

International Encyclopedia of Rehabilitation

Copyright © 2010 by the Center for International Rehabilitation Research Information and Exchange (CIRRIE).

All rights reserved. No part of this publication may be reproduced or distributed in any form or by any means, or stored in a database or retrieval system without the prior written permission of the publisher, except as permitted under the United States Copyright Act of 1976.

Center for International Rehabilitation Research Information and Exchange (CIRRIE)

515 Kimball Tower

University at Buffalo, The State University of New York

Buffalo, NY 14214

E-mail: ub-cirrie@buffalo.edu

Web: <http://cirrie.buffalo.edu>

This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.

Parents with Disabilities

**Paul Preston, Ph.D.
National Center for Parents with Disabilities
Through the Looking Glass
Berkeley, California**

Parents with disabilities include a broad spectrum of mothers and fathers of children of all ages. This article will describe: (1) population estimates and demographic characteristics of parents with disabilities and their families; (2) social and historical perspectives on parents with disabilities; (3) the impact of disability on parenting; (4) the children of parents with disabilities; and, (5) implications for future research and policy. Because of the scarcity of studies or information concerning parents with disabilities throughout the world, the data included in this article are drawn primarily from studies and resources developed within the United States, Australia and the United Kingdom. As such, not all of the information herein may be generalizable to other international communities. However, presenters and attendees from more than 40 countries at two recent international conferences on parents with disabilities have reiterated many of the perspectives and concerns discussed in this article (Preston and Jakobson 1998; Preston and Gray 2002). It is hoped that these discussions will serve as a catalyst for additional dialogue concerning parents with disabilities that will continue to address social bias, pathological assumptions and flawed research methodologies described herein that has characterized much of the information concerning this population.

Population Parameters, Size and Demographic Characteristics

There are millions of mothers and fathers with disabilities throughout the world -- whether they have become parents through birth, adoption or marriage. This heterogeneous population includes parents whose disability can be physical, systemic, cognitive, visual, auditory, developmental, psychiatric, or combinations of these (Kirshbaum and Olkin 2002). In its broadest sense, 'parents with disabilities' also includes those parents who typically do not identify themselves as having a disability, such as a Deaf parent, a parent of short stature, or a parent with diabetes; in addition, many cultures and communities eschew the term "disability" and would not self-describe using this label. An additional population that should also be considered are grandparents and other relatives who have a disability and are a child's primary caretaker. In the United States, there is an especially rapid increase in the number of grandparents in parenting roles; a 1999 study found that caregiving grandparents had greater than 50% chance of having a limitation in an activity of daily living (ADL) compared to non-caregiving grandparents (Minkler and Fuller-Thomson 1999). Although grandparents and other relatives may not be legally recognized as a child's "parent," nonetheless these primary caregivers and their children face many of the same issues as families of biological and adoptive mothers and fathers with disabilities. Another consideration in defining this population is whether to exclude parents whose child does not live with them; this is an especially salient issue in that many children of parents with disabilities are inappropriately removed from their parents' care, and most parents with disabilities have few financial and social resources to retain or regain custody of their children (Callow et al. 2008). Finally, non-disabled parents may develop a disability long after their children have grown and left home, and the impact of disability may

not be comparable to those families in which the parent has had a disability prior to or during the early parenting years. Keeping these important considerations in mind, for purposes of clarity this article primarily focuses on mothers and fathers with disabilities who have children under age 18 living at home.

Parents with disabilities exist in significant numbers in all countries of the world, yet documentation of this population is extremely limited. A major obstacle in estimating the number of parents with disabilities as well as their demographic characteristics is the lack of data. Although some national census data provide estimates of the number of people with disabilities or the number of parents within a given locale, there are almost no regional or national data that consider the combination of these two characteristics -- that is, parents who have disabilities. Instead, national estimates of the numbers of parents with disabilities are generally based upon projections from much smaller data sets or estimated by complex extrapolations. Even at the regional or local level, most systems and organizations serving parents or serving people with disabilities fail to collect data on the numbers of parents with disabilities who are included in their purview. As a result of the lack of substantive data at the local and national level, parents with disabilities remain a highly invisible population. Erroneous assumptions about the low prevalence of parents with disabilities affect the availability of resources or the motivation to create new resources specifically for parents with disabilities and their families.

In the United States, parents with disabilities represent approximately 15% of all parents of children under age eighteen (U.S. Bureau of the Census 1993; U.S. Dept of Health and Human Services 2002). The percentage of parents with disabilities is estimated to be even higher among notable groups: 24% of single parents have disabilities, 18.7% of all African American parents and 16.3% of Hispanic parents have disabilities (McNeil 1993). Additional studies estimating the number of U.S. parents with disabilities with children under age 18 have ranged from 6.9 million to 8.4 million (Hendershot et al., 2002; McNeil 1993; LaPlante 1991). This variance is largely a function of analyses of different national data sets that include differing definitions of disability and differing age criteria for children in the home. Even these national estimates lack many demographic details particular to families of parents with disabilities such as the types of parental disability, use of assistive technologies or personal assistance, or specific factors that may impede or promote parenting activities.

In the U.S., there is significant variation across major categories of disability in terms of the proportion of disabled adults who are parents (Toms Barker and Maralani 1997): 26% of adults with physical disabilities are parents, 24% of adults with a psychiatric disability, and 16% of adults with a cognitive disability. Adults with "sensory disabilities" represents the highest proportion of disabled adults who are parents: 40%; unfortunately, there is no distinction in available national data sets to clarify which of these parents are blind versus those who are deaf. As will be discussed, conflation of disabilities mars many statistics and studies concerning parents with disabilities.

An analysis of the data from the 1993 Survey of Income and Program Participation (SIPP) indicates a few notable differences when comparing disabled parents with nondisabled parents (Toms Barker and Maralani 1997; McNeil 1993). Overall, 30% of disabled adults are parents compared with 40% of nondisabled adults. Disabled parents are slightly older than nondisabled parents (39 years vs. 36 years), and disabled parents are somewhat less likely to be married than

nondisabled parents (75% vs 84%). Disabled parents are more likely to have a spouse with a disability compared to nondisabled parents (26% vs. 8%) and are also more likely to have a disabled child compared with nondisabled parents (14% compared with 3%). The greater prevalence of children with disabilities may be because some disabilities are genetically linked or because disabled parents are more likely to recognize and report disabilities in their children. Also, some disabled parents may be more open to adopting disabled children or this may be the only option available through some adoption agencies (Toms Barker et al. 1997a).

