnerable to depression due to isolation; poverty;

history of dependency, abuse, or exploitation; environmental barriers; barriers to health care; and health disparities. Depression is often unidentified and unaddressed in parents with disabilities, and the results of depression are often conflated with the impact of the disability. Women with disabilities experience a particularly high rate of depression with 30–59% being affected (Nosek et al., 2006). Screening for postpartum depression is advisable because a history of previous depression is a predictor of postpartum depression (Beck, 2001).

When women experience disability onset or worsening during pregnancy or postpartum they can be expected to experience reactive depression and grieving. Yet TLG’s research has documented the role of baby care adaptations in resolving maternal depression in such situations.

A mother with a post-natal 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 baby was not forming a relationship to the mother and the father was becoming overwhelmed. Baby care adaptations helped alleviate her depression, increasing a balance of functioning in the couple and allowing the relationship between mother and infant to flourish. (Kirshbaum, 2000, p. 17)

As Jeree Pawl has said about working with babies and families in general: “Pulling together the threads of hope and the evidence of possibility is our task” (Pawl, 2000, p. 5). Applying the infant mental health idea of “parallel process,” if we support one another in positive and empowering perspectives about families, we are more likely to support hope and problem-solving in the families we serve.

The Importance of an Early Focus on Adaptations

When serving particularly stressed parents with disabilities, it’s crucial to begin addressing parenting adaptation solutions concomitantly with psychosocial issues, establishing teamwork between infant mental health and occupational therapists from the outset. With the most stressed parents, the concrete, enlightening potential of baby care equipment and the new hope it brings about the parenting role can motivate addressing other problems, such as substance abuse or domestic violence. Unfortunately, records of custody cases of parents with disabilities seldom reflect consideration of adaptive issues (Kirshbaum, Taube, & Baer, 2003; National Council on Disability, 2012). A TLG vignette from the National Council on Disability report illustrates such a situation:

A young African-American mother with quadriplegia had had her baby removed at birth after testing had shown prenatal substance abuse. The social worker described the mother as forming no relationship to her baby despite weekly visitation. She thought the mother was psychologically incapable of forming a relationship with her child. In the six months since the baby had been born the mother had been provided no assistance in order to make it possible for her to hold or care for her baby in any way. Everyone, including the mother, just assumed this was impossible. The able-bodied grandmother did the care or left the baby in a playpen during the visits. During the first visit I saw a depressed mother who indeed appeared estranged from and disinterested in her baby. But when I showed her videotapes of parents with disabilities and their babies—images of possibilities—she asked if I could help her hold and feed her baby. So in the second visit, with a variety of frontpacks and pillows, she was able to hold her baby for the first time. She tenderly nuzzled and murmured to her, caressing with her lips, greeting her baby for the first time as mothers do immediately after giving birth. (National Council on Disability, 2012, p. 177)

When occupational therapists are included in intervention, they usually bring familiarity with how people with physical disabilities can live independently in the community; their practical problem-solving orientation is helpful even if they lack experience with parenting adaptations. Both parents and mental health providers, often unfamiliar with baby care adaptations, have difficulty predicting their potential impact. TLG’s occupational therapists have explained that both parents and providers lack a repertoire of “visual histories,” accumulated images of care by parents with physical disabilities as well as care incorporating baby care adaptations. For providers, this may lead to exaggeration of the difficulty, even disbelief in the possibility of care, precluding the development of solutions. Parents may apply patterns of “disability accommodation,” soldiering through the disability obstacles, as they have learned to do in other areas of their lives. Mothers can feel pressured to be “supermom,” wary about expressing needs or divulging difficulties out of concern about attitudinal bias and judgments (Rogers, Tuleja, & Vensand, 2004; Tuleja et al., 1998). As noted earlier, TLG has found that mothers with physical disabilities tend to overstress their own bodies during care in order to avoid stressing their babies. Mothers’ overuse of their bodies can result in secondary injury, such as repetitive stress or back problems. In turn, this can limit their parenting role and even result in separations due to hospitalization. The early introduction of baby care adaptations can reduce

supermom pressures and prevent secondary injury repercussions on the infant–parent relationship.

Once parents experience the use of the adaptations, they have voiced that the “can-do” attitude implicit in the baby care solutions opens up hope and possibilities. One mother with quadriplegia from a neuromuscular disability said she had assumed she would just be a passive observer of others taking care of her baby. With a range of baby care adaptations she was able to be the primary caregiver.

There are also practical timing reasons to establish adaptation teamwork early. Ideally, the teamwork should begin during pregnancy. There are often shifts in the assistive technology needs of the expectant mother due to weight and balance changes during pregnancy, for example, the need to begin using a walker, or manual or motorized wheelchair. Such equipment can also support care once the baby is born. It takes time to develop an adaptive nursery; it can even require a move to other housing or modification of the home. Parents with multiple stressors or lacking independent living experience will require plenty of time to integrate the use of the scarce community resources which can be mobilized.

