

## New Ways of Thinking About Parents with Intellectual Disabilities

by Bernadette Irwin

Parenting as a right for individuals with intellectual disabilities is a relatively new concept. In the last 40 years, there has been a paradigm shift in attitudes and practices toward individuals with intellectual disabilities who desire to be parents. Today, the most significant aspect of the national conversation about adults with intellectual disabilities who are or desire to be parents is that self-advocates, advocates, court personnel, policymakers, researchers, Guardians ad Litem and concerned members of the community are actually *having* that conversation about such a right. Several historical events have brought us to this new place.

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One of those events was the convening of a special task force of The President's Committee on Mental Retardation (now known as the President's Committee for People with Intellectual Disabilities) in February 1999. This study group brought together 75 national experts, including adults with intellectual disabilities, to examine the consequences of society's failure to adequately support individuals with mild intellectual disabilities who were living marginal lives. This task force examined the lives of young adults with intellectual disabilities with respect to areas of everyday life and made recommendations to the President. Among the areas examined was the right to parent. The results of these discussions were presented in the document *The Forgotten Generation – 1999 Report to the President* (President's Committee on Mental

Retardation, 1999). The recommendations included the following regarding the right to parent for individuals with mild intellectual disabilities (p. 81):

- Assure that people with mild cognitive limitations are able to participate in parenting classes while in school or as young adults.
- Offer...parenting classes for individuals with mild cognitive limitations early in the child welfare process.
- Help people with mild cognitive limitations to identify and network with natural supports that may exist, such as extended families, neighbors, church members and others who might provide information, advice or assistance on parenting issues.
- Increase affordable access to legal representation by increasing funds to legal services and protection and advocacy services. Tie this new funding to a mandate to use it for representation of individuals with mild cognitive limitations in civil matters, such as ...parental custody.
- Encourage agencies to involve resources experienced in working with individuals with mild cognitive limitations in providing assistance with child care and child protective services.
- Urge the Department of Justice to aggressively examine cases on parental rights issues under Title II of the Americans with Disabilities Act.
- Educate child welfare agencies, family courts and others that individuals with cognitive limitations can be competent and effective parents, and how best to support these individuals.

The report also stated, "People with mild cognitive limitations can be caring, concerned and competent parents if the appropriate supports and service are in place" (p. 81). It also said, "People with

mild cognitive limitations have the right to have intimate relationships, to get married and to have children and have a full family life" (p. 82).

At the June 2010 annual conference of the American Association on Intellectual and Developmental Disabilities (AAIDD), the first meeting of the Parents with Developmental Disabilities/Intellectual Disabilities Task Force was held. The first discussion item in the minutes of the task force was "*Everyone has the right to be in a relationship and have children.*" The recommendations of this newly-formed task force were surprisingly similar to those in *The Forgotten Generation*. Their recommendations included the following (AAIDD Parents with Developmental Disabilities/Intellectual Disabilities Task Force, 2010):

- Push for legislation to support parents with DD/ID. The task force members felt it was essential to have *parenting considered an essential life function*.
- Provide strengths-based training to psychologists since they are usually the professionals who are responsible for evaluating parents with DD/ID.
- Examine ways that supports for parents with DD/ID can be a component of waivers.
- Enhance the coordination of the child welfare and the DD systems.
- Push to have a change in the DD Act to identify parenting as a "natural part of family support."

It is also significant that the United Nations is addressing parenting by individuals with disabilities as a "right" in a treaty that is currently under development in the *Convention on the Rights of Persons with Disabilities* (United Nations, 2007). The United States is participating in the development of this document and when the U.S. signs this treaty, it will be obligated under international law to take "effective action" to eliminate dis-

crimination, and to render “appropriate assistance” to persons with disabilities, including parents with intellectual and other developmental disabilities under Article 23. This Article states that signatories “shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.”

An additional milestone in the paradigm shift regarding parents with intellectual disabilities occurred as the result of a two-day planning retreat in 2009 in which 12 individuals from Canada and several U.S. states came together to develop a strategic plan to formally address the needs of parents with intellectual disabilities. This meeting resulted in the founding of The Association for Successful Parenting: Enhancing the Lives of Families When Parents Have Learning Difficulties (TASP). During the retreat, the participants developed TASP’s Mission Statement (The Association for Successful Parenting, 2009):

We are dedicated to enhancing the well-being of at-risk parents with learning difficulties and their children. This primarily includes parents who may be identified as persons with intellectual disabilities or borderline intellectual functioning.

It also created the following Guiding Principles of TASP:

- We recognize that family life is complex.
- We move forward in step with self-advocates in this shared work.
- We acknowledge that all families need support and rely on inter-dependent networks.
- We accept that separation from parents is sometimes in the best interest of children.
- We believe that our expertise and resources may also benefit parents with other cognitive challenges and the people that support them.

TASP has also identified the following as the practices it uses in its work:

- Facilitating community partnerships and networking.
- Offering educational opportunities.
- Engaging in advocacy and ongoing system change to achieve social justice.
- Partnering with self-advocates to promote self-determination.
- Promoting evidence-based parenting skill assessments.
- Developing and endorsing evidence-based curricula for training.
- Honoring family autonomy, self-determination and parent strengths.
- Encouraging natural supports, community acceptance and inclusion.
- Developing individualized supports that utilize evidence-based practices.
- Consulting with partners in child welfare, early intervention, education, health care, disability services and family support.
- Working within interdisciplinary teams to individualize services.
- Establishing and raising quality standards in assessment, training, service and research.
- Promoting and conducting research.

Advocacy for the rights of individuals with intellectual disabilities with regard to parenting appears to have reached a critical mass. Local, state, national, and international organizations and agencies are addressing the needs and challenges of parents with intellectual disabilities. Public and private health care, education, housing, welfare, vocational, mental health and other social services, child and adult protective services, and the juvenile and adult court systems are beginning to recognize the need for coordinated, comprehensive and sustained services for these parents and their children. So, in 2010, as we are in the midst of a paradigm shift regarding parents with intellectual disabilities, where can people go to learn more about the emerging practice of supporting parents with intellectual disabilities? Here are some suggestions:

- The TASP Web site (<http://www.achancetoparent.org>) for information about membership, conferences, and ways to connect with others on this area of interest.
- The International Association for the Scientific Study of Intellectual Disabilities, Special Interest Research Group on Parenting with Intellectual Disabilities (see <http://iassid.org>, under SIRGs select “Parenting”).
- The Healthy Start (Australia) Web site (<http://www.healthystart.net.au>) to see their national strategy for serving children of parents with learning difficulties.
- Publications by three of the leading researchers on the topic of parents with intellectual disabilities: Dr. Alexander Tymchuk, Dr. David McConnell, and Dr. Maurice Feldman.
- The Web site of Through the Looking Glass (<http://www.lookingglass.org>), one of the first agencies in the U.S. to serve parents with disabilities.

There are many opportunities for top-down (social policy) and for bottom-up (grass-roots/community) action and conversation to enhance the lives of families when a parent has intellectual disabilities. I encourage you to explore the field, and keep the action and conversations moving forward.

#### References

- AAIDD Parents with Developmental Disabilities/Intellectual Disabilities Task Force (June, 2010). Meeting minutes and recommendations. Unpublished.
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*Bernadette Irwin is Co-President of The Association for Successful Parenting, and Assistant Department Director with the Department of Family Support Services at The Kennedy Krieger Institute, Baltimore. She may be reached at 410/298-2645 or [irwin@kennedykrieger.org](mailto:irwin@kennedykrieger.org).*