Perhaps the most significant difference between disabled parents and nondisabled parents is economic: more disabled parents are unemployed (48% vs. 22%) and are more likely to receive public assistance such as Temporary Assistance for Needy Families (TANF), Food Stamps or housing assistance. In a 1997 national survey of U.S. parents with disabilities, 23% of the sample had household incomes under \$15,000 (i.e., below the poverty line for a family of four) and 43% had incomes below \$30,000 (Toms Barker and Maralani 1997b). The economic impact is especially noteworthy considering disabled parents often have additional expenses connected with their disability (e.g., medicine, adaptive equipment, transportation or housing modifications). There may also be additional expenses caring for their children. For example, although paratransit or other alternative transportation designated for people with disabilities may be available for an adult with a disability, many paratransit systems prohibit transporting the non-disabled child of a parent with disability (e.g., to school or the doctor's office) even if accompanied by the parent. Similarly, the policies of Personal Assistance Services (PAS) varies widely from community to community, and many do not allow an attendant to assist a parent with a disability in bathing, feeding or otherwise caring for a disabled parent's non-disabled child (Doe 1995).

Social and Historical Perspectives on Parents with Disabilities

Parenting may be considered one of the last frontiers for people with disabilities (Kirshbaum 2000). The number of parents with disabilities can be expected to increase as more people with disabilities exercise a broader range of lifestyle options as a result of social integration, civil rights and new adaptive technologies. Yet, many communities and societies do not view "parenting" as a fundamental right for individuals with disabilities. Despite the Americans with Disabilities Act (ADA) and other comparable legislation designed to protect the rights of individuals with disabilities, the right to parent is almost never explicitly protected. For many individuals with disabilities, becoming a parent is often actively interfered with and overtly discouraged.

A longstanding societal concern about adults with disabilities becoming parents is that they will have children who are similarly disabled. In the first half of the 20th century proponents of the Eugenics movement influenced nearly thirty U.S. state legislatures to pass laws allowing the involuntary sterilization of people with developmental, mental, sensory and physical disabilities (Silver 2004). This legislative trend was based on the belief that these and other "socially inadequate" populations would produce offspring that would be burdensome to society (Lombardo 1996). The result of this policy was the forced sterilization of 60,000 American citizens, some as young as ten years old (Reilly 1991). By the 1970's most U.S. sterilization laws were struck down on procedural grounds and rules were adopted that prohibited sterilization by institutions receiving federal funding. However, parenting with a disability is still not guaranteed. Currently, seven U.S. states retain a judicial process by which people with

disabilities can be sterilized involuntarily (Leslie-Miller 1997). Moreover, the debate about whether people with disabilities should be allowed to reproduce has been complicated by the regular denial of access to Artificial Reproductive Technologies (Coleman 2002).

Concerns over whether or not a deaf or disabled adult will have a deaf or disabled child is considered offensive to many individuals who have a disability or are deaf (Doe 1997; Preston 1994). Such concerns undermine the accomplishments and self-worth of people with disabilities. Additionally, many disabled parents have life experiences and advocacy skills to provide positive role models for children with disabilities (O'Toole and Doe 2002).

An even more prevalent concern about parents with disabilities is: How can someone with a disability safely raise any child to become a productive member of society? As currently written, U.S. child custody laws reflect the historical bias against parents with disabilities, implying that parents with disabilities are incapable of properly caring for their children (Kirshbaum et al. 2003). Most U.S. states allow a parent's disability to be a factor in determining whether or not a parent should keep custody of their child. The National Study of Women with Physical Disabilities by the Center for Research on Women with Disabilities reported that women with disabilities were significantly more likely than those without disabilities to stay in a bad marriage for fear of losing custody of their children (Nosek et al. 1997). Rather than focusing on a parent's disability, factors that should be considered in child custody cases should be the same as for non-disabled parents including abuse, neglect or abandonment (Callow et al. 2008; Wates 1997). Further, parents with disabilities in danger of losing their children often cannot find accessible and disability-appropriate resources and supports to retain their children, and this is additionally compounded by substantially inadequate financial resources (Toms Barker and Maralani 1997b).

Responding to the increasing demands of parents with disabilities and their advocates, a few states have recently passed legislation to support and protect the rights of parents with disabilities. In 2003, a coalition of the Idaho State Legislature, Independent Living Centers and Service Systems created historic legislation – the first in the U.S. – that removed discriminatory language against parents with disabilities and included language to protect parents with disabilities from discrimination. Five laws were revised pertaining to divorce, child protection, termination of parental rights, adoption, and child/parent relationships. Underscoring the critical difference parenting adaptations can make for some parents with disabilities to better care for their children, California's Protection and Advocacy system sponsored bill AB 2152 that focused on coverage for parenting adaptations. Medi-Cal (California's Medicaid program) provides health care coverage for more than six million low-income children and families as well as elderly, blind, or disabled individuals. Under California law, Medi-Cal must now include adaptive parenting equipment as medically necessary durable medical equipment (DME) to enable a disabled parent to care for his or her child. The bill passed and became law in January 2001. In 2005, the Kansas legislature passed a bill removing discriminatory language against parents with disabilities, as well as requiring disability-appropriate testing and assessment tools if a parent is disabled. The bill was signed into law by the governor and went into effect in 2007 (Callow et al. 2008).

The history and policies of a society affect the degree of discrimination towards parents with disabilities, the availability of resources and even the option to parent. However, each adult with a disability also has a more immediate and localized context in which attitudes about disability

and the options to parent develop. The family-of-origin experiences of individuals with disabilities are especially crucial to parenting outcomes (Kirshbaum 1994). Often, family members give children with disabilities implicit and explicit messages that adult sexuality, relationships and parenting are not viable options. Even if an adult was not disabled as a child, he or she is still exposed to and incorporates negative familial and social messages about what it means to be disabled (Olkin 1999; Wates 1997). Many adults with disabilities report feeling isolated as children and even rejected by their families of origin; poor parent-child relationships between a child with disabilities and her parents may translate into similarly stressful relationships when that child grows up and becomes a parent (Rolland, 1994).

