Parents with developmental disability who have become parents and are raising their children

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Overview of presentation

Four Key Points

- Controversy about people with developmental/ intellectual disability becoming parents
- Current state of knowledge about parents with developmental/ intellectual disability and their children
- Regulatory and policy context affecting parenthood and implications for families and practitioners
- Improving services and resources to assist practitioners
Developmental Disability means a disability that is manifested in childhood or early adulthood which is attributable to intellectual disability or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behaviour similar to that of a person with intellectual disability.

Majority of research and practitioner knowledge is about parents with intellectual disability.

Terms used in the literature also include learning difficulties, cognitive impairment, intellectual limitations.
Becoming parents – societal responses

- In high income countries
  - History of institutionalization and ‘protection’
  - History of eugenics and desire to eliminate the ‘feeble-minded’- sterilization
  - Medicalization of intellectual disability – yet, this is NOT an illness

- In low and middle income countries
  - Often people with disabilities marrying is not so exceptional – it is quite ordinary!
    - Marriage and children for all except those with the most severe impairments
    - Marriage essential for women for financial security and protection
    - Extended family care for children, particularly in village communities
Remaining inaccurate beliefs about people with intellectual disability as parents

- children will inherit their parent’s disability
- people with intellectual disability are ‘childlike’- children themselves
- people with intellectual disability cannot learn
- parents with intellectual disability will abuse/ neglect their children knowingly or otherwise
Changing circumstances

For people with intellectual disability

- Changing practices with de-institutionalization and people are living in the community

- Research, policy and practice is now focused on developing the capabilities of people with intellectual disability to participate in the everyday life of their community

- This means that children with intellectual disability are now in school, and as adults may live independently, have a job, go out and meet friends and socialize and take their place as other citizens do in the community

- Is the case for parenting?
Actual circumstances

In many countries worldwide

- Involuntary or coerced sterilization remains likely for many women (and men) with intellectual disability

- Women with intellectual disability are sexually abused and maltreated in many different ways

- Sexuality education (if this is available) frequently focuses on risk, protection and avoidance

- Pregnancy for many women with intellectual disability occurs because of ignorance, coercion, control by a family member, or abuse NOT through their own choice
My mother never thought I could do anything. She’d never let me do things in the kitchen when I was growing up. I was never allowed to have my own money, she used to keep it and control what I could spend it on. My sisters always had their own money. They were allowed to do things. She made all my decisions for me. I was never in control of my own life. I was the one she saw as stupid and dumb. She never thought I’d be able to look after myself, or look after my children.
Parenting by people with intellectual disability is not a new research question


- “The feebleminded parent: A study of 90 cases” – an article by Phyllis Mickelson two years later (1947) in the *American Journal of Mental Deficiency*, 51, 644-653.

- Over 500 papers in the international literature

Phases of research

- Research up until around the 1990s focused on two main questions:
  - Can parents with intellectual/developmental disability be adequate parents?
  - Can people with intellectual disability be taught to become adequate parents?

- Research from around the 1990s to the present
  - How do parents manage parenting in their family and social context?
  - What are the living conditions of parents with intellectual disability compared with those of their non-disabled peers?
Main topics in the research literature

- Barriers to participation in the parenting role including protected upbringing
- Outcomes for the children of parents with intellectual disability
  - Children’s development
  - Child welfare – care and protection systems and responses
- Teaching and supporting parents with intellectual disability
- Strengthening social relationships of parents with intellectual disability
- Community participation of parents with intellectual disability
- Impact of disadvantaged position in society on parents and their children
What does the research tell us about parents and their parenting?

Parenting capability and support

- IQ is not a predictor of parenting capability
- Parents can provide good enough parenting with adequate supports in place
- Parenting capability is learnt (not inherited!) so can be taught/learnt
  - Parenting is enhanced by learning parenting skills using proven, effective parent education programs
  - Programs need to be specific, structured, situational, with opportunities for generalization
- Parenting support needs to be relevant to parents’ and children’s needs as these change over time
- Parents and their children need opportunities for social participation in community life
What does the research tell us about the social and environmental context?

