

Happily Ever After? When People with IDD Marry

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Objectives

Participants will:

- 1. Identify social forces that impact rights of people with IDD, historically and currently
- 2. Identify at least three barriers to intimacy and relationships among people with IDD
- Examine own positions about intimacy and relationships between people who have IDD
- 4. List three gaps in supports and potential solutions to each

Societal

Legal

Practical

Financial



Societal: A Historical Perspective

- Before the late 20th century, many states banned anyone with a disability from marrying.
- People with IDD were grouped with other "undesirables," such as people with mentally illness, epilepsy, alcoholism and even unwed mothers.
- As recently as 1980, 42 states had laws restricting individuals with disabilities from marrying.
- Today many of those restrictions have been lifted or greatly relaxed.

Societal: The Mind of a Child

- Mental Age: How a child of a specific age performs intellectually for that chronological age.
 - Does not consider maturity
 - Varies by test given
- First defined by the French psychologist Alfred Binet in 1905
- Used to infantilize people with disabilities



Societal: Eugenics

- Eugenics: the science of improving a human population by controlled breeding to increase the occurrence of desirable heritable characteristics. (Google Dictionary)
- Francis Galton proposed eugenics as a process for improving the human race
- Eugenics proposed that some people's genetic backgrounds were inferior to others.
 - Individuals with intellectual disabilities were assumed to have an inferior, defective genetic pool.
 - They were considered a reproductive threat to the integrity of the human gene pool
- During the early part of the 20th century, most people with ID were institutionalized. These institutions often sterilized their patients

Legal

- Skinner v. Oklahoma (1942)
 - Supreme Court case
 - Found that involuntary sterilization infringed on an individual's inalienable right to procreate.
 - Despite the court's ruling, some states and facilities continued the practice of sterilization
- Persons with ID have the same rights as any other citizen.
 This includes the right to marry and to have children.
- But there is no national law protecting marriage for people with disabilities.
 - Individual state laws (2004)

Marriage Rights of Individuals with Intellectual Disabilities https://www.questia.com/magazine/1G1-242843879/marriage-rights-of-individuals-with-intellectual-disabilities

Legal: A Sampling Across States

- Alaska... either party of unsound mind
- Arkansas... Incapable of consent due to age or understanding
- Colorado... Consent lacking due to mental incapacity
- Delaware... person of any degree of unsoundness of mind
- District of Columbia... Marriage of an idiot or adjudged lunatic
- Hawaii... lacking mental capacity
- Idaho... unsound mind
- Illinois... Capacity lacking (infirmity, alcohol, drugs, force, duress, fraud); physically incapable of consummating
- Indiana... Underage or mentally incompetent to consent

Annulment and Prohibited Marriage laws - Information on the law about Annulment and Prohibited Marriage - Prohibited Marriage - Underage, Consent, Sex, and Fraud - JRank Articles http://law.jrank.org/pages/11834/Annulment-Prohibited-Marriage-Ntml#ixzz4nPWFBC8N

Legal: A Sampling Across States

- Iowa... lacking capacity to consent
- Kentucky... Capacity lacking (force, fraud, mental incapacity, drugs, alcohol); physical capacity for marriage lacking
- Maine...Mental illness/retardation of sufficient degree
- Michigan...idiocy; physical incapacity to consummate
- Minnesota...Lacking capacity to consent (mental, alcohol, drugs, force, fraud); no physical capacity to consummate
- Mississippi...Incurable impotency, insanity, or idiocy; incapable of consent from lack of understanding
- Nebraska...mental illness or retardation at marriage
- Texas...mental incompetence
- Vermont...mental incompetence

Annulment and Prohibited Marriage laws - Information on the law about Annulment and Prohibited Marriage - Prohibited Marriage - Underage, Consent, Sex, and Fraud - JRank Articles http://law.jrank.org/pages/11834/Annulment-Prohibited-Marriage-Ntml#ixzz4nPWFBC8N

Autonomy, Decision-Making Supports, and Guardianship

Joint Position Statement of AAIDD and The Arc

Statement

All individuals with intellectual and/or developmental disabilities (I/DD)[1]have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

Practical: Are marriage & parenthood realistic goals for people with IDD?