The Impact of Disability on Parenting

In assessing the impact of disability on parenting, much of the research and existing resources often over-generalize across different disabilities, failing to consider important distinctions among disabilities as well as the differences in functional levels even within one category of disability (Kirshbaum and Olkin 2002). A parent's disability can be congenital or adventitious, stable, progressive or varying. The specific circumstances, degree and characteristics of a parent's disability can affect not only the parent's routine functioning and life experiences, but can also impact aspects of the parenting role as well as the child's experience. As discussed in the previous section, a disabled individual's family and community of origin can significantly enhance or undermine the experience of disability.

Numerous studies indicate that age of onset of disability is a significant variable in the trajectory of an individual's life (Olkin 1999). Further, several prominent activist disabled authors (Longmore 2003; Gill 1997) suggest that individuals who have a stable lifelong disability often have a less conflicted sense of their identity as a disabled person and greater experience finding and developing appropriate resources; this, in turn, may facilitate a family's adaptations to parental disability. In contrast, the sudden onset of disability during parenting years (e.g., through accident, war or such mid-adult diseases such as M.S.) may result in considerable trauma and family upheaval for both parent and the child. Similarly, the instability and unpredictability of conditions such as M.S. or bipolar disorder may create ongoing stress for family members. Disabilities and chronic illnesses characterized by intermittent pain or fatigue may affect routine physical parenting tasks such as bathing, feeding or playing. Certain disabilities or medical conditions may require frequent parent-child separations and interruptions in family routines due to medical treatments and hospitalizations. More severe and persistent symptoms or prolonged separations may ultimately impact the overall quality of the parent-child relationship (Rolland 1994).

Complementing the varying characteristics and history of a parent's disability are the characteristics of the child -- that is, the age and temperament of the child as well as whether or not the child also has a disability (whether similar to the parent's disability, or not). Many routine parenting tasks are age-specific (e.g., diapering an infant, modeling language or motor skills, assisting with a child's homework) -- and a parent's disability may affect a particular age-related parenting task. In some situations, a parent's disability may facilitate and enhance the parenting task. For example, a study on diapering by parents with physical disabilities (DeMoss et al. 1997) documents that, as long as appropriate modifications were available, parents who took longer to diaper their baby spent additional time interacting with their child and developing a positive parent-child relationship.

Through the Looking Glass, the first U.S. National Center for Parents with Disabilities, conducted the first and only national survey of U.S. parents with disabilities (Toms Barker and Maralani 1997). This was the largest study on parents with disabilities to date and yields data from a national sample of 1,200 parents with diverse disabilities: 70% of survey respondents identified their primary disability as physical; 13% as sensory; 7% as cognitive; 6% as psychiatric; and, 1% as other. One-third of all respondents reported having more than one type of disability. The results can be summarized in eight life areas related to parenting with a disability:

- 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.
- Adoption. 11% of disabled parents had children who were adopted, and over half of these parents adopted after they became disabled. 8% reported they experienced attitudinal barriers that interfered with or prevented adoption.
- Custody. 15% (of the predominantly physically disabled and well-educated sample) reported attempts to have their children taken away from them.
- Ability to conduct parenting activities. Disabled parents reported needing the most 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.
- 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 appropriate child care (6%).
- Need for adaptive parenting equipment. Barriers to obtaining adaptive parenting equipment were: cost (48%), lack of information about such equipment (44%), unavailability/not yet designed (32%), and there was no one available to make it (19%).
- Personal assistance services. 57% reported using personal assistance services for help with parenting. Problems with using personal assistance included: assistance was often not available when needed (54%), it was unreliable (46%), it interfered with the parent's role (38%), and personal assistants did not know how to care for children (35%).
- Inadequate housing. 43% of respondents reported facing at least one barrier with regard to housing for parents with disabilities: expense (33%), inadequate space (28%), and inaccessibility (25%).

- Insufficient transportation. Transportation was an issue that affected more aspects of parenting with a disability than any other issue. 79% reported transportation as a problem.
- 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%).

Although inappropriately stigmatized because of misguided assumptions about their parenting capabilities, many parents with disabilities have raised their families successfully. However, some families of disabled parents are vulnerable to dysfunction, even child abuse or neglect because of risk factors comparable to those within families of non-disabled parents. These risk factors include: low economic status, lack of social supports, lack of parenting knowledge, and the child's problematic behavior (Kirshbaum et al. 2003; Preston and Lou 1998). For those disabled parents who need information or services, disability-appropriate and accessible resources are virtually non-existent. Without appropriate information or intervention, in the most extreme situations parents with disabilities are at risk of losing custody of their children due to presumed negligence or maltreatment. In less extreme cases, a number of barriers may seriously impede adequate parenting and increase the risk of family dysfunction or dissolution.

Two groups of parents with disabilities are especially vulnerable to overt discrimination, lack of appropriate services and loss of their children: parents with intellectual disabilities and parents with psychiatric disabilities. Research literature cites 40-60% out-of-home placement rates for U.S. parents with intellectual disabilities (Kennedy et al. 1999). Yet, this high rate of removal reflects greater discrimination and lack of appropriate services for parents with intellectual disabilities and their children. In discussing the political and social discrimination faced by parents with intellectual disabilities, McConnell and Llewellyn (2003) argue that parents with intellectual disabilities are often held to a higher standard of parenting than non-disabled parents. Negative expectations and outmoded beliefs that children will eventually be maltreated and that parenting deficiencies are irremediable have contributed to children being removed from parents with intellectual disabilities despite lack of evidence for any abuse or neglect by the parent. Suggestions to help reduce discriminatory treatment include: banning the use of “intellectual disability” and “mental retardation” labels during court proceedings; developing specific guidelines for the application of child protection legislation; recognizing the value of parental inter-dependence; and, involving the parent directly in the decision-making process (Emerson et al. 2006; Llewellyn et al. 2002; Ehlers-Flint 2002; Llewellyn 1990). Adaptations in services and communication are crucial with this population of parents (Kirshbaum 1997). As one example of successful intervention services that have been tailored for parents with intellectual disabilities, Through the Looking Glass’ intervention services to parents with intellectual disabilities has resulted in a significantly lower rate of out-of-home placement (2-7%) since 1990 among parents with intellectual disabilities (Ehlers-Flint 2002; Kirshbaum 2000; Hansen and Corbus 2006). Tymchuck and Keltner (1991) further underscore the pathological bias in many research studies against parents with intellectual disabilities, pointing out that much of the literature on parents with intellectual disabilities has failed to distinguish between characteristics that facilitate and those that inhibit parenting abilities. Most of these studies have focused only on identifying parents with intellectual disabilities who provide inadequate childcare, rather than identifying predictors of adequate childcare such as coping and skill acquisition -- despite the

fact that a substantial number of parents with intellectual disabilities have provided adequate care.

