

Babycare assistive technology

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This article provides an overview of the baby care assistive technology work at Through The Looking Glass (TLG). TLG is a non-profit organization in Berkeley, California which since 1991 has been designing, fabricating and researching the impact of babycare assistive technology for parents with physical disabilities. TLG provides direct services, information and referral to a diverse group of parents with disabilities and parents of children with disabilities. In 1998, the first U.S. National Resources Center for Parents with Disabilities was established under the auspices of TLG.

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1. Introduction

For the majority of individuals in this country the idea of parenting with a physical disability is still a phenomenon and something about which to marvel. Most individuals can only imagine how someone with a disability can feed, lift, play and cuddle with his/her baby. They can only imagine because encounters of non-disabled people with parents with physical disabilities continue to be relatively rare. Yet, individuals with disabilities have been successfully parenting for years. The majority have been doing so without adaptations or professional guidance. When parents have looked to professionals such as occupational therapists for additional equipment resources and ideas, typically the therapists have used generic babycare equipment on the market to assist in overcoming barriers. Current generic equipment, however, falls short of providing the kind of assistance many parents with physical disabilities desire and need.

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The prevailing assumption that there are few parents with disabilities within the community, as well as the limited funding to develop parenting equipment solutions, has led to a lack of babycare equipment

resources. However, the number of individuals who can benefit from babycare assistive technology appears to be growing. Recent studies estimate there are at least 8.1 million U.S. families with children in which one or both parents have a disability, that is, 10.9% of all American families [7]. With the increase in individuals with disabilities choosing to become parents, (apparently due to the independent living movement and medical technology), professionals will continue to see a rise in the number of parents as clients.

There are also increasing numbers of parents with conditions associated with extended computer use such as repetitive stress syndrome in the wrists and hands. These parents do not necessarily identify as disabled or identify with the disability community, even though this condition can have a considerable effect on babycare ability [14]. Dual income households and the high cost of child care have increasingly placed grandparents in the role of providing child care, and in some situations, full time care of their grandchildren. Grandparents are another growing population that can utilize adaptive babycare equipment, since they may experience weakness, pain or fatigue as they age [13].

Comprehensive babycare assistive technology work has been occurring at Through The Looking Glass (TLG). This article will review the TLG intervention model and discuss pertinent findings and clinical outcomes from years of performing homebased assistive technology intervention. The work has incorporated designing, fabricating and disseminating babycare assistive technology to parents and/or caregivers with physical disabilities.

2. Review of related literature

Comprehensive adaptive parenting information was first published in the 1960s by the Rehabilitation of Disabled Homemaker Project, University of Connecticut [9,16]. Many of the equipment development concepts remain useful but the document is out of print. The Disabled Living Foundation in England has also produced a number of articles, although these have not generally been available in this country. Some of this material is incorporated in *Aids and Adaptations for Disabled Parents* [2]. This manual is illustrated with line drawings of adaptive ideas. Parks' *Help: When the Parent is Handicapped* [11] is the most comprehensive practical work concerning disabled parents produced in this country. It contains a number of adaptive ideas, but lacks illustrations and does not differentiate physical disabilities (its disability categories are retardation, deafness, blindness and physical disability).

Current information on adaptive equipment and techniques tends to be scattered in articles describing single cases. For instance, several brief articles, with limited distribution, have described simple modifications of child care equipment for parents with disabilities. These include *Parenting with a Disability* [4]; *And so to Bed—Accessible Children's Cots for Disabled Parents* [10]; *Case Example—Application of Assistive Devices* [1]; and *Infant Handling and Child Care Techniques for the Physically Disabled Parent* [8]. The Swedish Handicapped Institute has an illustrated manual of adaptive parenting equipment used by or developed for parents with physical disabilities (*Infants and their Parents with Mobility Disabilities {Smarnsforaldrar: med rörelsehinder}*, 1994); however, an English translation does not yet exist.

3. TLG's intervention model

TLG's intervention model emphasizes a non-pathological, or disability community orientation. The concept of environmental mismatch is an example of this approach. That is, 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. For example, a mother who uses a wheelchair is unable to use a standard diapering table. The issue is not that the mother cannot stand but rather that the table surface is too high and does not have space underneath to accommodate her legs as she sits in her wheelchair. This approach and method of discussing issues is not only more sensitive to the individual with a disability, it also focuses on the areas needing change.

