Historical Precedents

- Eugenic-era marriage prohibitions
- Involuntary sterilization of (mostly) women with mental disabilities in the U.S.: By 1937, 31 states allowed for coercive sterilization
- At least 50,000 people sterilized by 1949
- Sterilizations continued well into the 1970s, possibly later
- True extent of sterilization is unknown
Current Lines of Inquiry

- Parental skill/knowledge assessments
- Intervention evaluations
- Child outcome evaluations
- Qualitative investigations of parents’ perspectives
- Investigations of mother’s individual or interpersonal traits
Limitations of Existing Research

- Samples generally recruited from Child Protective Services – confirmed abuse and/or neglect cases
- Exceptionally small samples
- Focus on easily-measured child outcomes
- Limited life-course perspective
- Minimal data on fathers
- Few comparisons to other parents with similar socioeconomic status
Construct of Competence

- No legal agreement as to the minimum standards for adequate parenting
- No clinical agreement on adequate parenting
- How do we measure parenting or its consequences?
Parenting by Mothers with DD: Research Overview

- No differences in decision-making or maternal knowledge, when compared with mothers of similar socioeconomic status
- Greater likelihood of children’s removal from the home
- Mothers often lack the ability to generalize their learning to actual situations
- Respectful and supportive interventions can be fruitful - tailored for learners with cognitive limitations & limited literacy
Well-being of Mothers with DD

- Life circumstances best characterized by overwhelming problems
- Girls with cognitive disabilities significantly more likely to be abused, particularly sexually
- High rates of comorbid psychiatric disorders
- Mothers have low self-esteem & fewer social supports than other women
- Low education levels, little chance for economic prosperity/independence
Well-being of Children whose Mothers have DD

- Greater levels of delinquency & school failure
- Sustain higher rates of neglect
- Sustain lower rates of abuse
- Some adults report great satisfaction with care received as children
- Some adults have good educational & employment outcomes
Poverty

- Receipt of SSI leaves adults with DD below the federal poverty level ($512/month in 2000)
- At least 50% of the population with DD doesn’t receive SSI or DI
- Women with DD have among the lowest rates of employment (24%)
- 1/3 of people with DD live below the poverty level, v. 13% of others
Heightened Vulnerability to Abuse

- Cognitive limitations
- Reliance on caregivers
- Desires to be compliant & “pass” as normal
- Limited access to sex education & abuse prevention
- Sexual abuse often longstanding & often perpetrator is well-known and/or family
Comorbidity of Psychiatric Disorders

- 1/3 of people with DD have psychiatric or mental disorders, rates which far exceed that of the general population.
- Depression, among other mental disorders, has strong association with parenting difficulties - lack of nurturing.
Availability of Supports

- Traditional family support programs benefit families of children with DD, not parents with DD
- Limited support programs in scattered sites across country
- Few combined residential/social support programs
Parenting is a fundamental right

Termination of parental rights can only be done with “clear and convincing” evidence of harm to the child, inability to parent, or probability that inadequate care will persist

Parents have the right to due process protections
Characteristics of Child Welfare Cases involving Mothers with DD

- Extensive deference to expert testimony
- Establishment of mental retardation shifts burden of proof from state to parent
- Courts “resourcefully” legitimate termination decisions with formal findings regardless of the process (from Hayman, 1990)
Discriminatory Realities

- Presumptions of incompetence without evidence, when parent has DD
- Higher standard of minimal care held for parents with DD
- Mitigating circumstances (domestic abuse, poverty, inadequate social supports, successful completion of rehabilitation) are ignored
- ADA is voluntary compliance - burden of securing justice falls on injured party
- Unknown extent of removal of infants at birth
Research Recommendations

- Longitudinal research on parents & children’s well-being over the life course
- Use of parenting measures that capture the nuances of competence and caring
- Studies of parents who are not recruited through Child Protective Services
- Intervention studies
Policy Recommendations

- Global school curricula addressing sex education, parenting skills, violence/abuse prevention
- Aggressive measures to reduce the causes of poverty
- Enforcement of due process protections in termination proceedings
- Educational campaigns to reduce stigma
- Family-level supports and services