Babycare Assistive Technology for
Parents with Physical Disabilities:
Relational, Systems, & Cultural Perspectives

Megan Kirshbaum

In the past decade there has been a rapid increase in
the numbers of parents with disabilities, which
appears to be due to the independent living move-
ment, the civil rights movement for people with di-
abilities, and the resultant integration and expectation
of participating in all aspects of life. Approximately
half of these parents have physical disabilities. In the
United States there are almost six million children
under age 18 living with at least one parent with a
physical disability, or 8% of all children in households with parents (Survey of

The development of specialized
resources for parents with disabilities has
not kept pace with the rapid increase in
disabled parent families, and generic
resources and services for parents have
not yet responded to the needs of parents
with disabilities. Babycare presents a particu-
larly compelling example of the prob-
lem. There is a lack of adaptive parenting
equipment on the market and an absence
of universal design in babycare equip-
ment. Generally, parents with physical
disabilities have had to create their own
solutions to disability obstacles during babycare. From
1985 to 1988, Through the Looking Glass, an agency in
Berkeley, California, videotaped mothers with physical
disabilities and their babies during basic babycare.
Without intervention or assistive technology for bab-
care, most mothers developed ingenious solutions to
disability obstacles while their babies gradually adapt-
ed. There was a natural reciprocal adaptation process
that occurred through time (Kirshbaum, 1988).

Through the Looking Glass later dealt with parents
with physical disabilities in multiply stressed families who
were involved with children's protective services. In these
situations the absence of appropriate parenting equipment
compromised and undermined an appropriate evaluation
of parental capability and of infant/parent relationships
(Matthews, 1992). The following vignette is a particularly
poignant illustration.

A young African-American mother with quadri-
plegia 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 disabili-
ties and their babies—images of possibilities—she asked
if I could help her hold and feed her baby. So in the sec-
dond visit, with a variety of front packs 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 imme-
diately after giving birth.

It became clear from our work with these families
that one cannot assess the potential of a relationship
between a significantly physically disabled parent and a
baby without first providing whatever adaptive techniques and equipment make it possible for interaction to occur and an infant/parent relationship to develop. A mother with controlled movement only from her shoulders up, as in the preceding vignette, would have needed a great deal of such equipment—and that equipment did not exist.

Although Through the Looking Glass’s interest in babycare equipment development was initiated with particularly vulnerable families, its general applicability soon became clear. A research project from 1991 to 1994 found that parents with a wide variety of physical disabilities and degrees of disability may require or can benefit from assistive technology and adaptive strategies during care of their babies and toddlers. The absence of such equipment was creating practical problems, sometimes limiting parents’ roles in babycare and play, and increasing the need for personal care assistance or the involvement of non-disabled family members. Even if a parent struggled to manage care without appropriate equipment it could mean added stress, fatigue, or even secondary injury (TLG, 1994).

Through the Looking Glass approached the design and development of adaptive babycare equipment by building upon its extensive experience of normative parenting by people with disabilities: a visual history of many parent/baby dyads and their reciprocal adaptation. A sense of possibilities was informed also by the personal experiences of staff who were parents or family members with disabilities, and their cumulative informal experiences within the disability culture. In the first project focused on babycare equipment development more than fifty prototypes were developed (see De Moss, et al., 1995), field-tested, and evaluated as to their impact on parent functioning and the infant/parent relationship (TLG, 1994).

In this and two subsequent projects, occupational therapists have been developing babycare equipment during home visits with families. The equipment has been developed collaboratively with the parents over time, so that changing developmental needs could be addressed. Generally parents receiving babycare equipment have not requested psychotherapeutic services, though TLG offers home-based infant mental health/family therapy intervention. These research projects have created an ongoing dialogue among project occupational therapists, researchers, and clinicians who are specialists in family therapy and infant mental health, and among project staff with and without personal disability experience. In the midst of their groundbreaking and compelling work, the research team analyzes the impact of equipment, and explores the nature of interaction between the occupational therapists and families, as well as the process of change precipitated by equipment provision. The following comments represent the evolving point of view of a clinical member of this team.

**Considering the change issues**

The provision of babycare adaptive equipment can produce rapid and dramatic change in parent functioning, in the infant/parent relationship, and in couple or family division of labor. One mother with quadriplegia had expected to be a passive observer of her baby being cared for by others. Within weeks the equipment enabled her to be the primary physical caregiver of her baby. Increasing the role of parents with their babies is compelling work. When occupational therapists have facilitated such dramatic changes, well-assimilated by most families, it is disappointing when viable equipment is rejected or underutilized, or when other factors eclipse the impact of the equipment. The occupational therapists developing and providing the equipment are thrust into being agents of change within families, and therefore need to consider their work from a relational and systems perspective.