Another important aspect of TLG's intervention model is the close attention that is paid to how the adaptive equipment can affect the parent-child relationship and how it can interact with the family as a system [6]. This perspective has proven to be vital because it provides the framework for working with families and for understanding how families use the babycare equipment. In some situations, adaptive babycare equipment is readily integrated into the family: family members easily accommodate the increased functioning of the parent and consequent role changes in the family. In other families, assimilation of the equipment is more difficult. For example, in one family the non-disabled grandmother's role, before babycare equipment intervention, was to diaper and spoon-feed the baby. With intervention, which included adaptive babycare equipment, the mother was able to perform these tasks independently. The grand-mother 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. Had adaptive babycare equipment been

available for the mother and occupational therapist to use from the time of the baby's birth, this dynamic may never have developed. Perceived roles and work division, intergenerational dynamics, the couple relationship, disability issues, and the natural processes of becoming a parent for the first time, are interwoven elements that are considered in understanding the intervention outcomes of adaptive babycare equipment.

Another important aspect of TLG's intervention model is that the input of parents is central; they are considered integral team members to the development and assessment of the equipment. The occupational therapist is seen as an adjunct to the parent's and family's problem-solving for solutions to babycare obstacles. Some parents are extremely creative in coming up with solutions while others need more encouragement or experience, as in the case of individuals who are newly disabled. Successful problem-solving for the parent and the family brings confidence to tackle new disability issues as they arise.

4. Through The Looking Glass (TLG) – early research

TLG's work with parenting with a disability initially began in 1985 in response to the lack of support, and at times, negative reactions from professionals and the general public towards parents with disabilities caring for their babies [5]. The lack of awareness of how parents physically cared for their babies resulted in a project in which parents with physical disabilities and their babies were videotaped doing routine baby care without specialized assistive technology. The videotapes revealed that parents and their babies developed a natural reciprocal adaptation that evolved through time. One notable lifting adaptation documented a mother with paraplegia signaling her one month-old baby for a lift. Once signaled, the infant would curl up and remain still while the mother transferred him from one surface to another. The baby's compact, curled body made the transfer easier and more manageable for the mother. Overall, the majority of parents in the study were enormously resourceful at overcoming disability obstacles in order to meet their baby's needs [5].

Regardless of how resourceful most parents were, many would have desired more support and adaptation resources. For some parents the absence of parenting equipment limited their role in babycare and play and increased the need for personal care assistance or dependence on family members. This first project inspired several subsequent research projects which have focused on developing and fabricating adaptive babycare equipment and documenting its impact [13-15]. TLG has developed over 50 pieces of adapted babycare equipment (See descriptions and illustrations

of these equipment pieces in Adaptive Parent-ing Equipment: Idea Book 1 [3]).

5. Intervention team

The intervention team is made up of three occupational therapists, a researcher with a psychology background, and a family therapist with a doctorate in psychology. The occupational therapists are responsible for the following: assessing with the parent the need for babycare equipment, choosing appropriate equipment from an existing equipment library, designing equipment and introducing the equipment to the family. As part of the process of bringing the equipment into the home, the occupational therapist focuses on safety and appropriate use of equipment as well as the development of the parent's skill in using the equipment. The occupational therapists are responsible for interviewing the parents about their perceptions of doing the babycare activity both before and after intervention and videotaping the parent performing the babycare activities. Finally, the occupational therapists are responsible for conducting an observational assessment of the babycare activities, utilizing the videotaped activities.

The family clinician and researcher are integral team members. They are responsible for devising and completing the parent-child interaction measures both before and after intervention. In addition, they problem-solve with the occupational therapists about ways to support the parent-child relationship with the use of the equipment and provide feedback on disability-related family issues.

6. Impact of adaptive babycare equipment

The impact of the adaptive babycare equipment has been dramatic in most family situations. Overall, the equipment has decreased the barriers in the parent's environment, thereby increasing their functional babycare abilities. Consequently, parents' heightened abilities increased their involvement in performing babycare (e.g., dressing, diapering, carrying/moving, holding, transferring, bathing, feeding). In addition, most parents reported decreases in difficulty, fatigue and pain during babycare as a result of utilizing the adaptive babycare equipment. Another outcome observed with adaptive babycare equipment intervention is that as babycare tasks become easier parents become less focused on the physical demands of the task and consequently are able to engage in more positive interaction with their babies. Parents have also reported experiencing more confidence as care-givers, an increase in their satisfaction with how they complete babycare tasks and less worry about their child's safety during the activity [13,15].