Impact of living circumstances on parents and their health and wellbeing

- Living circumstances
  - neighbourhood
  - housing
  - material hardship
  - family composition / household structure
  - employment
  - income hardship
  - social support

- Health & Wellbeing
  - mental
  - physical
Parents with intellectual disability and their families compared to non-disabled parents

- Major findings across populations of parents with intellectual disability and non-disabled parents
  - Parents with intellectual disability do more poorly on measures such as birth outcomes, maternal health, child outcomes, involvement with child protection services

Except that

- When environmental adversity factors such as low social support, unsafe neighbourhood, poor mental health in family are taken into account the significant differences between disabled and non-disabled parents disappear

What does the research tell us about the children?

Children of parents with intellectual disability

- Young children are *more likely than not* to develop in line with their peers from similar socio-economic backgrounds.

- There is delayed development for some children *but only for those* who:
  - Have a pre-existing health condition, illness or disability
  - Live in poverty or disadvantaged circumstances including low socio-economic resources, unsafe neighbourhoods or who are exposed to risk factors such as domestic violence or maltreatment

HOWEVER.................................
Removal of children from parents with intellectual disability

In Australia, the United Kingdom, Canada, and the United States around 40%-60% of children will be removed from their parents on the grounds of:

- **Concern about neglect or future parenting of the child**
  - Parents are presumed to be incompetent so therefore the child is at risk
  - Parents are considered to lack the ability to learn so therefore the situation cannot be changed

- **System inadequacies to support parents raising their children**
  - Child welfare intervention addresses risk only NOT support
  - There is a lack of effective support services available in the community so therefore child welfare practitioners and the courts assume nothing can be done to help the parents
  - Child welfare, family services and health practitioners are not adequately trained to support parents with intellectual disability
Parents with intellectual disability and their children

- Generally thought to be not capable of being parents
- Leads to practitioners – and families – under-estimating their capacities and their wishes
- Systems that are not set up to support people with intellectual disability when they become parents
- Health and disability practitioners do not yet have the skills to support people with intellectual disability as parents and their children
- Concern about neglect and abuse of children based on parents being seen to be incompetent or ‘different’

- Many children being removed and parents struggling
Opportunities for change
CRPD and Optional Protocol Signatures and Ratifications

Signed  Signed Convention  Signed Convention & Protocol  Ratified Convention  Ratified Convention &

As of 8 July 2014

158 signatories to the Convention
92 signatories to the Optional Protocol
147 ratifications and accessions to the Convention
82 ratifications and accessions to the Optional Protocol

The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations.

Final boundary between the Republic of Sudan and the Republic of South Sudan has yet to be determined.

The line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. It does not, however, reflect the�� boundary between the two States.

*Appears without prejudice to the question of sovereignty.

**A dispute exists between the Governments of Argentina and the United Kingdom of Great Britain and Northern Ireland.

The labels in parentheses refer to the administering Power or the Plane involved in a special treaty relationship.

European Union, a regional integration organization as a State party to the Convention.

Cook Islands, a non-member State of the United Nations, is a State party to the Convention.
States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.

- (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

- (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

- (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.
Article 25 and Article 31

Article 25 – Health

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

Article 31 – Statistics and data collection

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
Goal 6 Ensure gender equality and women’s empowerment

Target 6.C

“Ensure that all girls and women with disabilities have access to sexual and reproductive health services on an equitable basis with girls and women without disabilities”

Target 6.D

“Increase measures to protect girls and women with disabilities from all forms of violence and abuse”

Goal 8 Improve the reliability and comparability of disability data
Advancing policy and practice

CRPD and Incheon Strategy

- Together represent significant regulatory advances with regard to:
  - Safeguarding fertility
  - Ensuring healthy sexuality and reproductive health
  - Opportunity for parenthood for persons with disabilities

- Implementing this in action requires significant commitment to overcoming:
  - Cultural and societal beliefs about persons with intellectual disability being incompetent and not capable of learning
  - The history of institutionalization and ‘protection’ particularly of women with intellectual disability
  - Being fearful about parenting for people with intellectual disability and their children and therefore ONLY regarded them within an ‘at risk’ context
What do organisations need to do?