All families vary in their tolerance of change, depending on their styles of coping, such as the “ability to exchange clearly defined roles flexibly” (role reorganization) and “utilize outside resources effectively” (Rolland, 1994). In the work with parents with disabilities and their babies, there are a number of intersecting change issues amplifying one another. The occupational therapists are introducing change at the point of what is frequently the birth or adoption of a first child to a couple, recognized as a normative yet stressful transition for a family. Existing differences between partners widen, and shifting roles or division of labor is linked with marital conflict (Cohan & Cohan, 1990; Cohan et al., 1991).

As discussed in family systems literature (Carter & McGoldrick, 1989; Levinson, 1978 & 1986) it seems that family life structure is reevaluated during transitional life-cycle periods. Rolland (1994) says that “transition periods are potentially the most vulnerable because previous individual, family, and illness life structures are reappraised in light of new developmental tasks that may require discontinuous change rather than minor alterations.” The transition to becoming a parent is such an upheaval. As Rolland (1995) describes, it is a “transition from a lower stress family system of two relatively
autonomous adults to the considerable demands of an inwardly focused, cohesive family unit with an infant."

In addition, disability frequently introduces changes that particularly affect families when they amplify developmental transitions, such as the onset of or exacerbation of disability during the transition to parenthood (Rolland, 1989 & 1994). Even where there is a lifelong or long-term disability in a parent the transition to parenthood tends to create disequilibrium in the parent’s disability coping, as well as surfacing individual, couple, and intergenerational issues regarding autonomy, functioning, and loss. In general, the intersecting sources of change are both a source of stress and an opportunity for growth.

**Applying an infant/parent relational perspective**

The process of change needs to be understood through the lens of the infant/parent relationship. Through the Looking Glass documented a gradual reciprocal process of adaptation without intervention in an observational study of mothers with physical disabilities and their babies (Kirshbaum, 1988; Kirshbaum & Kirshbaum, in press). Contrasting situations in subsequent clinical experience highlighted this process. For instance, when babies were removed from parents with disabilities and had inadequate visitation the reciprocal adaptation process could not occur. Babies had difficulty adjusting to the sudden changes required of them during visitations. For example, a mother with significant cerebral palsy and her baby were videotaped during a diapering after months of removal to foster care. The videotape documents interaction with a baby who had not had an opportunity to develop the patience to hold still for long diapering which usually develops over time in such dyads.

Within intact families a baby may have adapted to the way an able-bodied parent does care, such as carrying the baby from room to room upright on a shoulder. The baby may have difficulty adjusting to the disabled parent’s sudden increased role in an area of care, such as carrying the baby in a frontpack in the wheelchair. A change in parental functioning may require an adjustment period for both baby and parent. While coping with new skills a parent may need to tolerate the baby’s dissatisfaction with the role shift and the differences in physical handling. One mother with quadriplegia from spinal cord injury became anxious and abandoned equipment in response to her baby’s upset at the difference in care. Instead she chose to continue to utilize her able-bodied mother extensively.

In evaluating the impact of babycare equipment provision we found that the difficulty of doing the babycare activity decreased for most parents, and this was associated with improvement in some parent-child relationship variables. Parents "...engaged in more positive interaction with their babies during the babycare activity. We hypothesize that this is because parents were less burdened by the physical demands of the task" (De Moss, 1995).

The “adaptive stress” level, i.e., the degree to which the parent is preoccupied in struggling with disability obstacles, needs to be considered during assessment. If observation is limited to interaction where the parent is absorbed in a difficult babycare task it may only reveal reduced attunement to the baby, less interaction than is present in situations that are not difficult for the parent. For instance, a mother with cerebral palsy and no adaptive parenting equipment was trying to bathe her infant independently in a new way. To cope with her difficulties in balance while walking she was transferring her baby into a newly acquired wheelchair, and pushing the wheelchair to transport the baby to the bathtub. This meant navigating many obstacles in a small household that was arranged appropriately for a person who was ambulatory but that was too crowded to accommodate a wheelchair. Videotape analysis documented a lack of attunement during this arduous process, and a dramatic increase in attunement to her baby after the adaptive struggle was resolved and the baby was finally in the bathtub.