Another group of parents with disabilities who remain suspect to society and highly discriminated against are parents with psychiatric disabilities. While studies on this population suggest that parental psychiatric disability is itself a significant risk factor for children, many of the additional findings are compromised by over-generalizing about psychiatric disabilities (Ostler 2008; Goodman 1984; Riebschleger et al. 1993; Ritsner et al. 1991). These and other investigators also suggest that the effects of parental psychopathology and social deprivation on children are difficult to separate and probably synergistic (Nicholson et al. 1999; Nicholson et al. 1998; Rutter and Quinton 1984; Silverman 1989). These studies reiterate the importance of differentiating among types of psychiatric disability, enumerating risk factors as well as assessing family support and resources when investigating the impact of parental disability (Jacobsen et al. 1997; Riebschleger 1994; Silverman 1989).

Children of Parents with Disabilities

In the U.S. it is estimated that there are at least 15-20 million children of disabled parents and an additional 25-30 million adults who were raised by a disabled parent (Hendershot et al. 2002). The implications of being raised by a disabled parent have been the source of numerous studies, public conjectures and professional scrutiny -- all of which touch upon the fundamental rights of disabled people to be parents as well as the fundamental rights of children to be raised in an environment conducive to maximal development. Despite the lack of appropriate resources for most disabled parents and their children as well as persistent negative assumptions about these families, the vast majority of children of disabled parents have been shown to have typical development and functioning and often enhanced life perspectives and skills.

Many people assume that being raised by a disabled parent is potentially risky and even damaging to the child -- ranging from concerns over the child's physical safety to whether a disabled parent can adequately meet the child's social, emotional or developmental needs. Numerous studies on children of disabled parents conclude they are at-risk for: parentification -- that is, children who assume adult roles before they are emotionally or developmentally ready (Winton 2003; Aldridge and Becker 1993; Deshen and Deshen 1989; Small 1992); behavioral problems (LeClere and Kowalewski 1994); psychological impairment (Wagenheim 1985); delayed language development (Schiff and Ventry 1976); poor self-concept and distorted body image (Anthony 1970; Smith et al. 1993); psychodynamic conflict (Arlow 1976; Frank 1979); developmental delay (Bland et al. 1992; Schilling et al. 1982); and child-neglect or child abuse (Accardo and Whitman 1990; Greene et al. 1995; Milner and Ayoub 1980).

Yet, methodological problems call these pathological findings into question. Recent reviews of the literature identify several methodological shortcomings: not distinguishing types or degrees of parental disability; blurring age distinctions of children; conflation of parental disability and parental illness; over-generalizing from single case studies; and, exclusive use of clinical populations (Kirshbaum and Olkin 2002; Olsen 1996; Conley-Jung 1996). Additional reviews conclude that many of these studies are compromised by an inherent pathological bias, presuming incapable parents raising damaged children (Morris and Wates 2006; Olsen and Wates 2003; Kirshbaum 2000; Field and Sanchez 1999; Olsen 1996; Booth and Booth 1997a). These reviews confirm the widespread social prejudice many disabled parents report about their

rights or abilities to parent (Kirshbaum 1994; Preston 1994; Llewellyn 1990; Patterson and Witten 1987). Children of parents with disabilities are seen as victims, with "implicit and explicit criticism of disabled parents, their values, their choices and even their right to have children at all" (Conley-Jung 1996).

Nor do most studies enumerate important contextual factors – particularly known risk factors such as poverty or lack of adequate resources and supports (Newman 2005; Gorin 2004). Without considering these distinctions and contextual factors, problems within the family are invariably attributed to parental disability. Recent studies have questioned the negative effects of a parent's disability per se (e.g., Alexander et al. 2002; Booth and Booth 1997b; Cohen 1998; Rintala et al. 2000). Clinical experience suggests that predictors of problem parenting may be the same as those for non-disabled parents – particularly, a history of physical, sexual, or substance abuse in the parent's family of origin (Kirshbaum and Olkin 2002; Kirshbaum 1996; Olkin 1999). The availability of support and appropriate resources to the family was found to be an extremely important and predictive variable as well (Tymchuk 2006; Booth and Booth 1994; Ehlers-Flint 2002; Chowdry 2002; Rintala et al. 2000; Tymchuk 1992).

In one of the first major studies to contradict the prevailing negative research hypotheses and suggested outcomes for children of disabled parents, Buck and Hohmann (1981) found that children whose fathers had spinal cord injury displayed normal development in all areas investigated (personal adjustment, sex role identification, body image, health patterns, athletic interests, interpersonal relationships, parent-child relationships, values and attitudes). They concluded that children raised by parents with spinal cord injuries grew to be healthy well-adjusted adults. Although investigating different populations of disabled parents and their children, a number of other researchers have similarly adopted a non-pathological framework as well as clarifying important family characteristics (Conley-Jung and Olkin 2001; Mazur 2006; Kirshbaum 2001; Preston and Lou 1998; Preston 1996; Thurman 1985). Several consistent themes have emerged in these studies as a whole: a notable lack of norms and role models for parents and their children; more fluid and more flexible family roles; identification of external social and environmental obstacles as barriers to positive family functioning rather than as a result of the parent's disability; greater problem-solving skills among family members; and, a desire for greater public awareness and more informed practice. Most of these investigations conclude there is average to better-than-average development and functioning among children of disabled parents and found positive outcomes as well: enhanced coping and problem-solving skills; greater acceptance of difference; and, more positive attitudes towards disability (Olkin et al. 2006; Booth and Booth 1997a; Cohen 1998; Preston 1994).

Despite the above body of research, the pathological supposition that children of disabled parents will be parentified is pervasive and persists in research as well as legal and custody proceedings. Yet, recent studies question this assumption, finding instead that disabled parents frequently take on increased responsibilities and risks rather than stress their infants or ask their children for assistance (Morris and Wates 2006; Cohen 1998; Tuleja and DeMoss 1999); adolescents of disabled parents perform the same number of household tasks as teens of non-disabled parents (Olkin et al. 2006); some responsibilities are normal and appropriate within the disability community (Olsen and Clark 2003; Olsen 1996); and the availability of resources can be an important mitigating factor in the degree and type of assistance required within the family (Aldridge and Becker 1993; Preston 1996).