- Can people with limited mental abilities fully understand the ramifications of intimacy?
 - Understanding relationships, compromise, patience, etc.
 - Understanding sex and not being exploited, raped, physically or emotionally hurt
 - women and men with intellectual disabilities are much more susceptible to sexual abuse and women more prone to domestic abuse (http://thenadd.org/modal/bulletins/v10n5a1.htm)
 - Understanding risks and ramifications of sex
 - Sexually transmitted diseases
 - Birth control
 - Pregnancy
 - Parenthood
 - Some people with ID struggle with self-care so how can they care for a child?

What does the research tell us?



"Throughout history, many individuals married, raised children and did not come to the attention of service providers, because they were able to manage their lives."

https://www.mentalhelp.net/articles/reproductive-rights-for-people-with-intellectual-disabilities/

Successful Marriage: Is it possible?

- Hall (1974) reviewed fifteen studies going as far back as the 1920's and concluded there was considerable evidence that people with intellectual disabilities frequently had "successful marriages" (ie, no separations or divorces).
- Bass (1964) reviewed literature beginning in the 1940s and noted there was an increasing recognition of the ability of many people with intellectual disabilities to hold a job, marry and support themselves.
- Andron and Sturm (1973) surveyed 12 couples and found that they
 overwhelmingly felt that the companionship of marriage was much better
 than single life.
- Mattinson (1973) completed one of the most frequently quoted studies. Her research investigated 36 marriages where both partners had intellectual disabilities, many of whom had been previously institutionalized. The majority of the couples (25) were affectionate, happy and felt their lives were better married than single.
- Edgerton (1967) found similar results.

Successful Marriage: Is it possible?

- Floor, Baxter, Rosen and Zisfein (1975) did a follow-up study of previously institutionalized people regarding marriage and children.
 - They found the children were fairly well cared for, at least in their early years.
 - Frequent couple problems included chronically poor health of one partner, money management, and interference from "demanding relatives."
 - Marriages did better when one partner had average intelligence, and when a relative, landlord or employer supported them.
- Ann and Michael Craft (1979) completed a pilot study of 25 marriages; and a more detailed investigation of 45 other couples. Marriages had lasted up to 25 years. Findings suggested a better marital "success rate" and chance of happiness than the population at large.
- Koller, Richardson and Katz (1988) concluded that about half of the adults were in marriages that "appear to be going well."
- Kempton and Kahn (1991) found that married couples with intellectual disabilities had about the same chance of divorcing as non-disabled couples, and they preferred marriage over single life.

Parenting: Is it possible?

- Contrary to what many people think, people with intellectual disability can be good parents.
 - Field and Sanchez (1999) suggest that the ability of a parent to provide adequate child care cannot be predicted on the basis of intelligence alone. As with parents without disabilities, the ability to parent successfully depends on a wide range of factors.

Parenting: Is it possible?

- Grayson (2000) reviewed studies attempting to identify factors contributing to successful parenting. These factors include:
 - higher IQ (greater than 50 or 60)
 - being married or living with the child's grandparents or daily support from a high functioning adult
 - having fewer children or only one
 - adequate motivation and willingness to accept support from service providers or informal sources
 - training in the home to enhance generalization
 - appropriate parent models during childhood
 - good physical and mental health
 - adequate finances
 - low stress
 - adequate education and reading skills

http://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd

Parenting: Risks

- Four specific risk factors that are commonly associated with child maltreatment are:
 - Poverty
 - Behavioral health challenges
 - Domestic violence
 - Level of social supports

https://disabilitypartnership.wordpress.com/2017/04/01/supporting-parents-with-intellectual-disabilities-in-the-child-welfare-system/

