

Parenting with Intellectual Disabilities

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Historical Context

- Women with intellectual disabilities in the US have endured a repressive history
 - sterilization
 - segregation to prevent procreation
 - discriminatory beliefs that they can not be good parents
- Women with intellectual disabilities are
 - quite diverse
 - one of the most underserved populations

Context of Parenting

- Parenting occurs in a context influenced by:
 - socioeconomic status
 - emotional resources
 - social resources
 - relationship to larger community

Life Circumstances of Mothers with Intellectual Disabilities (ID)

- Onslaught of Crises
- Psychiatric Disabilities
- Discrimination
- Poverty
- Violence
- Lower educational attainment

Onslaught of Crises

- Eviction
- Homelessness
- Insufficient money for food
- Mental health problems
- Victimization from community members
- Disconnection of power and water
- Spousal/Partner abuse and rape
- Undiagnosed medical problems

(Booth & Booth, 1993b)

Poverty

- National Health Interview Survey Disability Supplement (NHIS-D) indicated that
 - 33% of persons *with* intellectual disabilities live below poverty level
 - 13% of persons *without* intellectual disabilities live below poverty level

(Larson et al., 2000)

Risks Associated with Poverty

- Violence
- Limited access to health care
- Reduced quality of life
- Poor physical health
- Diminished cognitive abilities

Resources Allocated to Support People with ID

- Supplemental Security Income (SSI)
 - eligibility predicated on poverty and a disabling condition that results in work incapacity
- Social Security Disability Income (SSDI)
 - income replacement program for those that have worked but can no longer work due to disability

Breakdown of Finances

- In fiscal year 2000 \$ 6.5 billion in SSI benefits paid to 776,000 adults with ID.
- In fiscal year 2000 \$3.2 billion in SSDI benefits paid to 536,000 adults with ID.
- Many persons with ID left below federal poverty level of \$746 (US Census Bureau, 2001).

Employment

- Employment rates for persons with ID below general population:
 - Women employed 23.5%
 - Men employed 27.4% (Yamaki, 1999)
- People with ID have lowest employment rates of any group of individuals in our **society** (Daniels & West, 1998).

Abuse

- “Rates of abuse for persons with disabilities are significantly higher than those for the general population, particularly for those with intellectual disabilities, although the number of studies are limited” (Sobsey, 1994)

Abuse cont...

- Children with disabilities are believe to be maltreated at a rate nearly twice that of children without disabilities (National Center on Child Abuse and Neglect, 1993)
- Verdugo et al (1995) study in Spain
 - 11.5% of children with intellectual disabilities were abused compared to 1.5% of children without disabilities

Abuse and Parenting

- When children have been abused they have an increased likelihood of abusing their children. This is a concern with persons with intellectual disabilities and parenting (Hall, et al. 1993)
- There is evidence that unwanted children are more likely to be abused (Pagelow, 1984)

Mental Illness

- One- third of person's with intellectual disabilities have mental illness or psychiatric disorders.
- Depression and other mental illness are recognized to negatively impact parenting abilities.
- Studies indicate that people with intellectual disabilities have lower self esteem.

Opposition to Parenting by Intellectual Disabled Mothers

- Historically professionals were concerned that genetic material would be transmitted to children.
- Currently, professionals are concerned that mothers with intellectual disabilities are incompetent and show deficiencies in providing parenting.

Trends in Research

- Assessments of parental skill or knowledge
 - mother's knowledge of child safety, emergency response, nutrition & decision making
- Perceptions about increased child abuse or neglect of children.
- In-depth examinations of parent's own perspectives of their lives.

Assessments of Parental Skill or Knowledge

- There is evidence that mothers with intellectual disabilities can benefit from intervention services that are respectful, supportive and tailored to cognitive disabilities.
- Children born to mothers with ID are at the same risks for developmental impairment, poor health and educational outcomes as poor children.

(Tymchuk, 1990; Tymchuk & Feldman, 1991)

Perceptions About Increased Child Abuse or Neglect of Children

- Neglect associated with intelligence disabled parents is usually related to inadequate training and supports. (Tymchuk & Feldman, 1991)
- Neglect has been identified as related to poverty. (Pagelow, 1984)
- Mother's with intellectual disabilities are significantly less likely to abuse their children than the general population. (Tymchuk, 1990; Tymchuk & Feldman, 1991)

In-depth Examinations of Parents' Own Perspectives of their Lives

- Very few of these studies have been conducted
- Research in ID and parenting offers the greatest promise of understanding the complexities faced by these parents, and how they can best be supported

Future Research Directions

- Parenting of adolescents or adult children
- Longitudinal investigations of the dynamics of parenting by women with ID, and how mothers and children fare over time
- Implications of the larger environmental and economic context on parenting by people with ID

Current Policy Trends

- Public policy toward mothers with intellectual disabilities is often manifested in court to terminate parental rights
- Children of parents with ID are more likely to be removed from family home than children from parents without disabilities
(Levesque, 1996; Watkins, 1995)

National Policy Standards

- Adoption Assistance and Child Welfare Act includes a goal of providing families with services necessary to preclude removal from families
- Act established a national standard of family preservation

Policy Reality

- For women with intellectual disabilities the intersection of family preservation policy and leads to dissolution of their families
- In several states, the existence of a mental disability in a parent is sufficient to terminate custody, without any evidence of child maltreatment
- Women with ID often do not have the resources to legally advocate for themselves
(Hyman, 1990; Watkins, 1995)

Policy Recommendations at the Societal Level

- Implementation of global school curriculum addressing:
 - Sex education, parenting skills, and violence and abuse prevention
 - Enactment of measures that address the causes and consequences of poverty
 - Expansion of research related to parenting and intellectual disabilities
 - Immediate enforcement of due process protection for women
 - Educational campaigns targeted to end stigmatization and prejudice against people with disabilities

Policy Recommendations at the Family Level

- Expansion of appropriate, respectful, and effective services available to women with ID and their families
- Services within Child Protective Services which can support families with ID
- Family Preservation Services that address needs of mother's with ID
- Address effects of poverty

References

This presentation is drawn from Susan L. Parish's chapter: "Parenting." In P. N. Walsh & T. Heller (Eds.), *Health of women with intellectual disabilities*, (pp. 103-120). Oxford: Blackwell.

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