Keeping Our Families Together: A Report of the National Task Force on Parents with Disabilities and their Families

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Introduction

Seventy-one representatives from 22 states and 11 countries met in Oakland, California on October 26, 1997 to establish the National Task Force on Parents with Disabilities and their Families. An International Division of the Task Force was also created. The National Task Force was convened by Through the Looking Glass (TLG) at the conclusion of the first International Conference on Parents with Disabilities and their Families. Nine additional Task Force members who could not attend this inaugural meeting forwarded their recommendations. This report was compiled by TLG staff, and is based upon recorded proceedings of Task Force meetings as well as draft versions which were circulated among Task Force members and posted on TLG’s website for comments.

As Task Force members, we represent an interdisciplinary group of mothers, fathers, family members, professionals and advocates from diverse disability communities throughout the United States. The overwhelming majority of this newly created Task Force are parents with disabilities and family members. It is our unwavering demand that our families -- disabled parents and their children -- no longer remain invisible among the nation’s families. Our overall mission is to promote social changes which will improve the lives of parents with disabilities and keep our families together.

National Needs of Parents with Disabilities

The Task Force began with a review of the recently completed National Survey of Parents with Disabilities. This survey of 1,200 parents identifies service needs, problems and options among the estimated 8.1 million parents with disabilities within the U.S. The survey sample differs from the national population in that it includes fewer minorities, more women and generally higher income and educational levels than the national population. Survey analysts anticipate that even higher numbers of parents would have reported challenges, barriers and service needs if more parents with lower incomes, lower education levels and more members of minority groups had participated. The results of this first national survey of parents with disabilities can be summarized in eight life areas related to parenting with a disability:

1. Pregnancy and Birthing. 44% of disabled parents reported that pregnancy and birthing for themselves or their partner was an issue affected by their disability: 36% reported that the provider’s lack of disability expertise caused problems during prenatal and birthing services, 31% reported that providers’ attitudinal problems caused barriers, 24% reported medical complications related to their disability during pregnancy or birth, and 18% reported problems with physical accessibility of the provider’s facilities.
2. **Ability to conduct parenting activities.** Disabled parents reported needing the assistance in recreation with their children (43%), traveling outside the home with their children (40%), chasing or retrieving children (39%), and lifting or carrying children (33%). Areas of assistance needed by parents varied according to the type of disability.

3. **Insufficient transportation.** Transportation was an issue which affected more aspects of parenting with a disability than any other issue. 79% reported transportation as a problem which interfered with or prevented routine and critical parent-child activities.

4. **Access to child care.** Cost was the most frequently identified barrier to child care (30%), followed by lack of transportation (20%), access issues (15%), lack of appropriate services (11%), and lack of information where to find child care (6%). While certain individual factors may be pertinent to all families, this underestimates the effects of multiple barriers such as cost, lack of access and lack of disability-appropriate services.

5. **Need for adaptive parenting equipment.** Barriers to obtaining adaptive parenting equipment were cost (48%), lack of information about such equipment (44%), the unavailability of such equipment or that it had not yet designed (32%), and there is no one to make this equipment (19%).

6. **Personal assistance services.** 57% reported using personal assistance services for help with parenting. Problems with using personal assistance were that it often was not available when needed (54%), was unreliable (46%), interfered with the parent’s role (38%), and assistants were inexperienced in knowing how to care for children (35%).

7. **Inadequate housing.** 43% of all respondents reported facing at least one barrier with regard to housing for parents with disabilities. The most frequently identified barriers to housing were: too expensive (33%), inadequate space (28%), and inaccessible (25%).

8. **Attitudinal barriers.** 42% of disabled parents reported facing attitudinal barriers including discrimination (32%), pressure to have a tubal ligation (14%), and pressure to have an abortion (13%). Despite the sample population’s high education level and the limited participation of parents with cognitive or psychiatric disabilities, 15% of parents reported attempts to have their children taken away. 8% reported they experienced attitudinal barriers which interfered with or prevented adoption.

**Task Force Objectives**

By consensus of those present, four objectives were identified for this formative meeting:
• To identify members of the Task Force.

• To identify key issues affecting parents with disabilities and their families.

• To develop priorities.

• To recommend initial strategies to address these priorities.

