Parents with Intellectual Disabilities

Families are Important
Families are not cast in molds. Families can be single parents raising children, gay or lesbian partners, a grandmother raising a grandchild, or a group of friends living together. By choice or by chance, families are the bonds we all form. Simple categories cannot house complex networks of relationships. Families have many variables. Using research literature, FamilyTrends describes different family forms and identifies characteristics common to certain family types. Because to really understand the needs of families—to shape policy and inform practice—we must begin by understanding families themselves.

Definition and Prevalence
By Laurie Selz Campbell
Parents with intellectual disabilities are persons who experience “significant limitations in intellectual functioning and adaptive behavior, as expressed in conceptual, social, and practical adaptive skills” (American Association on Intellectual and Developmental Disabilities, 2008). In recent years, the term “intellectual disability” has replaced “mental retardation” as a more accurate, appropriate, and useful term (Schalock, Luckasson, & Shogren, 2007).

Establishing an estimate of the number of families in which a parent has an intellectual disability is challenging. Historically, prevailing beliefs (even in human services) has suggested that parenthood was inappropriate, even immoral, for persons with intellectual disabilities. As a result, the issue was simply not addressed or tracked. Extrapolating from data on a few states that have attempted to collect prevalence data suggests that, in the United States, there are approximately 36,500 such families, and that, of these, about 1,000 reside in North Carolina.

However, these estimates are considered conservative at best, as this is a vulnerable group of parents who easily and often slip through the cracks of the service system.

Challenges and Protective Factors
Parents with intellectual disabilities have generally reported positive views of parenting, with one study reporting well over half of participants describing parenting as something that they “like” or “love” (Ehlers-Flint, 2002). These same parents were well aware of both the challenges and the satisfactions of parenting.

Epidemiological data suggest that the mere fact of a parent’s intellectual disability does not automatically result in intellectual or developmental disability in his/her children, although the risk is certainly increased. James (2004), in his review of developmental risks for children of parents with intellectual disabilities, cited data indicating that when neither parent has an intellectual disability, there is a 1% likelihood that child will have an intellectual disability. When one parent has an intellectual disability, the likelihood of such disability for children rises to 15%, and when both parents have intellectual disabilities, the likelihood increases to approximately 40%. Poverty of resources and environmental stimulation, a history of parental trauma or abuse, and isolation from needed services compound the developmental risks to children of parents with intellectual disabilities (James, 2004; McGaw, Shaw, & Beckley, 2007).

Social isolation and social networks.
Parents with intellectual disabilities are thought to be among the most socially isolated in the community (Llewellyn & McConnell, 2002). The lack of social support is especially critical for this vulnerable group, as they encounter multiple challenges, including limited education and job skills, difficulties with accessing...
services, and minimal avenues for self-advocacy. The family’s living situation appears to be a major factor influencing the type of supports to which parents have access. For example, Llewellyn and McConnell (2002) found that parents living alone with their children had primarily service-centered networks, gaining most of their support from service workers and other professionals. Those living with partners, spouses, or their own parents or guardians reported more family-centered (albeit sometimes conflictual) support networks.

An important finding was that, regardless of living situation, few parents identified supportive relationships with friends or neighbors, suggesting that they would be particularly vulnerable should there be a loss of family support. The importance of support is underscored by the finding that, for those parents whose support networks were perceived to be positive, associations with self-esteem and positive parenting practices have been found (Feldman, Varghese, Ramsay, & Rajška, 2002; Kroese, Hussein, Clifford, & Ahmed, 2002).

**The risk of abuse and neglect.**

It is important to separate facts from assumptions when considering the risk of child abuse or neglect in families in which a parent has an intellectual disability. James (2004) has suggested that the court system, often reflecting commonly held societal beliefs, may work from the assumption that an intellectual disability equates to a deficit in parenting, and that children would be better off with other caregivers. In their review of court proceeding in the United States and abroad, several researchers have found that parents with intellectual disabilities are overrepresented in child welfare proceedings. They are treated more harshly, and lose custody of their children at a significantly greater rate than do other adjudicated families, even those with other disabilities, including substance abuse or mental health disorders (Booth, Booth, & McConnell, 2005; Llewellyn, McConnell, & Ferronato, 2003; McConnell & Llewellyn, 2002). Concerns about neglect or abuse, and assumptions that parenting deficits cannot be remedied, precipitated many removals of children.