Providing babycare equipment can clarify psychosocial issues in the infant/parent relationship. It can clarify what are disability obstacles and what are psychosocial issues. For instance, if one makes it possible for a parent with a significant disability to give care adaptively and relate to her baby (allowing time to increase skills and physically adjust to the equipment or techniques), then one can evaluate whether the parent is motivated and psychologically able at this point to maintain an appropriate relationship with a child. One can expect a sudden increase in parental functioning to be stressful for the infant/parent dyad and to necessitate a transition. However, one can consider whether the relationship begins to develop at this point, or, instead, the parent becomes threatened by the reality of this possibility and opts out of the situation, for instance, by retreating into substance abuse or relinquishing custody. Although dramatic interactional changes can be produced through adaptive equipment and techniques (e.g., the
establishment of previously absent mutual gaze through appropriate positioning), a few parents (with histories of trauma) have had difficulty tolerating closeness and sustaining the intimate infant/parent relationship over time.

Sometimes the equipment intervention can reveal infant/parent relationship problems that need addressing. For instance, in one mother/infant dyad our analysis of reciprocity in videotaped interaction revealed patterns of misses in attunement that had been obscured before the physical obstacles to interaction were resolved by babycare equipment. Addressing disability issues appropriately brings clarity to the situation, suggesting what the focus of intervention really needs to be.

Applying a family systems perspective

Rolland (1994) discusses the tendency of families to have increased cohesion after the birth of an infant. Such a developmental point is described as a centripetal period when “both the individual member’s and family unit’s life structure emphasize internal family life. External boundaries around the family are tightened while personal boundaries among members are somewhat diffused to enhance family teamwork.” Paradoxically, during the transition to this period there may be so much upheaval and openness to change that there is a tendency to resist change and to revert to traditional roles.

Couples Issues

Rolland (1994) gives an example of a couple with an able-bodied mother, a father with a disability, and a new baby. “...Having a child made heightened skew in their relationship inevitable...Nancy has to bear the bulk of homemaking and child-care responsibilities on top of her job. It is crucial for the well-being of their relationship that they actively try to maintain a balance so that Nancy does not have to assume responsibility for all aspects of family life, which could cause resentment. Though Jim may be limited in his physical capabilities, he can handle any of the family’s emotional needs. To keep a balance will require open, direct communication and a willingness to challenge gender-role stereotypes.”

In this family the father’s lack of coordination and slowness in feeding became an issue with the mother and pediatrician, seemingly creating some friction. A resilient and creative person, the father responded to his visual problems with reading stories by telling stories instead. However, both situations could have been dealt with by providing adaptive equipment to enhance the physical capabilities of the father. Equipment interven-

tion can lessen “skew” in such a couple and soften imbalances in functioning or work load.

In our research projects several working new mothers initiated the equipment provision for their husbands with disabilities in order to feel comfortable about their husbands’ staying at home with the babies. A number of parents with disabilities reported feeling more central in their parenting role after the equipment intervention. One mother had been concerned that other family members would take over the babycare role completely and that she would be only an observer. With the equipment she became the primary caregiver for her baby and toddler. A father described the impact of equipment on his relationship with his child: “It helped me figure out how to get closer to [my child] both physically and emotionally. I think it helped her realize that I’m not just some guy around the house” (TLC, 1994).

Sometimes, given the degree of change occurring at the outset of parenting, creating changes in a couple’s role division seems to challenge the homeostasis or equilibrium of the family system. We have observed this particularly in couples with marked complementarity in functioning. For instance, a mother with hemiplegia gave birth to her first child. She ordinarily walked with a cane, but had balance problems and use of only one arm. A pattern of underfunctioning by the mother and the stress of the transition to parenthood seemed to trigger anger and physical abuse in the father. A prompt attempt was made to maximize the mother’s physical ability to function by providing an adapted crib and a reclined stroller with good support so the mother could move the baby from room to room safely. It was hoped that the ability to do her own babycare would eliminate one element of the need to remain in a battering relationship. Yet the requested equipment tended not to be used. The clinician, a woman with a disability, had to backtrack and focus on intervention that dealt with the abuse and supported a tolerance of a change in the balance of functioning in the couple. The abuse did not reoccur and there was subsequently a very gradual increase in the disabled woman’s functioning, proudly reported, over many years. She became much more active in the care of her next two children, and her husband increasingly took pride in her accomplishments and her strength.