Clarifying Infant Mental Health Issues Through Adaptations

THE EARLY INTRODUCTION of baby care adaptations, even piloting them during assessment, helps to guide infant mental health intervention. Once parents experience the effect of the baby care equipment, it is typically integrated smoothly into daily routines. However, sometimes addressing the physical baby care obstacles clarifies underlying relationship issues that can be addressed in infant mental health intervention. After a mother with significant cerebral palsy acquired an adaptive nursery, easing her physical care, her difficulties with empathizing with her baby’s experience were highlighted. Providing another mother with an adapted frontpack for holding her baby surfaced her aversion to physical closeness and her history of childhood abuse. Addressing the physical disability obstacles can be clarifying for parents, too. Once baby care adaptations were in place and care was physically possible, one highly stressed mother involved with the child welfare system, faced with the reality of the emotional commitment, relinquished the baby for adoption.

Teamwork Regarding Family Systems and Cultural Issues

Introducing adaptations can draw attention to family, role, or cultural issues that need consideration and can benefit from

Baby care adaptations can produce extremely rapid change in the functioning and role of the parent with a disability.

teamwork when addressing the parent’s functioning in baby care.

Infant mental health practitioners are familiar with entering the whirl of infant–parent and family life during home visiting. However, parental physical disability adds additional elements to the picture. Parents with disabilities may have personal assistants addressing their personal or household needs and involved with their children. One often sees a complex interplay of parent assistive technology within a home that may or may not be conducive to access and may or may not facilitate the presence of baby care adaptive equipment. The baby care adaptive equipment is often combined with adaptive techniques, and the dance between parent and child often involves natural reciprocal infant–parent adaptation and collaboration. Meanwhile parents, family members, and personal assistants may be working around the disability issues in the household, affecting the role of the parent with the baby.

A parent with a long-term stable physical disability is more likely to have integrated adaptations and developed skills and assertiveness while navigating this household teamwork. If the parent has a new or newly worsened disability, a disability complicated by cognitive difficulties or depression, or patterns of long-term dependency, working out household parenting roles and integrating adaptations can be more challenging and time-consuming.

Baby care adaptations can produce extremely rapid change in the functioning and role of the parent with a disability. Occupational therapists are often introducing the adaptations at the already change-laden transition to parenthood. Most parents and families flourish in the face of such changes. Sometimes the process is more difficult and results in rejection of adaptations the occupational therapist worked so hard to provide.

Occupational therapists can benefit from support from mental health practitioners who are familiar with homeostasis in the face of change in family systems. The transition to parenthood is understood to be a time of disequilibrium and role reorganization in couples and families when added changes, as from adaptations, could be difficult to integrate (Kirshbaum, 1997).

For example, in one family the non-disabled grandmother’s role, before baby care equipment intervention, was to diaper and spoon-feed the baby. With intervention, which included adaptive baby care equipment, the mother was able to perform these tasks independently. The grandmother no longer felt necessary in her role of care taking. In response, the mother used the equipment less often so the grandmother would continue to be more concretely involved with care of the baby. (Tuleja & De Moss, 1999, p. 72)

More consideration of cultural issues is especially important because of the ethnic diversity of parents with disabilities; for instance, analysis of the American Community Survey indicated that 13.9% of American Indian/Alaska Native parents, 8.8% of African American parents, 6% of White parents, 5.5% of Latino/Hispanic parents, and 3.3% of Asian/Pacific Islander parents have a disability (Kaye, 2012).

Always, family and cultural issues, including child care practices, are the background and foreground of the family caregiving dance.

A Samoan mother with hemiplegia, concerned about her ability to care for her newborn baby, requested an adapted crib. Once provided she only used the crib to store toys because it didn’t fit with her family’s infant care practices. (Kirshbaum, 1997, p. 25)

Learn More

Web Sites

THROUGH THE LOOKING GLASS & ITS NATIONAL CENTER FOR PARENTS WITH DISABILITIES AND THEIR FAMILIES

www.lookingglass.org
3075 Adeline St., Ste. 120
Berkeley, CA 94703
Phone: 1.800.644.2666 (VOICE)
TTY: 510.848.1005

THE NATIONAL CENTER FOR PARENTS WITH DISABILITIES & THEIR FAMILIES: THE LEGAL PROGRAM

www.pwd-legalprogram.org

Publications

ADAPTIVE BABY CARE EQUIPMENT: GUIDELINES, PROTOTYPES & RESOURCES
Vensand, K., Rogers, J., Tuleja, C. & DeMoss, A. (2000). Berkeley, CA: *Through the Looking Glass*.

ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN
National Council on Disability (2012).
<http://www.ncd.gov/publications/2012/Sep272012/>

Disability cultural issues need consideration as well. Parents who identify with disability culture may have a strong preference for providers with disabilities or who are part of the independent living disability community. They may not be willing to reveal needs and difficulties to cultural outsiders, out of concern about attitudinal bias.

Custody Situations

Recent TLG research has particularly targeted child welfare and family court practice with parents with disabilities and their children, documenting the prevalence of inappropriate practice (Callow, Buckland, & Jones, 2011; Fife, 2010; Kirshbaum et al., 2003; National Council on Disability, 2012). Rarely do professionals conducting assessments or providing services in these situations consider the need for an occupational therapist evaluation or the relevance of baby care adaptations.

Inappropriate removals can have devastating consequences for children, as another TLG vignette for the National Council on Disability report reflects:

Bobby's story illustrates the trauma endured by children when a family is wrongfully separated. In Kentucky, Louise, a grandmother in her early 60s, has arthritis and uses a walker. She has had custody of her two-year-old grandson, Bobby, since his birth. When Bobby's mother was arrested, she was asked if she had any children. She explained that her son lived with her mother. Social workers came to Louise's house and explained that they were removing Bobby but he could stay three more weeks, until his third birthday, since there was no immediate need for removal. The social worker added that it is "textbook" that Bobby would be better off with a young, healthy family than a grandmother who is "old and handicapped."

Louise did her best to explain the unexplainable to Bobby—that child welfare was taking him and she didn't know for sure when he could come home. Bobby was removed just after he turned three, and he engaged in developmentally appropriate protest for an extended period. The social worker viewed this as pathological; she repeatedly physically dragged Bobby away from Louise at the end of visitations, threatening to end contact if he did not "behave." Eventually, she acted on her threat: Citing how "upsetting" visitations were and Louise's poor choice in feeding him candy on a

visitation (she brought a marshmallow "Peep" to an Easter visitation) the social worker severely curtailed the visits.

At that point, Bobby became despairing and detached quite quickly. He refused to eat, and when he did eat, he vomited. Child welfare sent him for barium treatments to see if he was physically sick; he wasn't. He was then hospitalized for an injury sustained in foster care. Louise was not allowed to visit, and his foster parents chose not to. Bobby spent his hospitalization alone in a crib with a top to prevent him from getting out, surrounded by IVs and other invasive equipment. Bobby was then labeled as "willful" and considered a "high-needs, difficult child." This label was used as another reason not to return him to Louise. Bobby was eventually adopted; thankfully, the adoptive parents kept some contact with Louise. Her knowledge of his foster care history helps Bobby's adoptive parents understand the psychiatric work he requires to deal with his reactive attachment disorder, claustrophobia, and ongoing nightmares.

Efforts to move the court to acknowledge the discrimination and its effects met with complete truculence. The trial judge stated from the bench, "For the record, disability has nothing to do with this case." (National Council on Disability, 2012, pp. 125–126)

Addressing Baby Care Adaptations in Public Policy

IN 2001, I wrote an article for *Zero to Three* describing my first tentative experiences in public policy advocacy, which were encouraged as a fellow in ZERO TO THREE (Kirshbaum, 2001). The public policy role of TLG has evolved considerably since that time, resulting in the passage of legislation regarding parents with disabilities in Idaho and Kansas, and regarding baby care adaptations in California. The Idaho and Kansas legislation addressed baby care adaptation in assessment and intervention, even requiring such adaptations in custody situations (Callow et al., 2011).

Recently TLG has had a substantive role in advocating for, planning, and writing the National Council on Disability's extensive report, *Rocking the Cradle: Ensuring the Rights of Parents With Disabilities and Their Children*, submitted in October 2012 to President Obama. My chapters for this report specifically focused on adaptations in intervention and parenting evaluations.

Included in the report are drafts of state and federal legislation, developed by TLG's Ella Callow, which also addressed baby care adaptation issues. The following finding and related recommendations of the report highlight adaptation issues:

FINDING 4: *Parents with disabilities who are involved in dependency or family proceedings regularly face evidence regarding their parental fitness that is developed using inappropriate and unadapted parenting assessments. Resources are lacking to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques. (National Council on Disability, 2012, p. 311)*

Following this finding the report recommends that:

- States must mandate training for custody evaluators on parents with disabilities and their children;
- CMS [Centers for Medicare and Medicaid Services] must expand the definition of durable medical equipment (DME) to include adaptive parenting equipment
- States should establish adaptive parenting equipment reuse and loan programs. (The National Council on Disability, 2012, p. 312–313)

TLG has been honored to channel its many years of research and intervention experience to this major public policy effort. It is hoped that the result will be significant reductions in the obstacles facing parents with disabilities, their babies and toddlers, and the service providers who support families with disabilities. ♣

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