A notable caveat regarding how well resources may alleviate existing or potential problems within these families is whether or not these resources actually address the family's specific situation. One size does not fit all, and many programs and services purportedly for parents with disabilities are surprisingly inaccessible and inappropriate (Kirshbaum et al 2003; Preston and Gray 2002). To be effective, resources must be tailored to accommodate a variety of factors including: the specific nature of a mother or father's disability, the age and developmental needs of the child(ren), the family's ethnic and cultural history, the home and community environment, the presence of other family members, and how roles and responsibilities are understood within that particular family (Vensand et al. 2000).

Future Research and Policy Development

Parents with disabilities and their families remain invisible, discriminated against and significantly underserved due to continued societal discrimination, limited and flawed research as well as a lack of funding to provide disability-appropriate services for parents with disabilities and their families. Yet, despite these obstacles, the vast majority of parents with diverse disabilities continue to provide nurturing and secure environments for their children.

In addition to legislative efforts in some U.S. states, consumer organizations of parents with disabilities and their advocates in several countries have begun creating national networks, identifying and developing appropriate support and resources for parents with disabilities. These include: Australia (the New South Wales Network of Women with Disability http://www.femability.org.au/parenting_with_disability.htm); Canada (DisAbled Women's Network, DAWN <http://dawn.thot.net/>); United Kingdom (Disabled Parents Network <http://www.disabledparentsnetwork.com/> and Disability, Pregnancy and Parenthood international <http://www.dppi.org.uk/>); and, the United States (Through the Looking Glass <http://www.lookingglass.org>). Deaf parents are now included in forums and presentations on families at national and world-wide organizations of deaf and hard-of-hearing people including the World Federation of the Deaf, the National Association of the Deaf, Deaf Seniors of America and Deaf Way; previously, "parent" discussions and presentations had focused almost exclusively on deaf children. In 2000, the Committee on Parental Concerns and the National Federation of the Blind announced sponsorship of a blind parent mailing list that creates a forum for blind parents to share their experiences and offer peer-based support and information <http://www.tsbvi.edu/Outreach/seehear/fall00/nfblist.htm>; comparable to developments among Deaf organizations, "parenting" support and discussions were primarily focused on blind children.

In addition to addressing methodological flaws previously described in many studies on parents with disabilities, parents with disabilities and their families have called for non-pathologizing research that is more specific in its investigations and includes strong input from parents with disabilities and their children. Some of the more recent studies that address these concerns were conducted by researchers who were themselves parents with disabilities or family members of parents with disabilities. These studies include: parents with physical disabilities and their infants (Kirshbaum 2000; Tuleja and DeMoss 1999); parents with physical disabilities and their latency age children (Cohen, 1998); parents with physical disabilities, blind parents, and deaf parents and their adolescent children (Olkin et al. 2003); parents with spinal cord injury of children aged 6-12 (Rintala et al. 2000); mothers with spinal cord injury of children 3-16 (Alexander et al. 2002); new mothers with visual impairments (Conley-Jung 1996); mothers with

intellectual disabilities of children 6 months - 17 years (Ehlers-Flint 2002); pregnancy among women with physical disabilities (Rogers 2005); parents with intellectual disabilities (Booth and Booth 1994); children of parents with intellectual disabilities (O'Neill 1985); and, mothers with MS (Crist 1991).

Policies regarding family and social supports, such as personal assistance services, assistive technology, adapted services and communication, home modification and community access can profoundly affect routine family functioning and community participation of parents with disabilities and their families. Increasingly, researchers from the disability community (Longmore, 2003; Olkin, 1999; Gill, 1997) call for using a disability-culture perspective – that is, recognizing disability as a socially constructed concept, distinguishing difference from pathology, and identifying variables that promote resilience. This view shifts the emphasis from impairment to the stigma, prejudice, discrimination, marginalization, and disempowerment imposed on individuals with disabilities (Kirshbaum and Olkin, 2002). The disability community brings a unique expertise to parenting issues. Despite increasing efforts to acknowledge and promote cultural and linguistic competency within most social service support systems, there is little awareness of or knowledge about disability or Deaf culture among a wide array of social service providers. Disability and Deaf cultures challenge traditional stereotypes of incapable and helpless individuals, normalize the experience of having a disability or being deaf, encourage independent functioning, and provide positive role models and disability-appropriate solutions. These cultural perspectives are especially crucial when working with parents with disabilities and Deaf parents who are vulnerable to pervasive societal stigma and unwarranted pathological speculation over their parenting capabilities. Providers, typically unfamiliar with disability- or Deaf-culture perspectives, frequently assess functioning according to non-disabled norms, leading to health care and services that are inaccessible, disrespectful, and ultimately ineffective.

At its inaugural meeting in 1997, the U.S. National Task Force on Parents with Disabilities identified priority issues to improve the lives of parents with disabilities and their families (Preston and Jakobson 1998). These priorities called for an end to discriminatory practice, new regional and national policies that protect the rights of parents with disabilities, and increased access to disability-appropriate services for all parents with disabilities. The Task Force further emphasized that parents with disabilities and their families be the primary spokespersons for themselves in any legislation, research or services concerning parents with disabilities. Subsequent Task Force meetings have focused on specific issues and recommendations regarding policies and services in child protective services, housing, transportation, PAS as well as the need for professional training and licensing to address the needs of parents with disabilities and their families (Preston and Gray 2002; Preston 2006).

The International Division of the Task Force on Parents with Disabilities has strongly concurred with priorities and policy recommendations outlined by the U.S. Task Force, and emphasized the need for cultural diversity in the development of policies, research and services for parents with disabilities and their families. The Task Force also raised three critical areas of concern for parents with disabilities internationally: poverty, illiteracy and basic health care; without these fundamental rights, “millions of parents with disabilities throughout the world [are prevented] from being able to sustain lives for themselves and their families” (Preston and Jakobson 1998).