Sibling Issues

When equipment provision is for a parent with a baby who is not the firstborn, impact of parental functioning change on the siblings needs to be considered. One family requested adaptive parenting equipment for
the care of their second child. They felt that the lack of early baby care by the disabled father undermined the relationship between the father and the first child. While developing the equipment for this baby’s care, we also provided therapy to address the relationship with the first child. Otherwise, we can predict that the enhancement of the relationship with the second child would intensify problems with the first, creating additional stress in the family.

**Intergenerational Issues**

Until recently parents with disabilities were an invisible population. Most media coverage and networking of such parents have developed over the past five years. As a result, parents of children with disabilities tended not to anticipate parenting in the future lives of their children with disabilities. Perhaps as a result, we often see the parents of independent and high functioning people with disabilities question the ability of these competent adult children to become parents. A crisis may ensue, in which an expectant or new parent with a disability—vulnerable to suggestion during this transitional period—can feel intruded upon, undermined, or abandoned. At these points of developmental change, interactional rules regarding roles, functions, and autonomy are renegotiated, between generations as well as between partners. An informed mediator can facilitate the process.

A young African-American woman with moderate cerebral palsy was pregnant and frantic with anxiety. She and her partner wanted very much to have the baby, but her mother was intensely pressuring her to abort. She was maintaining her daughter was physically incapable of taking care of a baby, and the daughter’s own uncertainty about this was what made her consider discontinuing the pregnancy. She had been living independently in an apartment with her partner for several years and had a computer-programming job. Videotapes of parents with comparable disabilities taking care of their babies were shown to give the expectant mother and her partner a realistic idea of both difficulties and possibilities. She subsequently chose to have the baby. Initially the grandmother was hostile to the occupational therapist and the idea of providing babycare equipment. She was adamant about the impossibility of her daughter providing safe care. She tended to just take over the care at this point, reinforcing her daughter’s anxieties about her capability. A very respectful approach was necessary as the occupational therapist very gradually enhanced the functioning of the young mother, at first under close supervision of the grandmother. Videotapes of other mothers were used to demonstrate adaptive possibilities to both mother and grandmother. The occupational therapist, herself a mother with cerebral palsy, introduced the equipment and techniques in increments, as they could be tolerated by the grandmother and the relationship between mother and grandmother. The new mother gradually proved her abilities and asserted herself regarding excessive help postnatally from the grandmother. The couple regained their independence. A subsequent birth was calmly accepted by the grandmother, and the whole family is thriving.

**Personal assistant issues**

Relationships with personal assistants frequently become part of the family system. They often provide long-term personal care and childcare in the intimate home setting. Mothers with significant disabilities often are concerned that personal assistants will supplant their parenting role in the eyes of their children. Babycare equipment has the potential of lessening the role of personal assistants and maximizing the role of parents in childcare.

A mother with significant cerebral palsy consciously managed assistants in such a way as to maintain psychological centrality with her child, e.g., relating to him during diapering while the assistant did the physical work. This mother had a supportive partner, also with significant cerebral palsy, who also participated in childcare and play. The family was well integrated into the disability community, with an extensive support system. They utilized whatever adaptive babycare equipment was available to them at the time, actively participating in its development. In two other families with parents with significant cerebral palsy, equipment has been underutilized and a personal assistant was allowed to supplant (in one case) and lessen (in another case) the potential role of the mother. In both instances the mothers’ couple relationships and extended families were unsupportive and the mothers were not part of the disability community.

**Changing disability issues**

Many parents with fluctuating and gradually worsening disabilities have readily assimilated the babycare equipment into their families. However, few parents with acute or rapidly progressing disabilities have sought the equipment thus far. In such situations, as Rolland (1995) describes, one can expect an intensified transition, an inward or centrifugal pull, and an increase in cohesion in the family system and its member. Analogous to the onset of parenting, “the occurrence of
chronic illness in a family resembles the addition of a new member, setting in motion in the family a process of socialization to illness that requires high cohesion ... When the inward pull of the illness and the phase of the life cycle coincide, there is a risk that they will amplify one another" (Rolland, 1995).

The project has begun developing babycare equipment for a mother with multiple sclerosis, whose MS has been in exacerbation since her baby was a newborn. She recently began using a wheelchair and is beginning to use a personal assistant in her household. She is underutilizing the babycare equipment and minimizing her interaction with her toddler. Instead the able-bodied father does most of the care within the home and the child is usually with a grandmother in another household. A home-based clinician has been provided, herself with a disability, and the mother thus far is responding ambivalently to this individual.

