

Bringing Baby

Products for Parents with Disabilities

BY MARY GUTHRIE

People with disabilities face innumerable challenges in performing everyday activities. But when that person has a child, there's more than just self care to consider—there's also care for the child.

As more people with disabilities have children, therapists face new challenges as well. It becomes a matter of not just thinking about devices that help the person with a disability, but finding products to help that

person feed, bathe and play with his or her child. In the past, many parents and therapists relied on their own ingenuity. Now increasing numbers of off-the-shelf products are available, and there are resources for modifying existing products that make raising children in these situations easier.

Christine Jasch, an occupational therapist, has worked extensively with parents with disabilities. She works at the Rehabilitation Institute of Chicago and writes a column on the subject for the newsletter *Resourceful Woman*. (See "PrintResources.")

Jasch recommends baby-care catalogs such as One Step Ahead and The Right Start as sources for equipment for parents with disabilities. The items still sometimes need adaptation or creative applications, she says. A baby bottle warmer sold in a catalog, for example, comes in handy for a mother who uses a wheelchair. By using a tiny refrigerator next to the bed and the bottle warmer, the mother could avoid having to transfer out of the bed in the middle of the night to give the baby a bottle.

For mobility around the home, Jasch would consider a baby carrier or a bassinet on wheels. Other options for mobility would be a lightweight stroller or even a baby carrier secured in a child's wagon, she says.

Standard changing tables can be difficult for parents with disabilities to use comfortably, Jasch says, so parents who can't stand up comfortably or who use a wheelchair have difficulty

About 11 percent of U.S. families with children, or 8.1 million families, have one or more parents with a disability.

-Through the Looking Glass

Subjects Needed for Study on Mothers with Spinal Cord Injury

The Kessler Institute, West Orange, NJ., is seeking mothers with spinal cord injury for a study on parenting. The nationwide study plans to look at women who sustained a spinal cord injury before their child was 2 years old or before the child was born. Subjects will be interviewed for no more than three hours and will be compensated for their time. In addition, the subject's partner or significant other, and the participant's child (if over the age of 12) may be interviewed. Contact Maria Anan, Kessler Institute for Rehabilitation, 1199 Pleasant Valley Way, West Orange, NJ 07052; 800/435-8866.



Several catalogs and brochures highlight equipment or adaptable items for parents with disabilities.

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changing the baby. She suggests putting a changing pad on a desk that a chair can slide under, then the parent can use the drawers for baby wipes, diapers and other accessories. Another aid is a diaper cover traditionally made for cloth diapers. It is secured by Velcro and, for parents with limited dexterity, can be used to hold a disposable diaper in place.

Some parents, Jasch points out, don't have enough strength in their limbs to hold their babies or a big enough lap to offer a flat spot to perch. In that situation, she suggests the Sit 'N Secure from the One Step Ahead catalog or the Tot Safe harness from The Right Start, both of which can be adapted to help keep the child on the parent's lap.

Some of the products and resources now available are the result of individual odysseys in trying to find appropriate parenting aids. When Trish Day, who has

cerebral palsy, became pregnant two years ago, she had trouble finding a doctor who was knowledgeable about pregnancy and disability, suffered additional health problems, and encountered rude maternity store clerks. Even her hospital's delivery room didn't accommodate wheelchair-using mothers.

"It was almost as if having cerebral palsy and becoming a mother were two mutually exclusive notions," says Day, who lives in the Washington, DC., area.

During her pregnancy, Day searched for baby-care items she could use comfortably. In the back of her mind was the fear that, if she couldn't take care of the baby

Top 5 Picks by Through the Looking Glass

Through the Looking Glass is producing a publication listing off-the-shelf items that are useful to parents with disabilities. They will introduce the pamphlet at their conference on parenting in October 1997. Here's a preview:

- 1 Accessible Gates that attach to the wall and swing open. Called "Swing N' Lock" and "True Fit." Available at Toys "R" Us.
- 2 Battery-Activated Toy and Music Mobile. Called "3N1 Music Mobile USA Classic Bears." Available at Toys "R" Us.
- 3 Bibs with Velcro closures. Called "Pat-A-Bib." Available from One Step Ahead catalog.
- 4 Baby support cushion for breast-feeding. Called "My Brest Friend." Available from Right Start catalog.
- 5 Baby-changing pad. Called "EZ Changing Pad." Available from One Step Ahead catalog.

herself, she might lose the chance to raise it. "I had heard horror stories of mothers with disabilities whose children were taken away from them," she says.

One place she turned to was Through the Looking Glass, an organization in Berkeley, Calif. One of its projects was *Adaptive Parenting Equipment, Idea Book 1*. The book describes more than 40 items that can be built to assist parents with various disabilities. One concept Day got from the *Idea Book* was a bathtub that can be filled and drained easily from a wheelchair and requires no lifting of the baby.