**Task Force Members**

Members of the Task Force are listed at the conclusion of this report. Task Force correspondence, meetings and solicitations for additional Task Force members will be facilitated by Through the Looking Glass.

**Discussion of Key Issues**

Opening remarks by Task Force members reiterated the complexity of issues which impact parents with disabilities and their families including: employment, housing, transportation, education, child care as well as medical, legal and social services for parents and children. Although such issues are of concern to all families, our families -- those with parents with disabilities -- are routinely forgotten or excluded from adequate support and appropriate services. Inadequate financial resources for our families are compounded by inappropriate, inaccessible or simply non-existent services for parents with disabilities and their families. Mothers and fathers with disabilities and their families remain invisible to the vast majority of service providers. Although there are well-funded and well-developed resources that serve parents (including non-profit advocacy, day care, parent education programs), most mainstream service providers have failed to recognize that the adults and families they serve may include parents with disabilities. Similarly, although there is a growing network of consumer-driven disability services such as independent living centers as well as services focused on employment, education, transportation and housing, many disability service providers have failed to incorporate the needs of parents with disabilities. This lack of awareness and informed programs effectively excludes parents with disabilities from community resources and support. In the most extreme cases, this lack of support places families of parents with disabilities at risk of family dissolution. It is a testimony to our resiliency that many of our families have succeeded despite isolation, discrimination and extremely inadequate supports or services.

Violence and abuse affects many of our families: violence and abuse directed at disabled children who will one day grow up to raise their own children; violence and abuse directed at mothers and fathers with disabilities that impacts their ability to be good parents. Presumed abuse and presumed incapability also shadows our families: misguided accusations and
uninformed judgments can permanently sever parent from child. Knowledgeable assessments and appropriate interventions are critical to sustaining many of our families.

Task Force members also described how these areas of concern are affected by the diversity and variation in our families and our communities. These variations include the nature and histories of our disabilities, our family constellations, the ages of our children, our ethnicities and gender, the availability of economic and social resources, and regional and national policies which can promote but far too frequently exclude or ignore our families.

Task Force Priorities and Recommendations

The Task Force identified six overall priorities. For each priority, specific strategies were recommended to address the most critical areas of concern.

1) Promote recognition and inclusion of parents with disabilities and their families.

(a) Establish a national and international Task Force on parents with disabilities and their families. Task Force members have identified specific areas of interest and expertise. Task Force members will contact each other through e-mail, written and phone correspondence. Through the Looking Glass will facilitate Task Force activities by posting Task Force information on its website, preparing and circulating Task Force reports, and preparing and circulating a directory of Task Force members.

(b) Develop linkages to mainstream and disability oriented organizations directed at parents, families and/or adults with disabilities.

(c) Develop linkages with existing national parent organizations for non-disabled parents.

(d) Utilize existing disability awareness days to promote awareness of families of parents with disabilities.

2) Promote informed regional and national policies which address the needs of families in which one or both parents have a disability.

(a) Promote changes regarding Child Protective Services regulations and practices so that parents with disabilities are fairly and appropriately assessed regarding their parenting capabilities.

(b) Increase flexibility of Personal Assistance Services and change existing regulations so that routine child care activities are included as “an activity of daily living.”
(c) Create Fair Housing Laws and housing standards that meet the needs of parents with disabilities and their families.

(d) Promote changes in local, regional and national transportation policies to facilitate travel by parents with disabilities with their children.

(e) Insure that parents with disabilities have equal access to adoption services, including appropriate assessment of their parenting capabilities.

(f) Develop financial mechanisms at the federal level (such as a waiver system or tax deductions) to enable parents with disabilities to purchase the services and equipment necessary for them to raise their children.

3) Increase access to disability-appropriate services for all parents with disabilities and their families.

(a) Provide training regarding parents with disabilities and their families to both parents with disabilities and service providers who work with these families. This training must acknowledge the rights of disabled parents, be based within the appropriate disability cultural contexts, promote better understanding of the needs of parents with disabilities, and increase outreach to multicultural groups.

- Provide training to legal and social service professionals involved in custody cases including an understanding of daily parenting activities and the identification of knowledgeable resources.

- Provide training to medical schools and medical professionals about disability and about parenting.

- Coordinate nationally with the medical and therapeutic communities to recognize and respond to the needs of parents with disabilities and their families.

- Provide parenting education specific to parents with disabilities.