Parenting: Risks

- A 2011Canadian study determined that 10.1% of all child maltreatment cases opened for investigation (vs. substantiated cases) involved parents with cognitive disabilities
- In a 2005 case record review of child protection cases in four courts in Northern England, one in six cases involved at least one parent with an intellectual disability
- In a 2005 two-country study of Australia and England, disproportionate representation was found for the involvement of parents with intellectual disabilities in child protection proceedings in court

https://disabilitypartnership.wordpress.com/2017/04/01/supporting-parents-with-intellectual-disabilities-in-the-child-welfare-system/

Parenting: Higher Risk of Losing Children

- People with ID are at higher risk of losing custody because they have "cognitive disabilities"
- Courts try to balance the welfare of the child against the parents' rights.
- Lack of supports is the core problem in these cases

http://www.intellectualdisability.info/family/articles/parents-with-intellectualdisabilities

Parenting: Support

- McConnell, Llewellyn & Bye (1997) surveyed service providers and identified four principles associated with effective services to parents with I/DD:
 - Services need to be responsive to the parents' individual needs and focus on the whole family to ensure that interests of both parents and children are served.
 - Services must include long-term, ongoing supports because the needs of children change and parenting skills must change as children mature.
 - Services must consider the special learning needs of the parent.
 Learning must occur in the home, be repetitive, use demonstration and use resources that require little or no reading.
 - Services must assist parents in becoming part of their community.

http://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd

Parenting: Supports

- Home visiting programs
- Parenting groups
- Center-based programs
- Shared parenting models (Anderson & Lakin, 1998)
 - Shared parenting provides full-time support when the parent and child live in foster care together.
 - The foster provider acts as a "co-parent" to ensure the needs of children are met.
- UK's Parent Assessment Manual assesses skill gaps using a range of measures including rating scales, questionnaires, self-reporting, task setting and observation.

Parenting: Effects on Children

- Booth & Booth (1997) interviewed 30 adults brought up in a family headed by a parent or parents with intellectual disability.
 - Half of these adults had intellectual disability themselves.
 - They conclude that the children's destinies are not fixed by having a mother or father with intellectual disability.
 - Their experiences in leaving school to adult life were similar to other people from the same social class and neighborhoods.
 - Most of them maintained a valued relationship with their families.
 - There was little evidence of them assuming responsibility for "parenting their parent."

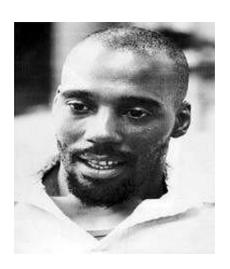
http://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd

 Emerson & Brigham (2014) parental intellectual disability was associated with increased risk of child developmental delay and child speech and language problems

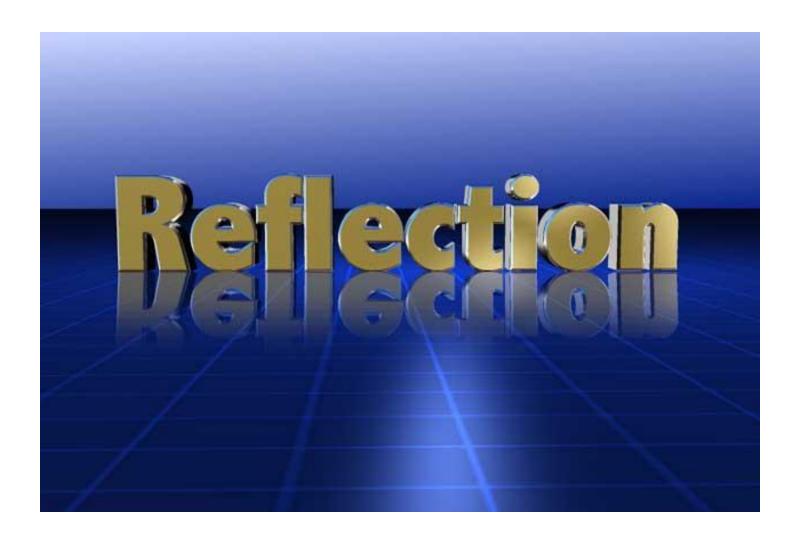
http://www.sciencedirect.com/science/article/pii/S0891422214000109

