

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

Report compiled by
Paul Preston, Ph.D.
Margaret Jakobson, Esq.

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“Keeping Our Families Together”

A Report of the National Task Force on Parents with Disabilities and their Families

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.

- 44
- 45 2. Ability to conduct parenting activities. Disabled parents reported needing the
- 46 assistance in recreation with their children (43%), traveling outside the home with
- 47 their children (40%), chasing or retrieving children (39%), and lifting or carrying
- 48 children (33%). Areas of assistance needed by parents varied according to the type of
- 49 disability.
- 50
- 51 3. Insufficient transportation. Transportation was an issue which affected more aspects
- 52 of parenting with a disability than any other issue. 79% reported transportation as a
- 53 problem which interfered with or prevented routine and critical parent-child
- 54 activities.
- 55
- 56 4. Access to child care. Cost was the most frequently identified barrier to child care
- 57 (30%), followed by lack of transportation (20%), access issues (15%), lack of
- 58 appropriate services (11%), and lack of information where to find child care (6%).
- 59 While certain individual factors may be pertinent to all families, this underestimates
- 60 the effects of multiple barriers such as cost, lack of access and lack of disability-
- 61 appropriate services.
- 62
- 63 5. Need for adaptive parenting equipment. Barriers to obtaining adaptive parenting
- 64 equipment were cost (48%), lack of information about such equipment (44%), the
- 65 unavailability of such equipment or that it had not yet designed (32%), and there is no
- 66 one to make this equipment (19%).
- 67
- 68 6. Personal assistance services. 57% reported using personal assistance services for help
- 69 with parenting. Problems with using personal assistance were that it often was not
- 70 available when needed (54%), was unreliable (46%), interfered with the parent's role
- 71 (38%), and assistants were inexperienced in knowing how to care for children (35%).
- 72
- 73 7. Inadequate housing. 43% of all respondents reported facing at least one barrier with
- 74 regard to housing for parents with disabilities. The most frequently identified barriers
- 75 to housing were: too expensive (33%), inadequate space (28%), and inaccessible (25%).
- 76
- 77 8. Attitudinal barriers. 42% of disabled parents reported facing attitudinal barriers
- 78 including discrimination (32%), pressure to have a tubal ligation (14%), and pressure
- 79 to have an abortion (13%). Despite the sample population's high education level and
- 80 the limited participation of parents with cognitive or psychiatric disabilities, 15% of
- 81 parents reported attempts to have their children taken away. 8% reported they
- 82 experienced attitudinal barriers which interfered with or prevented adoption.
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84 Task Force Objectives

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86 By consensus of those present, four objectives were identified for this formative meeting:

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- 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

129 uninformed judgments can permanently sever parent from child. Knowledgeable assessments
130 and appropriate interventions are critical to sustaining many of our families.

131
132 Task Force members also described how these areas of concern are affected by the diversity
133 and variation in our families and our communities. These variations include the nature and
134 histories of our disabilities, our family constellations, the ages of our children, our ethnicities
135 and gender, the availability of economic and social resources, and regional and national
136 policies which can promote but far too frequently exclude or ignore our families.

137 138 **Task Force Priorities and Recommendations**

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

142 143 **1) Promote recognition and inclusion of parents with disabilities and their families.**

144
145 (a) Establish a national and international Task Force on parents with disabilities and
146 their families. Task Force members have identified specific areas of interest and
147 expertise. Task Force members will contact each other through e-mail, written and
148 phone correspondence. Through the Looking Glass will facilitate Task Force
149 activities by posting Task Force information on its website, preparing and
150 circulating Task Force reports, and preparing and circulating a directory of Task
151 Force members.

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

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

158
159 (d) Utilize existing disability awareness days to promote awareness of families of
160 parents with disabilities.