Service managers and agency personnel

- **Build Knowledge**
  - Accurate, up-to-date knowledge from research to support evidence-based practice
  - Knowledge based on the living circumstances of parents with intellectual disability broadly **NOT on one or more instances/ anecdotes of parents in distress**

- **Change Attitudes**
  - Understand that the world has changed
    - *UN CRPD* and Article 23 and 25 and 31
      - Australia signed 2007, ratified 2008
      - Taiwan
What else do organisations need to do?

- **Learn Skills**
  - Ensure agency policy and practices are compliant with obligations that families have a right to and need support
  - Develop cross agency collaboration skills to ensure up-to-date disability inclusive policies and programs

- **Change Behaviours**
  - Welcome parents with intellectual disability as equally entitled to evidence based effective support
  - Institute evidence-based programs to support parents
  - Work collaboratively with other agencies to coordinate support
  - Provide comprehensive and accessible information, counselling and support which is fundamental to exercising free and informed choice
What do individuals need to do?

Practitioners and Families

- **Build Knowledge**
  - *Becoming and remaining* up-to-date with accurate knowledge and evidence about parents with intellectual disability and their families

- **Change Attitudes**
  - *Reflect* on your own attitudes – what is the basis for these? Are these accurate and fair? Are you willing to change your ideas based on up-to-date evidence?
  - *Reflect* on others’ attitudes – what can you do to be an informative change agent?
What do individuals need to do?

- **Learn Skills**
  - *Learn and become proficient* in evidence based programs for parents with intellectual disabilities and their families
  - *Parenting Young Children; Healthy and Safe; Me and My Baby; Me and My Community; Understanding and Planning Supports (UPS)*

- **Change Behaviours**
  - *Welcome parents with intellectual disability and their families* as equally deserving of respect, positive support and your best endeavours
  - *Engage with DPO’s* to learn from persons with disabilities with experience and expertise in being parents
  - *Develop networks and collaborations with practitioners* in family support and services, disability services, care and protection to institute and sustain cross-agency collaboration and co-ordination
  - *Engage with family members* to ensure that the choices of the person with intellectual disability about sexuality, intimacy and parenthood are respected and not violated
What needs to occur for better practice?

Fundamental actions

- Children and young people to receive evidence based programs promoting respect, choice and responsibility in sexuality, relationships AND parenting

- Service providers and family members to engage with DPO’s where there are persons with disabilities with experience and expertise in being parents

- Service providers to engage with family members to ensure that the choices of the person with intellectual disability about sexuality, intimacy and parenthood are respected and not violated

- Mainstream reproductive health services to enhance their capacity to respond to women with intellectual disability

  - Provision of comprehensive and accessible information, counselling and support which is fundamental to exercising free and informed choice
Healthy Start - Australian National Strategy

www.healthystart.net.au

Welcome to Healthy Start.

Healthy Start is a national strategy for professionals and volunteers in the health, welfare and education sectors who share a common interest in enhancing the lives of children and their parents with learning difficulties.

Parents with learning difficulties can parent successfully, but it is important that they receive support and education appropriate to their needs. Healthy Start’s mission is to increase the capacity of the service system to better support parents with learning difficulties and their children.

Helping parents with intellectual disability make sense of the child protection system in NSW

Information and tips for parents, lawyers, disability advocates and workers and family.
Disability, Pregnancy & Parenthood is the national information charity on disability and parenthood.

New website coming soon!
Supporting future parents

People have desires
Everyone has desires: good health, happiness, many friends, love, money, a job, a house, a family, a child... The same is true for people with an intellectual disability.

In recent years, ASVZ has acquired a great deal of knowledge and experience regarding the topic of a desire to have a child by people with intellectual disabilities. In 2008-2009, we compiled our knowledge and experience in The...
Conclusion

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