On December 13, 2006 the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities, and the Convention was opened for signature on March 30, 2007. The Convention is the first human rights convention of the 21st century and the first legally binding instrument with comprehensive protection of the rights of persons with disabilities (Byrnes et al. 2007). Article 23 of the Convention specifically addresses the rights of parents with disabilities:

Discrimination relating to marriage, family and personal relations shall be eliminated. Persons with disabilities shall have the equal opportunity to experience parenthood, to marry and to found a family, to decide on the number and spacing of children, to have access to reproductive and family planning education and means, and to enjoy equal rights and responsibilities regarding guardianship, wardship, trusteeship and adoption of children.

As of July 2008, there were 129 signatories to the Convention (United Nations 2008). The U.N. Convention underscores the growing paradigm shift away from pathological and paternalistic attitudes towards people with disabilities. The Convention emphasizes that “all people with all types of disabilities must enjoy all human rights [and] are capable of claiming rights and making decisions for their lives based on their free and informed consent as well as being active members of society” (Byrnes et al. 2007). These rights include parenting.

Although there is much work ahead to develop appropriate services, research and policies regarding parents with disabilities, in a very real sense the future is already here. In the first invited speech to the United Nations regarding parents with disabilities, Kirshbaum (2007) emphasized that the future of parents with disabilities is inextricably linked to children with disabilities:

Our children with disabilities need to be free of abuse and have models of secure attachment, love and support, but it’s also important not to over-protect or isolate them. They will need assertiveness and adaptability to overcome social obstacles, as well as caregiving experiences, relationships and social skills to prepare for parenting in the future.

References

- Accardo P, Whitman B. 1990. Children of mentally retarded parents. *American Journal of Diseases of Children*, 144, 69-70.
- Aldridge J, Becker S. 1993. *Children Who Care: Inside the World of Young Carers*, Loughborough (UK): Young Carers Research Group, Loughborough University.
- Alexander C, Hwang K, Sipski M. 2002. Mothers with spinal cord injuries: Impact on marital, family, and children’s adjustment. *Archives of Physical Medicine and Rehabilitation* 83, 24-30.
- Anthony E. 1970. The mutative impact of serious mental and physical illness in a parent on family life. In: Koupernick A and Koupernick C, editors. *The Child in His Family*. Vol. 1. New York: John Wiley and Sons.

- Arlow J. 1976. Communication and character: A clinical study of a man raised by deaf-mute parents. *Psychoanalytic Study of the Child*, 31, 139-163.
- Bland R., Smith N, Hollingworth M. 1992. Handicapped parents and disadvantaged children, *Children Australia*, 172, 12-17.
- Booth T, Booth W. 1994. Parenting under pressure: Mothers and fathers with learning difficulties. Buckingham, England: Open University Press.
- Booth T, Booth W. 1997a. Exceptional childhoods, unexceptional children: Growing up with parents who have learning difficulties. London: Family Policy Studies Centre.
- Booth T, Booth W. 1997b. Making connections: a narrative study of adult children of parents with learning difficulties. In: Barnes C, Mercer G, editors *Doing Disability Research*, Leeds: The Disability Press, pp. 123-140.
- Buck F, Hohmann G. 1981 Personality, behavior, values, and family relations of children of fathers with spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 62: 432-438.
- Byrnes A, Conte A, Gonnot J, Larsson L, Schindlmayr T, Shepherd N, Walker S, Zarraluqui A. 2007. *From Exclusion To Equality: Realizing The Rights Of Persons With Disabilities*. Geneva: United Nations.
- Callow E, Buckland K, Jones S. 2008 *The Disability Movement and a New Focus on Legislating Protection for Children in Families with Parental Disability*. Berkeley: Through the Looking Glass.
- Chowdry S. 2002. Deaf parents raising children: An initial study on Deaf parents in the San Francisco Bay Area with children aged 0-11 years. [dissertation]. London: International School of Social Work.
- Cohen L. 1998. Mothers' perception of the influence of their physical disabilities on the developmental tasks of children. [dissertation]. Alameda (CA): California School of Professional Psychology.
- Coleman C. 2002. Conceiving Harm: Disability Discrimination in Assistive Reproductive Technologies, 50 *UCLA L. Rev.* 17.
- Conley-Jung C. 1996. The early parenting experiences of mothers with visual impairments and blindness [dissertation]. Alameda (CA): California School of Professional Psychology.
- Conley-Jung C, Olkin R. 2001. Mothers with visual impairments or blindness raising young children. *Journal of Visual Impairment and Blindness* 911, 14-29.
- Crist, P. 1991. Motherhood revisited: Balancing parenthood and disability. *Occupational Therapy Practice*, 24: 34-47.

- DeMoss A, Jans L, Kirshbaum M. 1997. Assistive technology and parenting: Teamwork component. The parenting with a disability couples survey. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Deshen S, Deshen H. 1989. Managing at home: Relations between blind parents and sighted children. *Human Organization* 483: 262-267.
- Doe T. 1995. Personal Assistance Services and Policy Barriers for Parents with Disabilities. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Doe T. 2002 The Human Genome Project: Its Impact on People with Disabilities. [Abilities](#), Issue 32: 15-17.
- Ehlers-Flint L. 2002. Parenting perceptions and social supports of mothers with cognitive disabilities. *Sexuality and Disability* 201: 29-52.
- Emerson E, Hatton C, Llewellyn G, Blacker J, Graham H. 2006. Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50(12): 862-873.
- Field M, Sanchez V. 1999. Equal Treatment for People With Mental Retardation: Having and Raising Children. Cambridge: Harvard University Press.
- Frank H. 1979. Psychodynamic conflicts in hearing children of deaf parents. *International Journal of Psychoanalytic Psychotherapy* 7: 305-315.
- Gill C. 1997. Psychological solutions. *One Step Ahead: The Resource for Active, Healthy, Independent Living* 4: 12.
- Goodman S. 1984. Children of disturbed parents: The interface between research and intervention. *American Journal of Community Psychology* 12: 663-687.
- Gorin S. 2004. Understanding What Children Say about Domestic Violence, Parental Substance Abuse or Parental Health Problems. London: National Children's Bureau.
- Greene B, Norman R, Searle M, Daniels M, Lubeck R. 1995. Child abuse and neglect by parents with disabilities: A tale of two families. *Journal of Applied Behavior Analysis*, 284, 417-434.
- Hansen S, Corbus K. 2006. Designing Support Groups for Parents with Intellectual Disabilities. Berkeley: Through the Looking Glass.