It is difficult to form a relationship to a baby while experiencing intensive loss. An intervenor needs to persist in making room for the mother/child relationship during this intensive time of "inwardness" for the mother and for the family.

**Applying a cultural perspective**

Through the Looking Glass serves ethnically diverse families from many cultures. More than half of its clients are people of color. Since the agency's services usually occur in families' homes, respect for cultural context is critical. Cross-cultural therapy issues and attention to diverse childcare practices particularly need to be considered. Sometimes assistive technology and occupational therapists may be perceived as culturally alien; there may be wariness of outsiders and a strong preference for extended family support. The cultural "inwardness" may be amplified by the family developmental transition to parenting as well as the disability experience. Role and gender issues need to be considered from a cultural as well as systems perspective, as do beliefs about the capability, status, and privileges of people with disabilities.

Like all families, families of color vary in the degree of their identification with or integration into the disability community. They may exist almost completely in the nondisabled realm. But the most worrisome families may be isolated from both disabled and able-bodied communities, as well as their ethnic communities.

A Pacific Islander mother with hemiplegia received services five years after head injury. She was concerned about how she could take care of her newborn baby and was unnecessarily dependent on her able-bodied husband; their family unit was isolated from both the ethnic and the disability community. Initially the mother asked for an adapted crib. This got us in the household, but the crib was never utilized except to hold toys because it was not really in tune with the sleeping practices of the culture. Other initial efforts to quickly enhance her functioning with equipment seemed to backfire because the couple system could not tolerate a quick shift in the balance of functioning between the husband and wife. A Pacific Islander clinician with a physical disability began providing the home visit services, resulting in the gradual integration of the family into both disability and Pacific Islander cultures, and by increments, a dramatic increase in functioning.

It appears that intervention that is based in disability culture can often be readily accepted and lessen the family system's tendency toward "inwardness," even when the centripetal tendency is amplified by the transition to parenthood and disability. Interveners with disabilities are most readily accepted by many families. For others, the link with disability peers can be made through networking with other parents, support groups, the use of videotapes of other parents, as well as through experienced providers who can convey a "visual history" of possible babycare solutions by numerous parents with disabilities.

Elsewhere I have discussed the role of social stigma, oppression, and pathological or negative intervention in intensifying family systems' centripetal movement in response to disability (Kirshbaum, 1994).

It seems that disability culture's reframing of the meaning of disability can be an antidote and a buffer, lessening the tendency toward "inwardness" and isolation. This article represents an initial consideration and comparison of instances when intervention based in disability culture was effective, to instances when other factors, such as dyadic or family systems issues, particularly influenced outcome.

**Conclusion**

The discussion has considered instances of babycare equipment provision through the lens of the infant/parent relationship, the lens of the family system, and through the lens of the culture. In reality, of course, all these perspectives, as well as the intra-psychic level, need to be interwoven.

Occupational therapists faced with abandoned or underutilized equipment have a tendency to critique and alter the equipment, further escalating change (Tuleja, 1997, personal communication). In evaluating the impact of equipment provision, we found that the
occupational therapists were frustrated by limitations on the changes they had produced in functioning of disabled parents in certain families (e.g., due to underutilization of equipment). The same families reported they were pleased with the effect of the equipment and the degree of change produced in parent functioning and family role. It is important to recognize that change and include the transition to a family's own pace. Through the Looking Glass has based its equipment development on the normative inventiveness of parents with disabilities. Perhaps we can also model the intervention process regarding the equipment on the natural reciprocal adaptation process that we earlier documented in parent/infant dyads who were receiving no intervention (Kirshbaum, 1988). Parents naturally adjusted their innovations in babycare to their varied tolerances of change, targeting the role changes that fit into their lives. This argues for parents to be even more integral and active members of the babycare equipment development process. Finally, it is important to support relationships affected by so much change, and this can be implemented through joint work by occupational therapists and clinicians who are trained in infant/parent and family therapy.

Megan Kirshbaum has been a clinician in the disability community for 23 years, has extensive personal family experience with disability, and directs Through the Looking Glass's national Research and Training Center on Families of Adults with Disabilities.

References


This article was made possible by grants from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education: FIFH133G10146 and RRRC #H1333B30076. Its contents do not necessarily represent the policy of that agency and the reader should not assume endorsement by the Federal Government.