7. "Supermom" and disability accommodation

Over the years in working with parents with physical disabilities we have observed a number of incidents where there were dramatic differences between the parents' and the occupational therapists' impressions of how difficult a particular babycare task was for the parent. This discrepancy was puzzling and so the occupational therapists asked the parents to elaborate more about their experience of difficulty when performing a baby-care task. Feedback from these parents has led us to hypothesize that the word difficult may be too charged to use with parents who have a disability. Some parents were reluctant to say that a given task was difficult because of issues related to what is referred to as the "supermom phenomenon". This description refers to someone who pushes herself to the utmost limits in order to appear capable of handling all situations or challenges both at home and at work. The supermom influence occurs both with non-disabled and disabled mothers as a result of internal and external pressures. However, for the mother with a disability there may be additional pressure to be a supermom. This may occur because a mother with a disability is less likely to receive social support or may even experience blatant prejudice with respect to parenting. This lack of support can compel mothers to appear completely capable of doing babycare activities without any need for assistance, lest their parenting abilities be questioned.

Another element that we suggest contributed to the perceptual differences between the parents and the therapists is disability accommodation. Because parents with physical disabilities confront obstacles in their environment on a daily basis, they accommodate to the physical challenges they routinely face. The accommodation or increasing tolerance for task difficulties eventually leads parents to perceive that a given task places no more than average demands upon them. We suggest that if the parent did not accommodate to these challenges, they would be in a continual state of stress. Several parents have reported that only after intervention did they realize how challenging the babycare task had been previously.

8. Babycare task demand

Another aspect which may have contributed to differences in parents' and occupational therapists' perceptions of difficulty has to do with how *difficulty* is experienced by the parent. An initial assumption when this work began was that if a babycare task required a lot of effort on the part of the parent then this task must be difficult. Parent feedback helped us realize that this was not always the case. For example, one parent reported that although she had to do a significant amount of set-up to bathe her child (i.e., get the infant

tub, place it in the shower) she would not describe bathing her child as difficult but rather described it as requiring a lot of effort. Similarly, other parents were reluctant to call babycare tasks difficult. The physical requirements of a given task and a parent's particular disability issues (e.g., weakness, fatigue) place different demands upon parents. These demands might not be experienced as purely difficult but rather as requiring extra effort. The concept of task demand seemed to encompass both factors—difficulty and effort. Task demand is defined as the amount of work load placed upon the parent throughout a given babycare activity. High task demand placed upon the parent by the environment and/or child can either increase the effort needed to complete a task and/or make the task difficult. The three major task demand influences are: parent organization, child influences (e.g., kicking, rolling, etc.), and environmental mismatch. The environmental mismatch refers to the elements in the environment which do not match the physical abilities of the parent.

What we learned from parents about task demand indicates that occupational therapists need to incorporate both the parent's and their own impressions of parent's performance of babycare activities. Using terms such as task demand rather than terms such as difficulty when describing the impact of performing babycare activities is respectful and more accurately represents the parent's experience.

9. Occupational therapist's clinical reasoning

We have found that the occupational therapist's deductive clinical reasoning seems to be influenced by how much experience they have in working with parents who have physical disabilities. As one might expect, each therapist's clinical reasoning is very complex. Included in their clinical reasoning, therapists use theory (e.g., body mechanics, task analysis, work conservation) together with their visual history of how people move and their own personal movement reference when assessing parents' physical functioning during a given babycare task. Visual history refers to the accumulations of numerous visual images of the way individuals, both disabled and non-disabled, perform functional tasks. At TLG, differences in the therapists' amount of visual history or experience observing parents with disabilities care for their babies appeared to have a direct influence on their assessment of task demand. Two of the therapists had more extensive visual histories of parents with disabilities caring for babies than the third therapist. Interestingly, the third therapist tended to assess the parent's task demand in doing some of the babycare tasks as greater than the other two therapists.

Another element observed in the clinical reasoning of TLG occupational therapists was movement

reference. This refers to the internal template or reference point of how one uses one's body to perform functional tasks. Different movement reference points produced variations in therapist's impressions of how difficult or demanding a task was for a parent. For example, one occupational therapist who has hemiplegia cerebral palsy interpreted a parent's performance of diapering with one hand as not very challenging. In contrast, the other two therapists assessed the parent's diapering as demanding. The therapist who has cerebral palsy described her movement reference as one aligned with her visual image of parents doing babycare activities with one hand.

Visual history and movement reference appear to have important implications for those situations in which inexperienced professionals are requested to assess, either by the courts or physicians, the competence of a parent with a physical disability to care for their baby. Proper assessment needs to include adaptive babycare equipment and should be completed by someone with experience and a well developed visual history of how parents with disabilities care for their babies.