(b) Establish a centralized library of resources and information on parenting with disabilities. Such materials should be interdisciplinary, encompass professional as well as parent concerns, be available in multiple formats, and emphasize a non-pathological perspective on parents with disabilities and their families.

(c) Develop curricula on parenting with a disability to be included in professional/graduate school training programs including Obstetrics, Occupational Therapy, Nursing, Social Work, Psychology and Family Law.
(d) Develop model programs for keeping our families together and replicate these nationally and internationally.

(e) Increase the number of accessible child care sites and improve accessibility of all sites.

(f) Increase accessible recreation programs and sites.

4) Increase the availability and the development of adaptive parenting equipment.

(a) Encourage and support those manufacturers currently producing equipment that works.

(b) Review regulations regarding cribs and car seats, including strategies to deal with liability issues such as good Samaritan laws.

(c) Promote a better network for exchange of information among parents with disabilities nationally.

(d) Establish local lending networks for recycling adaptive parenting equipment through Independent Living Centers, social service agencies, rehab hospitals and university programs.

(e) Educate corporations about the needs of parents with disabilities.

(f) Develop catalogs on parenting devices and distribute to wheelchair and medical supply companies.

(g) Link with assistive technology centers.

(h) Link with university engineering projects.

(i) Train professionals regarding adaptive parenting equipment.

(j) Increase funding for adaptive parenting equipment.

5) Promote parents with disabilities and their families as the primary spokespersons for themselves.

(a) Promote the inclusion of parent and family member perspectives and experiences in legislation, research and services concerning parents with disabilities.
(b) Encourage research which addresses the concerns and issues of parents with disabilities and their families.

(c) Establish a library of funding resources to enable more parents with disabilities and family members to develop disability and family appropriate programs, services and research.

(d) Develop mechanisms for parents with disabilities to contact each other and share information regarding resources and services.

(e) Encourage existing programs and service providers working with parents with disabilities and their families to document their work and the local/regional needs of parents with disabilities.

(f) Provide parent contacts to legislators and researchers through the National Task Force membership directory.

(g) Provide the media with positive images of parents with disabilities.

6) Advocate for parents with disabilities across all disability categories, across all ethnic groups, and across all family constellations.

(a) Increase outreach to parents including diverse disability and Deaf communities, families of color, rural, non-English speaking populations, lesbian and gay communities, as well as to parents and communities not self-identified as “disabled.”

(b) Redirect moneys into keeping families together, and work with existing and new systems (e.g., tax laws, subsidies) to be oriented toward family unification.

(c) Promote recognition that the cost of living is significantly higher for disabled parents than for non-disabled parents.

International Division

An International Division of the Task Force was created by members representing 11 countries and the Native American Sovereign Nations. As international Task Force members, we strongly concur with the critical need for training of parents with disabilities and professionals. In addition to reviewing and supporting the objectives of the Task Force, as an International community we are particularly concerned that poverty issues among parents with disabilities and their families be recognized and addressed. Illiteracy and lack of basic health care prevents millions of parents with disabilities throughout the world from being able to sustain lives for themselves and their families. The International division of the Task Force
strongly advocates improved literacy and access to basic health care as a fundamental step to improve the lives of parents with disabilities and their families. Additionally, as international members, we emphasize the need to recognize and welcome cultural diversity in the development of policies and services to parents with disabilities and their families.

In order to address the critical need for access to resources and information, the International Division proposed to create a three-tiered communication system:

(1) A network of International Task Force members.

(2) A compilation of available international funding sources.

(3) A compilation of resources and research on parenting with a disability.

The system would function primarily through e-mail and mail correspondence among international members. If resources are available, information would also be stored in a centralized library such as the one currently in place at Through the Looking Glass. Copies or citations of such information could be available upon request. Portions of this information could also be posted and updated on a website.

**Additional Copies and Information**

Additional copies of this Task Force report are available from TLG for $3. Copies are also available in Braille, large print and on floppy disk. The report can also be viewed at TLG’s website: www.lookingglass.org. The National Survey of Parents with Disabilities was one of twelve research projects under TLG’s National Rehabilitation Research and Training Center on Families of Adults with Disabilities. The final 220 page report on this survey -- *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities* (Toms Barker, Maralani, 1997) is available for $25 from TLG.

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