161 162 **2) Promote informed regional and national policies which address the needs of families in** 163 **which one or both parents have a disability.**

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

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169 (b) Increase flexibility of Personal Assistance Services and change existing regulations
170 so that routine child care activities are included as “an activity of daily living.”
171

- 172 (c) Create Fair Housing Laws and housing standards that meet the needs of parents
173 with disabilities and their families.
174
- 175 (d) Promote changes in local, regional and national transportation policies to facilitate
176 travel by parents with disabilities with their children.
177
- 178 (e) Insure that parents with disabilities have equal access to adoption services, including
179 appropriate assessment of their parenting capabilities.
180
- 181 (f) Develop financial mechanisms at the federal level (such as a waiver system or tax
182 deductions) to enable parents with disabilities to purchase the services and
183 equipment necessary for them to raise their children.
184

185 **3) Increase access to disability-appropriate services for all parents with disabilities and**
186 **their families.**
187

- 188 (a) Provide training regarding parents with disabilities and their families to both
189 parents with disabilities and service providers who work with these families. This
190 training must acknowledge the rights of disabled parents, be based within the
191 appropriate disability cultural contexts, promote better understanding of the needs
192 of parents with disabilities, and increase outreach to multicultural groups.
193
- 194 • Provide training to legal and social service professionals involved in custody
195 cases including an understanding of daily parenting activities and the
196 identification of knowledgeable resources.
197
 - 198 • Provide training to medical schools and medical professionals about disability
199 and about parenting.
200
 - 201 • Coordinate nationally with the medical and therapeutic communities to
202 recognize and respond to the needs of parents with disabilities and their
203 families.
204
 - 205 • Provide parenting education specific to parents with disabilities.
206
- 207 (b) Establish a centralized library of resources and information on parenting with
208 disabilities. Such materials should be interdisciplinary, encompass professional as
209 well as parent concerns, be available in multiple formats, and emphasize a non-
210 pathological perspective on parents with disabilities and their families.
211
- 212 (c) Develop curricula on parenting with a disability to be included in
213 professional/graduate school training programs including Obstetrics, Occupational
214 Therapy, Nursing, Social Work, Psychology and Family Law.

- 215
216 (d) Develop model programs for keeping our families together and replicate these
217 nationally and internationally.
218
219 (e) Increase the number of accessible child care sites and improve accessibility of all
220 sites.
221
222 (f) Increase accessible recreation programs and sites.
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224 **4) Increase the availability and the development of adaptive parenting equipment.**
225

- 226 (a) Encourage and support those manufacturers currently producing equipment that
227 works.
228
229 (b) Review regulations regarding cribs and car seats, including strategies to deal with
230 liability issues such as good Samaritan laws.
231
232 (c) Promote a better network for exchange of information among parents with
233 disabilities nationally.
234
235 (d) Establish local lending networks for recycling adaptive parenting equipment
236 through Independent Living Centers, social service agencies, rehab hospitals and
237 university programs.
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239 (e) Educate corporations about the needs of parents with disabilities.
240
241 (f) Develop catalogs on parenting devices and distribute to wheelchair and medical
242 supply companies.
243
244 (g) Link with assistive technology centers.
245
246 (h) Link with university engineering projects.
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248 (i) Train professionals regarding adaptive parenting equipment.
249
250 (j) Increase funding for adaptive parenting equipment.
251

252 **5) Promote parents with disabilities and their families as the primary spokespersons for**
253 **themselves.**
254

- 255 (a) Promote the inclusion of parent and family member perspectives and experiences in
256 legislation, research and services concerning parents with disabilities.
257

- 258 (b) Encourage research which addresses the concerns and issues of parents with
259 disabilities and their families.
260
- 261 (c) Establish a library of funding resources to enable more parents with disabilities and
262 family members to develop disability and family appropriate programs, services
263 and research.
264
- 265 (d) Develop mechanisms for parents with disabilities to contact each other and share
266 information regarding resources and services.
267
- 268 (e) Encourage existing programs and service providers working with parents with
269 disabilities and their families to document their work and the local/regional needs
270 of parents with disabilities.
271
- 272 (f) Provide parent contacts to legislators and researchers through the National Task
273 Force membership directory.
274
- 275 (g) Provide the media with positive images of parents with disabilities.
276

277 **6) Advocate for parents with disabilities across all disability categories, across all ethnic**
278 **groups, and across all family constellations.**
279

- 280 (a) Increase outreach to parents including diverse disability and Deaf communities,
281 families of color, rural, non-English speaking populations, lesbian and gay
282 communities, as well as to parents and communities not self-identified as
283 “disabled.”
284
- 285 (b) Redirect moneys into keeping families together, and work with existing and new
286 systems (e.g., tax laws, subsidies) to be oriented toward family unification.
287
- 288 (c) Promote recognition that the cost of living is significantly higher for disabled parents
289 than for non-disabled parents.
290