10. Equipment utilization and impact

The intervention process has revealed that the occupational therapists began with a number of assumptions about how parents would utilize the equipment. The first assumption was that all parents would want to perform all the babycare tasks if equipment was available to them. Secondly, we assumed that the parent would want to be independent in completing the babycare tasks. Thirdly, we assumed that the parent would perform the babycare activities as often as needed. What we discovered was that, as is true for non-disabled parents, parents with disabilities sometimes choose to do activities with their partner as a team. Responsibility for babycare tasks changes through-out the day. For example, a husband might change the baby's diaper before leaving for work. Households may divide up the babycare tasks between caregivers to reduce individual work loads. How the equipment impacts the parent depends upon the roles and work division within the household.

One might not expect these issues to be as relevant for a parent with a recent injury or recent disability exacerbation receiving babycare intervention on a rehabilitation unit. Babycare roles and work division are not likely to have been firmly established immediately following significant changes in physical functioning. However, the occupational therapist can explain to the parent, perhaps during their hospitalization, that roles and work division will naturally emerge. The therapist can demonstrate how the equipment will give the

parents the ability to choose their roles and how they would like to be involved in their baby's care.

11. "Can do" attitude

One of the most powerful outcomes of TLG's work has been the influence of the occupational therapists' positive "can-do" attitude towards the parent's ability to care for his/her baby as they choose. At the end of intervention, parents are asked for general comments concerning the equipment intervention. A recurring theme has been that parents find the therapists' positive attitudes refreshing because such a response to their parent-ing has been so rare. Additionally, this can-do attitude has had an extremely powerful impact on parents' self-confidence about their ability to care for their babies. Clearly, many parents continue to encounter inadequate support from the community, some family members and professionals. In fact, some women are pressured to terminate their pregnancy or relinquish their children because some individuals are unable to imagine how women with disabilities are able to care for their babies [12, p. 51]. We believe that attitudinal bias toward parents with disabilities can be improved through gaining a visual history of the many ways parents with disabilities care for their babies. This visual history would ideally include the use of adaptive babycare equipment because of its positive impact upon parents' physical abilities and on parent-child interaction.

12. Guidelines for equipment development

Until babycare equipment is available on the market, parents and occupational therapists will continue to develop equipment on their own. Connecting parents to knowledgeable occupational therapists continues to be a challenge. Occupational therapists can provide parents with needed adaptive equipment expertise and fabrication resources necessary to develop babycare equipment. In conjunction with parents, TLG occupational therapists have developed more than 50 pieces of equipment over the course of three research projects and much has been learned in the process. The following are suggestions for developing babycare equipment and working with parents with physical disabilities and their families.

13. Child growth

The type of adaptive babycare equipment a parent may need during the first two years of a child's life can change frequently because of the rapid increase in weight and rapid changes in the child's development. Effective equipment intervention needs to anticipate these changes. If adaptations are developed too late or the fabricator takes too long in the creation process,

the child may have outgrown the equipment. Considering the ongoing development of the child is also a safety measure. For example, anticipating that the child will be rolling soon, it will be necessary to fabricate a trunk safety strap for a diapering surface.

14. Long term nature of occupational therapy intervention

Unless it is possible to anticipate all the pieces of equipment and adaptations a parent may need, which has not occurred in our experience, babycare equipment intervention is long-term and the amount of contact with the parent fluctuates frequently as needs change. In addition to developing the equipment, some of the activities performed by the occupational therapists are: keeping equipment current to the child's developmental level as well as any changes in parent functioning; frequent equipment tune-ups; and monitoring proper use of the equipment. Current funding systems do not support long term intervention, yet, this work is critical for safety and effective use of babycare equipment.

15. Transitional tasks

Transitional tasks are activities such as transfers, carrying and moving and positional changes, which are physical activities that usually begin and end a baby care activity (BCA) and are the essential links between most BCA's. We generally found that transitional tasks are the most demanding aspect of the babycare activity. Most adaptive babycare equipment design is centered around transitional tasks. When solving transitional task obstacles for parents, many babycare activity issues are usually simultaneously solved. For example, if a lifting harness is developed for transferring the baby to the diapering table, the harness can also be used for carrying and moving, can assist with holding, and can be used to transfer the baby to a variety of surfaces. We recommend that parents and professionals initially look to transitional tasks as a starting point for developing babycare equipment.

16. Moving toward universal design

When therapeutic settings serve a number of parents each year, (even if just a small number), it is worth rotating equipment among families by setting up a lending library. Lending libraries are the most effective and cost saving when the equipment has a universal design. Pieces of equipment that use universal design can accommodate all users. The time, energy and money spent on modifying a piece of equipment can be minimized *or eliminated* when the adaptation is designed for the parent with minimal functional abilities. The

universal design concept should be considered when designing or adapting any piece of babycare equipment.