In fact, in their study comparing parents with intellectual disabilities who lost custody of their children to a similar group who had not lost custody, researchers found no significant differences in the severity of children’s behavior problems, nor in mothers’ levels of adaptive behavior (Aunos, Goupil, & Feldman, 2003). Mothers with custody reported higher community involvement and satisfaction with services. The authors suggested that some custody decisions may not be based on clear evidence of dysfunction, and recommend improved services to mothers both with and without custody.

**What Helps? Interventions.**

Researchers have noted prevailing beliefs about intellectual disabilities in general, and parents with intellectual disabilities in particular, suggesting that learning and skill development are minimal at best. In addition, Aunos & Feldman (2002), in their review of attitudes toward sexuality and childbearing for people with intellectual disabilities, found that most respondents (families and service providers) considered such activities inappropriate. These beliefs, it is argued, may have served to impede the development of high-quality interventions (Aunos & Feldman, 2002, Espe-Sherwindt, 1993). Feldman (1994) found, in a review of 20 outcomes studies of parent education for parents with intellectual disabilities that, even though satisfaction and short-term progress were apparent, the gains did not always persist or generalize well to the parents’ home environments, and thus the impact on children was not as positive as was hoped.

Fortunately, a number of innovative interventions have been developed and implemented with promising results. The mere fact of having an intellectual disability or a low IQ is a relatively poor predictor of parenting competence and outcomes; researchers have found that, in fact, specific skill and knowledge deficits related to parenting are quite often able to be remedied (Llewellyn & McConnell, 2002). An intervention utilizing self-instructional, audiovisual childcare manuals resulted in high levels of parent satisfaction and significant improvement in parenting skills, with improvements persisting at six months (Feldman & Case, 1999; Feldman, Ducharme, & Case, 1999). A randomized trial of a 10-week home-based intervention addressing child health and safety demonstrated that parents improved in their ability to recognize dangers in the home and to implement precautions, with gains persisting at 3 months (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003). A similar home-based intervention focusing on childcare skills resulted in improved family preservation outcomes for group of families at risk for child neglect (Feldman, 1998).

Other interventions have focused on the development of supportive peer relationships and reduced reliance on formal, professional supports. One such intervention resulted in immediate and long-term benefits for parents, and secondary benefits for children (McGaw, Ball, & Clark, 2002).

Research on the best ways to address the needs of parents with intellectual disabilities suggests that there are often considerable differences in the perceptions of the parents themselves, their family members, and their service providers. Parents in one such study (Llewellyn, McConnell, & Bye, 1998) reported feeling over-served in some domains, but under-served in others (for example, child development guidance, vocational support,
accessing community resources, and developing friendships). Wade, Mildon, and Matthews (2006) surveyed parents with intellectual disabilities regarding "helpful" and "unhelpful" practices, and found that parents strongly preferred practices that were focused on their specific needs and priorities, and that fostered their active involvement and participation.

**Implications for policy & practice.**

There is consensus among experts in the field (for example, Espe-Sherwindt & Crable, 1993; McConnell & Llewellyn, 1997; Ray and Rubinstein, 1994; Tymchuk, 1999) that, because this is a group of families with multiple challenges and vulnerabilities, effective services must be carefully with several critical guidelines in mind.

- They must address children’s changing developmental needs as well as those of parents in a flexible and long-term manner, changing in intensity and focus as needed
- They must occur as much as possible in the family’s natural home and social environment. They must foster and build on informal supports, encouraging friendship, community involvement, and advocacy.
- They must be designed with the needs of adult learners with limited literacy in mind. They must promote problem-solving, self-esteem, and understanding of the parenting role in a way that is consistent with the concerns, priorities, and values of parents
- They must address a wide range of needs, including those related to housing, healthcare, education, vocational skills, and economic self-sufficiency.

Clearly, program models that provide for the kind of comprehensive, individualized, and flexible services described above must be designed in an integrated and truly multi-disciplinary manner. In a compelling article co-authored by a researcher and a father with an intellectual disability, (Strike & McConnell, 2002), the parent’s words eloquently express what the above guidelines might mean for service providers. He reminds the reader that the foundation for effective services is that of honesty, respect, and “looking beyond the disability” to see the entire parent and family.

**References**


**Annotated Bibliography**

For more information on these and other references on this topic, please visit the Annotated Bibliography section of the FamilyTrends website (www.familytrends.org). This section summarizes the research literature and other helpful sources for a particular FamilyTrends Brief. Journals for Social Work, Psychology, Marriage and Family, Public Policy and other similar disciplines are referenced. This list will be updated periodically in order to capture the most recent literature.
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