291 **International Division**
292

293 An International Division of the Task Force was created by members representing 11 countries
294 and the Native American Sovereign Nations. As international Task Force members, we
295 strongly concur with the critical need for training of parents with disabilities and
296 professionals. In addition to reviewing and supporting the objectives of the Task Force, as an
297 International community we are particularly concerned that poverty issues among parents
298 with disabilities and their families be recognized and addressed. Illiteracy and lack of basic
299 health care prevents millions of parents with disabilities throughout the world from being able
300 to sustain lives for themselves and their families. The International division of the Task Force

301 strongly advocates improved literacy and access to basic health care as a fundamental step to
302 improve the lives of parents with disabilities and their families. Additionally, as international
303 members, we emphasize the need to recognize and welcome cultural diversity in the
304 development of policies and services to parents with disabilities and their families.
305

306 In order to address the critical need for access to resources and information, the International
307 Division proposed to create a three-tiered communication system:
308

- 309 (1) A network of International Task Force members.
- 310
- 311 (2) A compilation of available international funding sources.
- 312
- 313 (3) A compilation of resources and research on parenting with a disability.
- 314

315 The system would function primarily through e-mail and mail correspondence among
316 international members. If resources are available, information would also be stored in a
317 centralized library such as the one currently in place at Through the Looking Glass. Copies or
318 citations of such information could be available upon request. Portions of this information
319 could also be posted and updated on a website.
320

321 **Additional Copies and Information**

322

323 Additional copies of this Task Force report are available from TLG for \$3. Copies are also
324 available in Braille, large print and on floppy disk. The report can also be viewed at TLG's
325 website: www.lookingglass.org. The National Survey of Parents with Disabilities was one of
326 twelve research projects under TLG's National Rehabilitation Research and Training Center on
327 Families of Adults with Disabilities. The final 220 page report on this survey -- *Challenges and*
328 *Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities* (Toms
329 Barker, Maralani, 1997) is available for \$25 from TLG.
330

331 For additional information, please contact:
332

333 Through the Looking Glass
334 2198 Sixth Street #100
335 Berkeley, CA 94710
336 phone: 1-800-644-2666 (voice), 1-800-804-1616 (TTY) or 510-848-1112 (voice)
337 fax: (510-848-4445)
338 e-mail: TLG@lookingglass.org
339 Website: www.lookingglass.org
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National Task Force on Parents with Disabilities and their Families

Task Force Members, January 1998

Missoula, MT

Janet Abelson
AC Transit Accessibility Advisory Committee
El Cerrito, CA

Darlene Bubis
Through the Looking Glass
Berkeley, CA

MaryJo Alimena
Project STAR
Wexford, PA

Rebecca Clawson
Bloomington, MN

Adrienne Asch, Ph.D.
Wellsley College
Wellesley, MA

Connie Conley-Jung
Alameda, CA

Donnella Barron
Alabama Department of Rehabilitation Services
Homewood, AL

Doug Cook, Ph.D.
University of Washington
Seattle, WA

Ann Bell
Batavia Center for Independent Living, Inc.
Batavia, NY

Katherine J. Corbett
Disabled Women's Alliance
Berkeley, CA

Teresa Bennett
University of Illinois
Champaign-Urbana, IL

Fred Dickinson
Modesto Independent Living Center
Modesto, CA

Leatta Bergeson
Southwest Center for Independent Living
Springfield, MO
Ruth Blumer
Seattle-King County Department of Public Health
Issaquah, WA

Sharon Dixon
Birth and Family Services
Gardena, CA

Renee Hintz Bourke
Eastern Washington University
Spokane, WA

Tanis Doe, Ph.D.
DisAbled Women's Network
Victoria, British Columbia CANADA

Liz Bowen
Walnut Creek, CA

Robin Donnelly
North Brunswick, NJ

Nikki Brown-Booker
Through the Looking Glass
Berkeley, CA

Florence Adong-Ewo
Disabled Women Network & Resource Organization
Kampala, UGANDA