17. Adaptive techniques

Adaptive babycare equipment alone may not be enough to alleviate the babycare task demands placed upon the parent. TLG has found adaptive techniques to be an essential aspect in performing babycare tasks. Adaptive techniques are alternative ways or strategies of doing tasks which reduce demands on the parent or make a task viable at all. Adaptive techniques can be useful alone or in conjunction with equipment. For example, the following burping technique could be used with adaptive equipment such as a fanny pack (a seat support for the child). In the burping technique called Sit & Lean, the parent holds the baby on their lap, with the baby facing away from the parent's body (baby's back is against the parent's chest). The parent then leans forward, which tilts the baby forward and produces a burp. Adaptive techniques can also facilitate the child's assistance. For example, one technique is to teach the baby to lift his/her bottom up during diapering so the parent can easily slide a diaper underneath. Occupational therapists should consider adaptive techniques in combination with babycare technology to decrease the task demands for the parent.

18. Fabricators

Currently, finding someone to make babycare equipment modifications has been one of the most frequently asked questions we receive. TLG's main fabricator is a wheelchair repair shop. The shop has multiple capabilities required for creating babycare equipment: industrial sewing machine, metal working as well as woodworking. Unfortunately, it is difficult to find a shop with such expertise. Some alternatives are shoe repair shops and sail-makers since they have industrial sewing machines that make stronger stitches than standard sewing machines. Other skilled technicians include woodworkers, welders, and seamstresses. The most inexpensive option is if disabled parents have friends or family who can make the adaptations.

At the present, finding professionals such as occupational therapists experienced in babycare assistive technology to assist with the design and fabrication can be difficult. In addition, occupational therapists have reported problems in getting reimbursement for babycare assistive technology intervention from medical insurance companies and state programs. Occupational therapy students or rehabilitation engineering students may be an inexpensive alternative. A limitation in working with students is that the academic schedule may not

correspond with the child's rapid changes in development or the urgency of the parent's needs.

19. Housing limitations

The physical layout of the home and any space restrictions can have a significant impact on the type of equipment that can be utilized by the parent. Many families with disabilities are on a fixed income and may be living in a small apartment and already have a considerable amount of personal assistive technology. Space restrictions and an idea of where equipment will be used within the home are important equipment development considerations.

20. Marketing babycare assistive technology

For the most part, generic babycare equipment on the market has failed to encompass the needs of individuals who function differently from most. Yet, with some relatively small modifications, this market could be expanded to fit parents or grandparents with disabilities and even benefit non-disabled individuals. TLG's future goals include bringing as many appropriate pieces of equipment as possible into the generic babycare market to benefit the most people while at the same time minimizing cost.

Some pieces of babycare equipment are specialized for parents with significant disabilities. One such piece is the babycare tray (for a description and illustration of this equipment [3]). The tray attaches to the front of the motorized wheelchair and allows a parent to diaper, feed and play with his/her child without having to transfer the baby. Getting this tray design to market may be challenging because the number of people who would utilize this specialized equipment is small. One possible solution would be to have specialized equipment available to parents in lending libraries within Independent Living Centers or State Technology Centers across the country. This solution would provide the parent with a significant disability access to specialized babycare equipment for the short duration of need, at a low or possibly no-cost basis.

21. Conclusion

For many individuals with disabilities becoming a parent can be thought of as the last frontier to conquer with respect to accessibility and equal rights. Babycare assistive technology allows parents with physical disabilities more choices in how they are involved in their baby's care, through the elimination or decrease of barriers in the environment. TLG has shown that assistive baby-care equipment can increase parents' participation in babycare, decrease parents' experience of task difficulty and fatigue, and increase positive interactions between the parent and child during baby-

care activities. TLG research has provided the groundwork for the overall objective of increasing the availability of babycare technology intervention to parents with disabilities across the country. TLG will continue to develop and refine adaptive babycare equipment and work towards bringing appropriate equipment to specialized and generic markets. In addition, TLG is continuing to measure adaptive equipment outcomes in order to support the reimbursement of intervention services (equipment and professional services) and to provide guidelines for appropriately assessing parents with physical disabilities. Finally, TLG's new National Resource Center for Parents with Disabilities will provide training and resources to professionals such as occupational therapists, nurses and doctors concerning parenting with a disability and the role of babycare assistive technology.

For additional information or resources please contact the authors at Through The Looking Glass by mail, phone, or email. The mailing address is: Through The Looking Glass, 2198 Sixth Street, #100, Berkeley, CA 94710-2204, USA. TLG has two national toll-free numbers: (800) 644-2666 (voice) and (800) 804-1616 (TTY). TLG can also be contacted by email: TLG@lookingglass.org or visit their website at www.lookingglass.org.

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