- Hendershot G, Olkin R, Abrams, K. 2002. Disabled Parents of Adolescents: Data from the National Health Interview Survey. Conference paper presented at the American Public Health Association meetings in Philadelphia, November 2002.
- Jacobsen T, Miller L, Kirkwood K. 1997. Assessing parenting competency in individuals with severe mental illness: A comprehensive service. *Journal of Mental Health Administration* 242: 189-199.
- Kennedy R, Garbus L, Davis S. 1999. *Different moms*. Arlington (TX): ARC Publications.
- Kirshbaum M. 1994. Family context and disability culture reframing: Through The Looking Glass. *The Family Psychologist* 10 (4): 8-12.
- Kirshbaum M. 1996. Mothers with physical disabilities. In: Krotoski D, Nosek M, Turk M. editors. *Women with physical disabilities: Achieving and maintaining health and well-being*. Baltimore (MD): Paul H. Brookes, p 125-134.
- Kirshbaum M. 1997. Parents with disabilities and their babies. In Makas E, Haller B, Doe T. editors. *Accessing the issues: Current research in disability studies*. Portland (ME): The Society for Disability Studies and The Edmund S. Muskie Institute of Public Affairs. p 47-59.
- Kirshbaum M. 2000. A disability culture perspective on early intervention with parents with physical or cognitive disabilities and their infants. *Infants and Young Children* 132: 9-20.
- Kirshbaum M. 2001. Tales from the frontlines: A practitioner's first experiences in public policy advocacy. *Zero to Three* 216: 26-28.
- Kirshbaum M, Taube D, Baer R. 2003. Parents with disabilities: Problems in family court practice. *Journal of the Center for Children and the Courts* 4: 27-48
- Kirshbaum M, Olkin R. 2002. Parents with physical, systemic or visual disabilities. *Sexuality and Disability* 201: 29-52.
- Kirshbaum M. 2007. 2007 International Day of Families at United Nations Headquarters: Families and Persons with Disabilities. [Internet] [Berkeley, CA] Through the Looking Glass [cited 2007 June 5]. Available from: http://lookingglass.org/training/2007_trng.php
- La Plante M. 1991. Disability in the family. Conference paper presented at the annual meeting of the American Public Health Association, Atlanta, GA, November 1991.
- LeClere F, Kowalewski B. 1994. Disability in the family: The effects on children's well-being. *Journal of Marriage and the Family* 56: 457-468.
- Leslie-Miller J. 1997. From Bell to Bell: Responsible reproduction in the twentieth century. *Maryland Journal of Contemporary Legal Issues* 8: 123-150.

- Llewellyn G. 1990. People with intellectual disability as parents: Perspectives from the professional literature. *Australia and New Zealand Journal of Developmental Disabilities* 164: 369-380.
- Llewellyn G, McConnell D, Russo D, Mayes R, Honey A. 2002. Home based programs for parents with learning difficulties: Lessons from practice. *Journal of Applied Research in Intellectual Disabilities*, 15(4): 341-353.
- Lombardo P. 1996. Medicine, eugenics and the supreme court: From coercive sterilization to reproductive freedom. *Journal of Contemporary Health and Policy* 13(1): 1-25.
- Longmore P. 2003. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press.
- Mazur E. 2006. Positive and negative events experienced by parents with acquired physical disabilities and their adolescent children. *Families, Systems and Health*, Sum 2006, 242: 160-178.
- McConnell D, Llewellyn G, Mayes R, Russo D, Honey A. 2003. Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual and Developmental Disability* 282: 122-134.
- McNeil J. 1993. *Americans with disabilities: 1991-92*. U.S. Bureau of the Census, Current Population Reports, P70-33. Washington, DC: U.S. Government Printing Office.
- Milner J, Ayoub C. 1980. Evaluation of 'at risk' parents using the child abuse potential inventory. *Journal of Clinical Psychology* 36: 945-948.
- Minkler M, Fuller-Thomson E. 1999. The health of grandparents raising grandchildren: Results of a national study. *American Journal of Public Health*, 899: 1384-1389.
- Morris J, Wates M. 2006. *Supporting Disabled Parents and Parents with Additional Support Needs*. Social Care Institute for Excellence: Adults' Services Knowledge Review 11. Bristol, England: The Policy Press.
- Newman T. 2003. *Children of Disabled Parents: New Thinking about Families Affected by Disability and Illness*. Lyme Regis: Russell House Publishing.
- Newman T. 2005. Parents, disability and illness: The impact on children. In: Newman T, Wates M. editors. *Disabled Parents and Their Children: Building a Better Future – A Discussion Document*. Ilford, England: Barnardo Press.
- Nicholson J, Nason M, Calabresi O, Yando R. 1999. Fathers with severe mental illness: Characteristics and comparisons. *American Journal of Orthopsychiatry* 691: 134-141.
- Nicholson J, Sweeney E, Geller J. 1998. Mothers with mental illness: The competing demands of parenting and living with mental illness. *Psychiatric Services* 495: 635-642.

- Nosek M, Foley C, Hughes R, Howland C. 2001. Vulnerabilities for abuse among women with disabilities. *Sexuality and Disability* 193: 177-189.
- O'Toole C, Doe T. 2002. Sexuality and Disabled Parents with Disabled Children. *Sexuality and Disability* 201: 89-102.
- Olkin R. 1999. *What Psychotherapists Should Know about Disability*. New York: Guilford.
- Olkin R., Abrams K., Preston P, Kirshbaum M. 2003 *Comparison of Parents with and without Disabilities Raising Teens: Information From the NHIS and Two National Surveys*. Technical Report, NIDRR Field Initiated Research Grant H133G990130.
- Olkin R, Abrams K, Preston P, Kirshbaum M. 2006. Comparison of parents with and without disabilities raising teens: Information from the NHIS and two national surveys. *Rehabilitation Psychology* 511: 43-49.
- Olsen R, Clarke H. 2003 *Parenting and disability: Disabled parents' experiences of raising children*. Bristol, UK: Policy Press.
- Olsen R. 1996. Young carers: Challenging the facts and politics of research into children and caring. *Disability and Society* 111: 41-54.
- Olsen R, Wates M. 2003. *Disabled Parents: Examining Research Assumptions*. Dartington, England: Research in Practice Press.
- O'Neill A, 1985. Normal and bright children of mentally retarded parents: The Huck Finn Syndrome, *Child Psychiatry and Human Development* 154: 255 - 268.
- Ostler T. 2008. *Assessment of Parenting Competency on Mothers with Mental Illness*. Baltimore (MD): Brookes Publishing.
- Patterson J, Witten B. 1987. Myths concerning persons with disabilities. *Journal of Applied Rehabilitation Counseling*, 18: 42-44.
- Preston P. 1994. *Mother Father Deaf: Living between Sound and Silence*. Cambridge (MA): Harvard University Press.
- Preston P, Lou M. 1998. *Adapting Through the Looking Glass' Intervention Model for Deaf Parents and their Children*. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Preston P. 1995. Mother father deaf: the heritage of difference. *Social Science and Medicine* 40(11): 1461-1467.
- Preston P. 1996. Chameleon voices: interpreting for deaf mothers and fathers. *Social Science and Medicine* 42(12): 1681-1690.