Financial

- Where do we live?
 - State regulations
 - Protective approach
 - Minimize risk
 - Group home
 - Individual home
- What about our benefits?
 - Exceeding assets limit
 - Loss of benefits, including medical







Resources

- 1. Reproductive Rights For People With Intellectual Disabilities https://www.mentalhelp.net/articles/reproductive-rights-for-people-with-intellectual-disabilities/
- 2. Marriage Rights of Individuals with Intellectual Disabilities https://www.questia.com/magazine/1G1-242843879/marriage-rights-of-individuals-with-intellectual-disabilities
- 3. Joint Position Statement of AAIDD and The Arc http://aaidd.org/news-policy/position-statements/autonomy-decision-making-supports-and-guardianship#.WW0Wp4RuJ0w
- 4. Annulment and Prohibited Marriage laws Information on the law about Annulment and Prohibited Marriage Prohibited Marriage Underage, Consent, Sex, and Fraud JRank Articles http://law.jrank.org/pages/11834/Annulment-Prohibited-Marriage-Prohibited-Marriage.html#ixzz4nPWFBC8N
- 5. https://www.nature.com/scitable/forums/genetics-generation/america-s-hidden-history-the-eugenics-movement-123919444
- 6. https://www.mentalhelp.net/articles/reproductive-rights-for-people-with-intellectual-disabilities/

Resources

- 7. The NADD: http://thenadd.org/modal/bulletins/v10n5a1.htm
- 8. The Arc: http://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd
- 9. Jewish beliefs http://eng.beithillel.org.il/responsa/marriage-for-those-with-intellectual-development-disorder/
- 10. Couples therapy http://thenadd.org/modal/bulletins/v10n5a1~.htm
- 11. Living Longer: http://abcnews.go.com/Health/MindMoodNews/syndrome-couples-marry-live-longer-face-questions-sex/story?id=11862336
- 12. Parent's View http://lindaatwell.com/how-can-two-special-needs-people-marry/
- 13. Historical perspective: https://www.mentalhelp.net/articles/reproductive-rights-for-people-with-intellectual-disabilities/
- 14. Parents with IDD http://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd
- 15. Living apart/group home rules http://www.dailymail.co.uk/news/article-2353342/Mentally-disabled-married-couple-authorities-tried-make-live-apart-finally-place.html
- 16. AAIDD http://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.WW0Wp4RuJ0w

Resources

- 17. Sexuality https://aaidd.org/news-policy/policy/position-statements/sexuality#.WW0Wz4RuJ0w
- 18. <a href="http://law.jrank.org/pages/11834/Annulment-Prohibited-Marriage-Prohibited-Marriage-Prohibited-Marriage-Natural-Prohibited-Marriage-Prohibited-Marriage-Natural-Prohibited-Marriage-Prohibited-P
- 19. Benefits http://www.disabilitysecrets.com/resources/will-marriage-affect-my-disability-benefits-social-securi
- 20. News https://www.usatoday.com/story/news/nation/2014/05/02/intellectual-disabilities-relationships/8636141/
- 21. Research: http://www.tandfonline.com/doi/abs/10.1080/13668250412331285136
- 22. Cyber https://cyberpsychology.eu/article/view/6734
- 23. UK http://onlinelibrary.wiley.com/doi/10.1111/jar.12254/full
- 24. Mothers w IDD http://onlinelibrary.wiley.com/doi/10.1111/jar.12169/full
- 25. Anderson, L. & Lakin, K.C. (1998). Parents with cognitive limitations: What do we know about providing support? Impact: 11(1), 6-7.
- 26. http://www.intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.info/family/articles/parents-with-intellectualdisability.">http://www.intellectualdisability.info/family/articles/parents-with-intellectu
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