Susan Brueckmann
American Indian Choices

Sharon Fallis
Training Towards Self Reliance
Sacramento, CA

Tammy Flatmo

The Arc of Snohomish County
Everett, WA

LaDonna Fowler
American Indian Choices/ AIDL Project
Polson, MT

Ann Guerra
Grass Valley, CA

David B. Gray, Ph.D.
Washington University School of Medicine
St. Louis, MO

Diane Grzymko
Kessler Institute for Rehabilitation
West Orange, NJ

Tim Hanisak
Holly Hill, FL

Sherrie Hansen, Ph.D.
Through the Looking Glass
Berkeley, CA

Gisela Hermes
bifos e.V.
Kassel, GERMANY

Carol Howland
Baylor Center
Research on Women with Disabilities
Houston, TX

Pat Israel
Disabled Women's Network
Toronto, Ontario CANADA

Lydia Jakovac
Elsternwick, Victoria AUSTRALIA

Margaret Jakobson, Esq.
Protection and Advocacy
Oakland, CA

Florence Kiewel

Summit Independent Living Center
Columbia Falls, MT

Megan Kirshbaum, Ph.D.
Through the Looking Glass
Berkeley, CA

Yuko Konta
Tokyo JAPAN

Lisbeth Krawiecki
The Marcus Center
Atlanta, GA

Stephanie Levandusky
National Multiple Sclerosis Society
Philadelphia, PA

Jeanette Lee
Yooralla Society: Independent Living Services
South Melbourne, Victoria AUSTRALIA

Hal Lewis
J.F. Kennedy Center
Children with Developmental Disabilities
Denver, CO

Lizzie Longshaw
National Centre for Disabled People of Zimbabwe
Bulawado, ZIMBABWE

Jeanne Lukacek
Wellsley College
Wellesley, MA

Meg Magnan
Decatur, IN

Paula Martin, OTR
Fishersville, VA

Glenda McCray Lang
Birth and Family Services
Gardena, CA

Katie Meecham
Through the Looking Glass
Berkeley, CA

Effie Meehan
Yooralla Society
Parents with a Disability Community Project
St. Albans, Victoria AUSTRALIA

Chinda Misra
Toledo, OH

Pilar Murray, Esq.
Tacoma, WA

Richard Mushiga
People with Disabilities
Kampala UGANDA

Peninah Mutinda
Kamukunji Disabled Group &
Handicapped Mobility Alliance
Nairobi KENYA

Bishnu Prasad Neupane
Nepal Disabled Women Society
Lalitpur, Bagmati NEPAL

Donna Newkirk
University of Alaska
Anchorage, AK

Rhoda Olkin, Ph.D.
Walnut Creek, CA

Richard Olsen, Ph.D.
Nuffield Community Care Studies Unit
Leicester University
Leicester ENGLAND

Barbara Phalen
Seattle-King County Department of Public Health
Renton, WA

Lynne Poole
Shepherd Center
Alpharetta, GA

Paul Preston, Ph.D.
Through the Looking Glass
Berkeley, CA

Julie Reistin
Colorado Cross Disability Coalition
Denver, CO

Judi Rogers, OTR
Through the Looking Glass
Berkeley, CA

Enza Ronaldi
The Centre for Independent Living in Toronto
Toronto, Ontario CANADA

Kerstin Sandberg
The Swedish Handicap Institute
Stockholm SWEDEN

Donna Scandlin
Office of Disability and Health
Chapel Hill, NC

Lynda Schafer
Langhorne, PA

Sandie Shepard
The ARC of Spokane
Spokane, WA

Meenu Sikand
Canadian Association of Independent Living
Etobicoke, Ontario CANADA

Beth Smith
Through the Looking Glass
Berkeley, CA

Diana Soderberg
DAWN Ontario
Thunder Bay ON CANADA

Jennie Spallone
Buffalo Grove, IL

Laureen Summers
American Association for the Advancement of Science

Washington, D.C.

Mitchell Tepper
The Sexual Health Network
Huntington, CT

Linda Toms Barker
Berkeley Planning Associates
Oakland, CA

Christi Tuleja, OTR
Through the Looking Glass
Berkeley, CA

Sandra Welner, MD
Women's Health Program
Washington, D.C.

Lynda Wheeler
North Bay Regional Center
Santa Rosa, CA

Donna White
Through the Looking Glass
Berkeley, CA

Michael Winter
Federal Transit Administration
Department of Transportation
Washington, D.C.