- Preston P, Gray D. 2002. Summary Report and Recommendations: 2002 Meeting of the National Task Force on Parents with Disabilities and their Families. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR National Resource Center for Parents with Disabilities and their Families Grant No. H133A04001.
- Preston P. 2006 Visible, Diverse and United: A Report of the Parents with Disabilities and Deaf Parents Task Force. [Internet] [Berkeley, CA] Through the Looking Glass. [cited April 10, 2008] Available from: http://www.lookingglass.org/task_force/index.php
- Preston P, Jakobson M. 1998. Keeping Our Families Together: A Report of the National Task Force on Parents with Disabilities. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Reilly P. 1991. The Surgical Solution: A History of Involuntary Sterilization in the United States, 2 1991.
- Riebschleger J, Freddolino P, Kanaga B, Miller J. 1993. Invisible People: Children of Parents with Mental Illness. Conference on State Mental Health Agency Services Research and Program Evaluation. The National Association of State Mental Health Program directors Research Institute Inc., Annapolis, Maryland, 1993.
- Riebschleger J. 1994. Good days and bad days: The experiences of children of a parent with a psychiatric disability. *Psychiatric Rehabilitation Journal* 28(1): 25-31.
- Rintala D, Herson L, Hudler-Hull T. 2000 Comparison of parenting styles of persons with and without spinal cord injury and their children's social competence and behavior problems. *Journal of Spinal Cord Medicine* 23: 244-56.
- Ritsner M, Karas S, Drigalenko E. 1991. Genetic epidemiological study of schizophrenia: two modes of sampling. *Genetic Epidemiology* 8: 47-53.
- Rogers J. 2005. The Disabled Woman's Guide to Pregnancy and Birth. New York: Demos Medical Publishing.
- Rolland J. 1994. Families, Illness and Disability: An Integrative Treatment Model. New York: Basic Books.
- Rutter M, Quinton D. 1984. Parental psychiatric disorder: Effects on children. *Psychological Medicine* 14: 853-880.
- Schiff N, Ventry I. 1976. Communication problems in hearing children of deaf parents. *Journal of Speech and Hearing Disorders* 413: 348-358.
- Schilling R, Schinke S, Blythe B, Barth R. 1982. Child maltreatment and mentally retarded parents: Is there a relationship? *Mental Retardation* 205: 201-209.

- Silver M. 2004. Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History. *Geo. Wash. L. Rev.* 72(4): 862-892.
- Silverman M. 1989. Children of psychiatrically ill parents: A prevention perspective. *Hospital and Community Psychiatry* 4912: 1257-1265.
- Small E. 1992. Growing up fast, *Social Work Today* May 7, 1992: p. 10.
- Smith N, Bland R, Grey C. 1993. Handicapped parents with non-handicapped dependents. *International Journal of Rehabilitation Research* 16: 157-159.
- Thurman S. 1985. *Children of Handicapped Parents: Research and Clinical Perspectives*. Orlando (FL): Academic Press.
- Toms Barker L, Kirshbaum M, Haight-Liotta S, Nisen F, Cupolo Freeman A, Jakobson, M. 1997a. You May Be Able to Adopt: A Guide to the Adoption Process for Prospective Mothers with Disabilities. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Toms Barker L, Maralani V. 1997. Challenges and strategies of disabled parents: Findings from a national survey of parents with disabilities. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Toms Barker L, Mizoguchi N, Smith C. 1997b. Estimating the cost of living for adults with substantial disabilities. Through the Looking Glass, Berkeley, CA. Technical Report, NIDRR Research and Training Center on Families of Adults with Disabilities Grant No. H133B30076.
- Tuleja C, DeMoss A. 1999. Baby care assistive technology. *Technology and Disability* 111(2): 71-78.
- Tymchuck, A., Keltner, K. 1991. Advantage profiles: a tool for health care professionals working with parents with mental retardation. *Issues in Comprehensive Pediatric Nursing* 14: 155-161.
- Tymchuk A. 1992. Predicting adequacy of parenting by people with mental retardation. *Child Abuse and Neglect* 16: 165-178.
- Tymchuk A. 2006. *The Health and Wellness Program: A Parenting Curriculum for Families at Risk*. Baltimore: Paul H. Brookes.
- United Nations. 2008. Convention on the Rights of Persons with Disabilities. [Internet] [Geneva] United Nations. [cited 2008 July 19]. Available from: <http://www.un.org/disabilities/default.asp?navid=12&pid=150>

- U.S. Bureau of the Census. 1993 Survey of Income and Program Participation SIPP U.S. Bureau of the Census: Washington, D.C.
- U.S. Dept. of Health and Human Services, National Center for Health Statistics. National Health Interview Survey, 2000 [Computer file]. 2nd ICPSR version. Hyattsville, MD: U.S. Dept. of Health and Human Services, National Center for Health Statistics [producer], 2000. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 2002.
- Vensand, K., Rogers, J., Tuleja., DeMoss, A. 2000. Adaptive Baby Care Equipment: Guidelines, Prototypes and Resources. Berkeley, CA: Through the Looking Glass,
- Wagenheim H. 1985. Aspects of the analysis of an adult son of deaf-mute parents. Journal of the American Psychoanalytic Association 332: 413-435.
- Wates M. 1997. Disabled Parents: Dispelling the Myths. Cambridge, UK: National Childbirth Trust.
- Winton C. 2003. Children as Caregivers: Parental and Parentified Children. Boston: Allyn and Bacon Press.