Through the Looking Glass is a community-based, nonprofit agency that started in 1982. It serves families with parents or children with all categories of disability. Nearly 80 percent of the organization's staff are disabled, parents of disabled children, or members of families with disabilities. This team of psychologists, social workers, therapists, special educators, engineers, researchers and others assist families in the San Francisco Bay Area, as well as nationally and internationally, through the Research and Training Center on Families of Adults with Disabilities, also based in Berkeley. The federally funded research and training center's activities include a clearinghouse of materials related to parenting with a disability, a network of parents with disabilities, assistive technology

Print Resources

■ **Resourceful Woman: Women with Disabilities Striving Toward Health and Self-Determination:** The newsletter of the Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago, has a column called Resourceful Parenting. Contact the Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago, 345 E. Superior St., Room 106, Chicago, IL 60611; 312/908-7997; e-mail: jpsparkle@aol.com

| *Adaptive Parenting Equipment, Idea Book 1:* As part of its ongoing research into adaptive equipment and techniques for physical-

ly disabled parents and their babies, Through the Looking Glass developed this handbook of ideas for how more than 40 pieces of adaptive equipment can be used. The items are not available off-the-shelf, but most can be fabricated by adapting existing products. The cost is \$10 to parents or family members and \$25 to professionals or the general public. Contact Through the Looking Glass, 2198 Sixth St., Suite 100, Berkeley, CA 94710-2204; 510/848-1112.

■ **The Right Start catalog:** While this catalog does not have items specifically for parents with a disability, it includes a wide variety of useful items that can be adapted or used off-the-shelf. Contact The Right Start, 5334 Sterling Center Drive, Westlake Village, CA 91361-4627; 800/548-8531. Its

products are also available at The Right Start stores nationwide.

■ **The One Step Ahead catalog:** This catalog does not have products specifically for parents with a disability, but has many items for baby care that could be useful to a parent with a disability. Contact One Step Ahead, P.O. Box 517, Lake Bluff, IL 60044; 800/274-8440.

Parenting With a Disability: Through the *Looking Glass*; This free newsletter contains articles of interest to parents with disabilities and their family members. It is published three times a year. Contact Parenting With a Disability; Through the *Looking Glass*, 2198 Sixth St., Suite 100, Berkeley, CA 94710-2204; 800/644-2666; e-mail: TLG@lookingglass.org

research, training of professionals and lay people regarding parents with disabilities, and consultation services for parents and professionals.

Through the Looking Glass estimates that in the United States, about 11 percent of families with children, or 8.1 million families, have one or more parents with a disability.

Day and her husband decided to share their experiences through a site on the World Wide Web. (See "Web Resources.") They have an e-mail exchange group for parents with disabilities and a section on equipment, which displays a wheelchair-accessible crib, bathtub and changing table and a wheelchair lap tray for breast-feeding. The site also lists other Web

sites, as well as books and organizations of interest to parents with disabilities.

One product on their Web site is the Over the Shoulder Baby Holder, a hands-free sling manufactured by C.D.M., San Clemente, Calif. Lisa Janice Cohen, an occu-

Parents With Disabilities and Their Families

October 23-26, 1997

Oakland, Calif.

Oakland Marriott Hotel

An international conference focusing on parents with disabilities and their families will be sponsored by Through the Looking Glass, October 23-26, Oakland, Calif. Through workshops, panels and presentations, the conference will provide a forum for practitioners, researchers and parents to exchange information about service delivery to parents with disabilities and their families. The conference will offer information for both consumers and professionals on a wide range of subjects relating to parenting with a disability.

Contact Through the Looking Glass, 2198 Sixth St., Suite 100, Berkeley CA 94710; 800/644-2666, 510/848-1112; e-mail: TLG_conference@lookingglass.org

Bag Company's Super Pac (Model SP1000). It's a wheelchair backpack that can be used as a diaper bag. The bag releases from the wheelchair with a squeeze for carrying by handle or strap. It has 10 pockets inside and out and a circular pull-ring on the zipper.

Web Resources

■ **Through the looking Glass:** <http://www.lookingglass.org>

■ **The Family Village:** <http://www.familyvillage.wisc.edu/>

■ **The National Parenting Center:** <http://www.tnpc.com/>

■ **Parenting with a Disability:**

<http://www.parentsplace.com:8000/dialog/get/disability.htm>

■ **Trish and John Day's site:**

http://ourworld.compuserve.com/homepages/Trish_and_John/

pational therapist who distributes the product, says it works well for people with disabilities, because it encourages good posture by supporting the baby's head and keeping its legs together for the first few months. The parent's posture is also protected in that the sling uses the whole body for support instead of just the shoulders or arm and hip, Cohen says.

Another product listed on the Days' Web site is the Advantage

More practical information about adaptive equipment for parents with disabilities will be available at an international conference sponsored by Through the Looking Glass, October 23-26, in Oakland, Calif. The conference will provide a forum for parents, professionals, academics and others to gather and exchange ideas about how to improve the delivery of services to families affected by disability. |